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Non-Biological Caregivers' Experiences of Fetal Alcohol Spectrum Disorder (FASD) Support Groups

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Non-Biological Caregivers' Experiences of Fetal Alcohol Spectrum Disorder (FASD) Support Groups

by

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THESIS

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Wilfrid Laurier University

ABSTRACT

Caregivers of children with Fetal Alcohol Spectrum Disorder (FASD) are an extremely valuable resource, and supporting a stable and nurturing home environment may be the most achievable intervention to improve the child's prognosis. Very little research has been done to explore effective interventions that focus on the FASD caregiver, rather than the child, for the purposes of preventing caregiver burnout and placement breakdown. The central purpose of this study is to explore non-biological parent caregivers' experiences of FASD caregiver support groups in order to capture a better understanding of the value of this resource as one part of a continuum of care for families affected by prenatal alcohol exposure. In addition, useful data is gathered and presented concerning participants' overall experiences as a FASD caregiver, adaptive attitudes that appear to promote wellness among caregivers, and participants' views concerning needed resources in addition to support groups.

To accomplish this goal, semi-structured interviews were completed with seven non-biological parent FASD caregivers who were attending a variety of different FASD support groups. Qualitative analysis was employed to identify important themes and draw conclusions. This study revealed that support groups are generally beneficial to non-biological caregivers, although not always in the ways anticipated prior to group attendance. Support groups were particularly helpful in their ability to reduce caregiver isolation by offering a non-judgmental forum where caregivers meet with peers who become invested in seeing their families succeed, where their struggles and emotions are normalized, and where they receive mentorship, education, advocacy, practical tools, and

support in reframing problem behaviours as symptoms of their child's disability. Certain elements of group structure were associated with more positive evaluations of support group usefulness, including monthly meetings led by a skilled group leader who was also a fellow FASD caregiver, having the group divided according to ages of the children, and having a consistent structure and routine that ensured that all caregivers' needs could be attended to at each meeting. Participants saw online forums for support among group members in between meetings as a valuable tool and found one-to-one mentorship outside of the group during crisis points to be particularly helpful.

Although participants spoke very positively about the beneficial impact of the support groups, overall, they also talked about some of the potential negative impacts of groups. This included hearing horror stories that created fear for their own futures, and a variety of issues related to unhealthy group process and leadership issues. Although the intent of this study is not to establish a "gold standard" for caregiver support groups, it provides a helpful framework for group leaders to assess areas for growth and change in their support groups and to highlight the potentially hurtful or damaging aspects of group participation.

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CHAPTER ONE: INTRODUCTION

This study explored the experiences of non-biological caregivers of a child with Fetal Alcohol Spectrum Disorder (FASD) with FASD caregiver support groups. FASD refers to a continuum of brain defects as a result of prenatal exposure to alcohol, and includes the terms Fetal Alcohol Syndrome (FAS), Partial Fetal Alcohol Syndrome, Alcohol-Related Birth Defects, and Alcohol Related Neurological Disorder (Chudley et al., 2005). Affecting at least an estimated 9.1 in 1000 live births (Sampson et al., 1997), FASD can have significant impacts on physical development, central nervous system functioning, cognitive functioning and behaviour. Primary disabilities commonly associated with FASD include a failure to connect actions with consequences, learning difficulties, concrete thinking patterns, inability to read social cues, lying, stealing, and impulsivity (Streissguth, Barr, Kogan, & Bookstein, 1996). Without support, individuals with FASD can develop and later become entrenched in a cycle of secondary problems that include homelessness, poverty, mental health issues, addictions, disrupted school experience, unemployment, inappropriate sexual behaviours and recurrent trouble with the law (Streissguth et al., 1996).

Several researchers have concluded that early diagnosis and a stable, non-abusive home environment are among the critical early interventions that can mitigate the chances of a child acquiring these secondary disabilities associated with FASD (Streissguth et al., 1996; Weiner & Morse, 1991; Zevenberg & Ferraro, 2001). It is notable, due to the complex nature of this disorder and the demands inherent in caring for a child with FASD, that few of these children remain in the care of a biological parent throughout childhood, and an estimated 80% of children with FASD grow up in the child welfare system (Jones, cited in Jones, 2003). Most children with FASD experience chronic shifts in their caregiver arrangements, rarely staying in any one caregiver home for more than two years (Stratton, Howe & Battaglia, 1996). Thus, it seems important to explore what factors might best support those in a caregiver role for a child with FASD, in order to maintain each stable and nurturing home environment as long as possible. This research proposal is based on the assumption that providing support to the caregiving unit may aid in reaching this goal, and the intent is to explore how and to what extent support groups for caregivers of children with FASD can be helpful.

Thus, this study's main focus was to explore caregivers' perceptions of the usefulness of FASD caregiver support groups. Numerous caregiver support groups have already formed across Canada as part of a grass-roots initiative to meet the needs of families struggling to care for a child with FASD. Many of these groups have formed in the absence of paid, professionally trained leaders, in an effort to meet the needs of the FASD caregiver community through education about the disorder, advocacy, and mutual aid.

It is critical that these support groups be studied in order to determine whether or not they meet their primary objectives of emotional support and mutual aid, and what aspects of the groups are most effective in this regard. Important questions include:

- In what ways are the groups helpful to caregivers and in what ways are they not helpful?;
- What components of the group sessions are most appreciated by and helpful to families, and what aspects are not?;

- Are FASD caregiver support groups a continued source of support on a long-term basis, or do the benefits dwindle over time?;
- Do support groups assist families caring for FASD individuals of any age?;
- Are caregiver support groups sufficient as a stand-alone intervention tool, and if not, what is missing?;

This research provides a preliminary understanding of the benefits and limitations of FASD caregiver support groups, and offers direction to the future development of successful intervention strategies that might improve or complement these groups. Relatedly, this research also uncovers caregivers' broader experiences and needs with regard to issues such as loss and grief, burnout, stigma, and involvement with social service professionals.

Social Location and Motivation of the Researcher

My motivation for conducting this research was to challenge social work professionals to provide excellence in practice to FASD caregivers, who are critical partners in supporting individuals affected by FASD as they seek to develop the skills to live stable and healthy adult lives. I accept that helping professionals have not done enough to assist these families, and, at times, in spite of the best intentions, our efforts have been unhelpful, hurtful, and even harmful, as we have attempted to assist caregivers in their daily challenges.

Although I have no known natural connection to an individual with FASD, I have experienced some of the struggles related to providing support to several youth whom I suspect may have been exposed prenatally to alcohol. I have sought out training in this area, joined a local FASD task force and have been involved in advocacy related to FASD in the political arena. I carry both privilege and biases related to my status as a white, middle-class, Christian, heterosexual woman.

Overview of the Thesis

The remainder of the thesis is divided into five chapters. Chapter Two presents a review of the literature on FASD, including issues of diagnosis and intervention. The methodology of this study is discussed in Chapter Three. Chapter Four presents the results of the qualitative analysis of participant interviews. Finally, Chapter Five provides a discussion of the results including implications for practice and future research.

CHAPTER TWO: REVIEW OF THE LITERATURE

This chapter will begin by exploring the literature concerning the brief history of FASD, including public perception of the disorder, evolving terminology concerning effects of prenatal alcohol exposure, diagnostic models for FAS, an overview of the mechanics of brain damage due to prenatal alcohol exposure, the development of diagnostic screening tools and research on prevention messages. Second, the lived experiences of individuals with FASD will be discussed. Third, literature on FASD interventions including interventions in the schools will be reviewed. The fourth section will discuss home-based FASD intervention strategies, and after presenting the challenges faced by FASD such as loss, grief, self-sacrifice and burnout, I will explore current interventions focussed on supporting the caregiver. The fifth section will provide support for the potential usefulness of support groups for FASD caregivers by exploring the proven benefits to other caregiver populations such as those caring for the elderly, chronically or terminally ill, adults with mental illness. I will conclude by identifying gaps and inconsistencies in the research and provide evidence for the value of the present study.

History of Fetal Alcohol Spectrum Disorder

On the Trail of an Unknown Teratogen

Prenatal alcohol exposure was thought to be harmless until a French paediatrician, Dr. Paul Lemoine, noticed commonalities in growth, motor development, behavioural problems, head circumference and facial features among children in the orphanage where he was employed (Lemoine, 2003). Lemoine hypothesized that an unknown syndrome was responsible for the unique presentation of these children, and he eventually determined that maternal alcoholism was the common link. Prior to this discovery, it was widely accepted that prenatal alcohol exposure was benign, although there was some suspicion that inebriation at the time of conception could be harmful. As a result, Lemoine's discovery, published in 1967, was generally ignored until American physicians, Dr. David Weyhe Smith and Dr. Kenneth Jones, came across Lemoine's research and found similar commonalities among children in their practices (Lemoine, 2003). Jones and Smith (1973) coined the term, "Fetal Alcohol Syndrome" and provided detailed descriptions of the facial dysmorphology and physical anomalies still used in diagnosis today.

Jones, Smith, Ulleland and Streissguth (1973) later theorized that the teratogenic properties of alcohol was known thousands of years ago and provided quotes from the Bible, examples from Ancient Greek and Roman literature, and from writings during the time of the gin epidemic. However, Abel (1997, 1999, 2001) argued that these quotes were clearly taken out of context and he strongly challenged the validity of using these historical texts to demonstrate an awareness of the dangers of prenatal alcohol exposure.

Public Perception of the Emerging Disorder

Public awareness of the dangers of prenatal exposure to alcohol and the impact of FASD has ebbed and flowed over the years as there has been much debate and disagreement within the medical field concerning the risk and prevalence. One writer describes FASD as a widespread public concern in the following excerpt;

> FAS (with craniofacial deformities and mental retardation) has been recognized for three decades and can be enlikened to the tip of an iceberg – a conspicuous but relatively rare phenomenon. The FAE (primarily mild to severe CNS disturbances) can be enlikened to the iceberg itself – not rare, but submerged from view, enormous in dimension, and disastrous in social consequences. (Olney, Ishimaru, Bittigau, & Ikonomidou, 2000, p.519)

In contrast, Armstrong and Abel (2000) submitted a harsh critique of FASD advocates whom they charge with casting FAS as a greater crisis than it really is. These authors argue that "moral panic has inflated fear and anxiety about the syndrome beyond levels warranted by evidence of its prevalence or impact" (Armstrong & Abel, 2000, p. 276) and that it is

> ...Within [a] dual context of the new temperance zeitgeist and the concern about the victimization of children prevailing in America that FAS emerged as a social problem in the 1970s, evolved into a moral crusade in the 1980s with its disturbing images of children 'wounded' (Greenfield, 1989) or 'bruised before birth (Steacy, 1989) and became transmogrified into a moral panic characterized as 'child abuse in the unborn fetus' (Apolo, 1995) in the 1990s. (Armstrong & Abel, 2000, p. 276)

These authors are partially responding to early researchers' recommendations that all pregnant alcoholic women should be counselled regarding the option of aborting fetuses exposed to heavy amounts of alcohol for fear of the possible ill-effects (Smith, Jones & Hanson, 1976), which does appear to be an overreaction considering the fact that the actual occurrence of FAS is quite low even among infants born to alcoholic mothers.

Armstrong and Abel (2000) continued their critique by arguing that FAS is inextricably linked to poverty, and that messages about it being an "equal opportunity" disorder, without regard for race or socioeconomic status, are harmful to the advancement of FAS research because they are inaccurate and are simply efforts to garner attention from the middle and upper classes. Abel (1995) reviewed several epidemiological studies and concluded that FASD is *not* an equal opportunity disorder, indicating that low socio-economic status emerges as a risk factor. However, these conclusions are surprising, because among the 12 American studies out of the 35 reviewed, none of the studies included samples with upper class participants. Although some of the studies completed internationally had a cross-sectional group of participants, I would argue that epidemiological studies should not be compared on an international basis because of the possibility of varying diagnostic techniques and definitions of FAS.

Further, even if studies were completed using a cross-section of various income levels, there are serious concerns about how and when physicians diagnose FAS, and whether or not there is more resistance to questioning wealthy, white women about their drinking habits than there is to questioning a poor woman of colour living in an urban centre. Until such a time where routine screening of all patients and of all live births takes place with a measure more reliable than the self-report of drinking patterns of the mother, true epidemiological estimates will have a high likelihood of inaccuracy and results may be skewed to reinforce negative stereotypes.

Golden (1999) presented an interesting chronology of the "demedicalization" of FAS, whereby the author argues that knowledge and authority concerning FAS and its implications have been stripped from the medical community and rest more on public opinion and political issues. Golden writes;

> In its brief history FAS had many definitions: medical problem, public health concern, symbol of maternal misdeeds, evidence of moral decay within particular communities, and finally a desperate tactic employed by death penalty opponents. Each definition overlaid, but did not fully obscure, the previous one... ...Central to the reframing of FAS from a medical problem to a social problem was the fact that FAS became public currency traded by politicians, lawyers, and public health advocates for various ends. And as it passed from hand to hand, the imprint of the medical community that had first engraved it into the public record began to fade. (Golden, 1999, p.287-288)

Golden (1999) points out that public debate concerning FASD initially became wrapped up in the abortion/right to life debates when physicians recommended aborting fetuses of alcoholic mothers and was fuelled by fear brought on by the birth defects caused by Thalidomide and the Rubella outbreaks. Warnings to pregnant women turned into consternation for bad mothering, followed by the racialization of FAS leading to further disdain of the mothers, and the subsequent movement towards the punishment of women who continued to drink during pregnancy. Punishments included imprisonment or the apprehension of their children, and when FAS became a defence used in court cases to defend capital crimes, individuals with FAS became seen as "victimizers" instead of "victims" (Golden, 1999).

Another central aspect of the public perception of FASD is that it is a "native problem," linking FASD to previously established negative stereotypes about Aboriginals and alcohol abuse. Fuelling this perception were early studies conducted by non-native researchers, primarily on reserves. For example, in a study of an isolated native community in British Columbia, researchers concluded that the rate of FAS/FAE was 19% (Robinson, Conry & Conry, 1987). However, findings of this study should be taken with caution, as it reported that there were 116 children, but only 45 mothers. If a handful of mothers drank throughout multiple pregnancies, then the presence of these siblings would skew the results to suggest that more native women were consuming alcohol during pregnancy than what may be true. Indeed, the authors report that five mothers had given birth to 54% (12 out of 22) of the children in the sample who were diagnosed with FAS/FAE.

This distinction is important because it changes the focus of prevention in this community – alcohol consumption may not be so much a widespread issue in this native community, as it is a persistent issue among certain women who are sexually active, are not using effective means of birth control, and have no access to or are not choosing to access supports to help them stop drinking. These findings may be more reflective of the need for the community to come together to determine a response that is culturally relevant to address the most problematic issues. Sadly, studies like this one have been misinterpreted and misconstrued in a way that is damaging to Aboriginal communities and have become yet another means of marginalization and colonization.

Salmon (2007) appears to support this interpretation, and points out the absence of Aboriginal voices in the discourse about FASD in native communities. The author challenges FASD prevention programs geared specifically towards Aboriginal culture, arguing that there is no one "Aboriginal" culture, that many young Aboriginal women identify with more than one Aboriginal people group, or that many have not been raised with any ties to their ancestry, due to colonialism. Further, Salmon contends that the implementation of programs directed exclusively at Aboriginal women, particularly in the absence of prevention materials geared toward any other ethnic group, reifies and reproduces the notion of FASD as an "Aboriginal problem," and it works against decolonization by promoting negative stereotypes and racializing the issue.

The Search for Uniformity and Accuracy in Describing Prenatal Alcohol Exposure

Over time, it became evident that prenatal alcohol exposure caused a continuum of harmful side effects throughout the pregnancy, and the term "Fetal Alcohol Effects" (FAE) was introduced to describe individuals with a variety of problems stemming from prenatal alcohol exposure but without all of the necessary features implicating a diagnosis of FAS, namely central nervous system dysfunction, growth deficiency and unique facial characteristics (Clarren & Smith, 1978). However, the term FAE became problematic in that its non-specificity led to its overuse (Sokol & Clarren, 1989), particularly in children with behaviour problems whose parents were suspected to be alcoholics (Calhoun & Warren, 2007). Sokol and Clarren (1989) recommended that the term be eliminated because of a lack of consensus regarding the meaning of the term in different professional circles. FAS/FAE was later renamed once again as Fetal Alcohol Spectrum Disorder (FASD) (Streissguth & O'Malley, 2000) as an umbrella term which a report by the Institute of Medicine (IOM) used to describe the full range of disabilities including (a) FAS (must include facial anomalies, growth retardation, and central nervous system abnormalities) with and without maternal confirmation of prenatal exposure to alcohol; (b) partial FAS (confirmed exposure to alcohol, but not having all of the criterion required for full FAS); (c) Alcohol-Related Birth Defects (ARBD) which relates to the presence of a variety of congenital anomalies; and (d) Alcohol-Related Neurodevelopment Disorder (ARND), which refers to a smaller head circumference, brain structure anomalies and/or behavioural issues and cognitive abnormalities not otherwise attributable to environmental factors or normal developmental behaviours (Stratton et al., 1996).

ARBD and ARND are not mutually exclusive and may both be present in the same individual (Stratton et al., 1996). These terms generally imply that there was not definitively confirmed prenatal alcohol exposure and can be useful for diagnosing adults, due to the inability to observe the hallmark facial characteristics which tend to fade over time (Stratton et al., 1996).

The report from the IOM provided a detailed description of each of the diagnostic criterion for FAS (Stratton, et al., 1996). Facial abnormalities associated with FAS include short palpebral fissures, flat upper lip, smooth philtrum and flat midface. Growth deficiencies associated with FAS include low birth weight and slight stature as the child ages. Central nervous system abnormalities span a variety of indicators including smaller head circumference, structural brain abnormalities, poor fine motor skills, gait, poor hand-eye coordination, and hearing loss (Stratton, et al., 1996). The diagnostic criterion for partial FAS involve some or all of the above abnormalities, in addition to behavioural and learning difficulties that cannot be attributed to developmental level, environment, or family factors such as poor impulse control, social skills deficits, difficulties with mathematics and other abstractions, and problems with memory, attention, and judgment (Stratton, et al., 1996).

Delineating Practical and Comprehensive Diagnostic Criteria for FAS

In an effort to establish clear and concise procedures to guide the diagnosis of expressions of FAS, Canadian researchers published a comprehensive overview of diagnostic criteria including some minor revisions to the IOM diagnostic requirements of partial FAS to ensure accurate assessment of the level of brain damage (Chudley, et al., 2005). They also included photographic representations of the implicated facial features of FAS to facilitate measurement of facial dysmorphology, and a description of differential diagnoses that should be considered prior to considering a diagnosis related to prenatal alcohol exposure (Chudley, et al., 2005). This model also drew on Astley and Clarren's 4-digit diagnostic code developed in 2000. Hoyme et al. (2005) developed a similar model to the Canadian one, which is currently being used more widely because it has been tested with multiracial participant groups and has demonstrated reliability. Wattendorf and Muenke (2005) have also prepared a useful photographic comparison of the differing presentation of facial characteristics across four different racial groups.

Chudley et al. (2005) also recommend that diagnosis should be accomplished through a formalized assessment involving an interdisciplinary team including a case manager, a physician, a psychologist, an occupational therapist and a speech-language pathologist. The authors accommodated rural Canadians who would be unlikely to have access to such a wide variety of practitioners by permitting consultation via teleconferencing. Ideally, the authors seek to see diagnostic teams established across Canada to facilitate diagnosis, and, as knowledge in this area increases, to offer recommendations for effective supportive interventions.

Yet, this is clearly only the beginning. Although physicians are engaged in research to clarify and formalize the diagnosis of FAS, it is not currently recognized in the DSM-IV (Burd, 2006), and there is even less agreement and more controversy regarding formal diagnostic criteria for non-FAS expressions of FASD. These factors contribute to numerous practical difficulties for those affected by FASD because many support services including respite, special needs education, supportive housing, and social assistance have eligibility guidelines for service that do not include FASD. Often, these individuals have needs too great to fit into "mainstream" services, they lack the diagnosis of a recognized "mental health" concern and are thus excluded, and they may have an IQ that is too high to be considered for support under "developmental disability" services. With no funding body designated to provide appropriate services to individuals with FASD, the onus lies on the family to assume the costs of necessary supports or to use exceptional advocacy skills to compel community agencies to move outside their mandate to provide the necessary services.

The Mechanics of Prenatal Alcohol Exposure

Current research is focussing on the specific impact that prenatal exposure to alcohol has on the developing brain. Some interesting preliminary findings have emerged, shedding light on various aspects of fetal brain development, and may contribute to an awareness of how, when, and why different aspects of this disability are present in different individuals, based on factors such as timing and level of exposure. One group of researchers has used Magnetic Resonance Imaging to compare white matter density in individuals with FASD in comparison to non-affected children, and their findings added support to the theory that decreased myelination or "disorganized fibre tracts" are the result of heavy prenatal alcohol exposure, which may account for some of the cognitive deficits associated with FASD (Sowell, et al., 2008). Another group of researchers studied the impact of alcohol exposure during the brain growth spurt of the third trimester, finding that ethanol has the capability of "triggering massive neuronal suicide" in animal studies (Olney et al., 2000, p.515). This group argues that these findings identify the mechanism and timeline that account for the reduced brain mass and behavioural abnormalities in non-FAS expressions of FASD. They indicate that the precise timing of the exposure determines which particular set of neurons are deleted, which subsequently results in unique "constellations of neurobehavioural disturbances" (Olney et al., 2000, p.519).

Welch-Carre (2005) provides a comprehensive overview of past literature that has explored the mechanisms contributing to FASD. She notes the research of others who found that cell death is caused by both necrosis and apoptosis (cell suicide), that the "death of a cell line can affect production, migration and differentiation of future cell lines" (p.219), that oxidative stress caused by increased free-radicals caused by the metabolism of alcohol can create damage, especially when a reduction in anti-oxidants to break down the free-radicals occurs. Glial cells are prevented from migrating, resulting in neurons developing in the wrong area of the brain, and receptors are disabled and therefore the brain messages are not communicated. The brain regions primarily affected by alcohol exposure are the basal ganglia, corpus callosum, cerebellum and the hippocampus, which accounts for the deficits in executive functioning such as memory, problem-solving and learning from past behaviour, which are hallmarks of FASD (Welch-Carre, 2005).

Further, Riley & McGee (2005) identify eight factors believed to impact the degree and presentation of alcohol-related brain damage. These include the amount of alcohol consumed, maternal drinking habits, the developmental stage when exposure occurred, genetic factors, factors related to the mother (e.g., socioeconomic status, "synergistic reactions to other drugs," (p.360), and nutrition.

The Search for Definitive Diagnostic Tools

Much of the current research on FASD focuses on diagnostic tools and prevention of this irreversible damage to the developing brain. Recent published studies have explored the development of diagnostic tools such as the testing of an infant's meconium following birth for trace amounts of alcohol (Bearer et al., 2003; Chan, Caprara, Blanchette, Klein & Koren, 2004), studying eye movement patterns (Green, Munoz, Nikkel, & Reynolds, 2007; Medina, Krahe, & Ramoa, 2005), studying nominal reference errors in children's narratives (Thorne & Coggins, 2008) and different brain imaging techniques to identify the physiological structures damaged by alcohol (Cortese, 2004;

Cortese et al., 2006; Ma et al., 2005). These studies have particular importance because physiological markers can aid in diagnosis in the absence of accurate information from the mother about alcohol consumption during pregnancy.

Even where contact with the biological mother is possible, it is also important to consider the difficult position that physicians face concerning the screening of pregnant women, and in addressing the possibility of FASD in the process of diagnosing children with behavioural problems. A valid concern was raised at the National Task Force on Fetal Alcohol Syndrome and Fetal Alcohol Effect (2003) regarding the reluctance of physicians to pursue a diagnosis of FAS because of the implications it had concerning maternal behaviour. Other barriers include a lack of training on FASD, beliefs about the possible negative impact of the diagnosis, stigma, and the scarcity of effective interventions (Gahagan et al., 2006). In a survey distributed to psychologists in the United States, researchers found that less than 4% of respondents felt adequately prepared to identify FAS and over half indicated they were "very unprepared" to make an FAS diagnosis (Wedding et al., 2007).

A report commissioned by Public Health Agency of Canada explored other issues of physician reluctance and recommended the use of standardized screening tools for all pregnant women, better training on how to diagnose FAS, and guidelines concerning the advice to be given to pregnant women who have consumed alcohol (Tough, Clarke, & Cook, 2005). Another study indicated that physicians with a higher percentage of Aboriginal patients were more likely to take a comprehensive birth history including details about prenatal alcohol exposure, and they felt better equipped to provide support to pregnant women with addictions (Tough et al., 2007). This raises further serious questions regarding the discrepancies between FASD prevalence estimates in Aboriginal versus non-Aboriginal communities, in that the failure to regularly assess all patients in a similar way can result in the under-reporting of FASD in privileged groups and contribute to the racialization of FASD.

Gahagan et al. (2006) also found surprising discrepancies in the opinions of physicians concerning the consumption of alcohol during pregnancy. In their survey of paediatricians in the United States, 16% of respondents believed that occasional drinking during pregnancy was safe, particularly in the last trimester. Forty-five percent of participants never addressed the risks associated with prenatal alcohol exposure with female adolescent patients, and only 34% of respondents felt confident in their abilities to provide treatment for children with FAS.

Presumably, if physicians operate under the assumption that light drinking is not harmful during pregnancy, and physicians are hesitant to talk about FASD, much less diagnose it, then early signs of FASD might be overlooked or attributed to other disorders such as ADD/ADHD, ODD, Anxiety, Tourette's, and so forth, creating a "diagnostic alphabet soup": one diagnosis is piled on top of another as caregivers are referred from one physician to the next as their child's lags become more prominent over time and previous diagnoses can no longer account for the difficulties. Considering the importance of early intervention for children with FASD, it is critical to develop routine, standardized checks and balances to ensure that prenatal exposure to alcohol is considered and assessed sooner so that any symptoms of FASD can be monitored.

Routine screening of all pregnant women that includes standardized tools may be necessary to increase the likelihood of getting accurate information about prenatal alcohol exposure. A recent study showed that 50-60% of pregnant women in the United States reported consuming alcohol, and 20% indicated they had engaged in binge drinking or drank at levels associated with alcoholism during this time (Caetano, Ramisetty-Mikler, Floyd, & McGrath, 2006).

Although self-reports tend to be seen as untrustworthy because of the likelihood for women to conceal or underreport their drinking habits during their pregnancy (Morrow-Tlucak, Ernhart, Sokol, Martier, & Ager, 1988), researchers have developed tools that are less likely to trigger a denial-based response because there is no "socially correct" answer (Chang, 2001, p.206). The T-ACE tool, developed by Sokol, Martier, and Ager (1989) and the TWEAK (Chan, Pristach, Welte, & Russell, 1993) are two such models used to identify women whose drinking patterns might place them at a higher risk for conceiving a child with FAS, and can also be used by physicians to open up a dialogue about the potential risks of drinking during pregnancy. Although these tools are aimed at identifying women at risk of heavy alcohol use and would be less fruitful in identifying women with mild or moderate drinking patterns, they still have value in clinical practice.

Recent research has also developed a cost-effectiveness analysis concerning universal application of meconium testing on all newborn babies in Ontario (Hopkins et al., 2008). At a cost of only $150 per live birth, universal meconium testing is favoured by the authors because it increases the likelihood of early identification of non-FAS expressions of FASD by 70%, which could subsequently lead to other interventions to support literacy and implement protective factors to buffer against the development of secondary disabilities. Meconium, the first stool deposit of a newborn, begins to accumulate in the 13th week of pregnancy and would contain high levels of fatty acid ethyl esters in infants exposed prenatally to alcohol (Caprara, Nash, Greenbaum, Rovet, & Koren, 2007). Hopkins et al. (2008) indicated that early identification raises the quality of life for individuals with FASD and increases their earning potential in their adult years. They add that public awareness of mandatory meconium testing may also have a significant preventative impact, in that pregnant women may be less likely to consume alcohol if they knew that it would be detected by physicians at birth.

One problem regarding mandatory meconium testing would be the possibility of women electing not to seek medical services during childbirth in order to evade detection of their alcohol use and the possible repercussions with child protective services that may follow. This could create unsafe birthing practices, posing a risk to both mother and child, and may serve to further marginalize and isolate women with addictions.

Neonatal hair testing may provide an alternative means of gathering information about heavy prenatal alcohol exposure from the last trimester, and it may be accessible for up to three months after birth (Caprara et al., 2007). However, the authors note that both meconium and hair sample testing methods need further development before they are ready for widespread use because of the potential for false positives, as some factors in the maternal diet can cause the presence of certain fatty acid ethyl esters.

In many instances, such as among children in the care of child protective services and among those who are adopted, screening that involves the biological mother may not be possible. In search of alternatives that can assist in diagnoses, researchers have also turned their attention towards whether or not a behavioural phenotype can be developed that would reliably distinguish behavioural patterns unique to children affected prenatally by alcohol from other disorders.

One such screening tool currently being assessed for this purpose is the use of the Child Behaviour Checklist (CBCL), typically used to identify behavioural patterns of children with ADHD from healthy controls (Caprara et al., 2007), to determine if it can assess a FASD behavioural phenotype as well. This approach builds on earlier research by Streissguth, Bookstein, Barr, Press, and Sampson (1998) with their proposal of the Fetal Alcohol Behaviour Scale (FABS), although FABS was initially developed as a means of describing FASD in a meaningful way that would be consistent across different demographic groups such as age, race, and gender and was never intended for use in diagnosis. Kodituwakku (2007) has done work similar to Caprara et al. (2007) to work towards establishing a behavioural phenotype that can be used for diagnostic purposes. The author contends that individuals with FASD display a "generalized deficit in processing complex information" (p. 199), particularly when multiple regions of the brain are required to complete the task. Kodituwakku (2007) proposes that individuals with FASD chiefly struggle with the *integration* of information. Niccols (2007) points out that the development of a behavioural phenotype would be extremely valuable in that it supports the early identification of FASD when prenatal exposure to alcohol cannot be confirmed.

Moore et al. (2002) have also investigated the development of a screening tool for non-FAS expressions of FASD, as they presented that this group still had a tendency towards different facial structures, but that they are different from what is seen in full FAS.

Research on the Prevention of FASD

In recent years numerous studies have focussed on prevention and education, such as measuring the effectiveness of alcohol-free pregnancy public awareness campaigns (Boulter, 2007; Branco & Kaskutas, 2001; Glik, Prelip, Myerson, & Eilers, 2008; Hankin, 2002), assessing public perception about the dangers of alcohol consumption during pregnancy (Abara, 2004; Kyksan & Moore, 2005; O'Connor, 2003; Stutts, Patterson, & Hannicutt, 1997), and gauging the degree to which family physicians and pediatricians feel they have enough knowledge in order to diagnose fetal alcohol related disorders (Gahagan et al., 2006). These studies have made important contributions toward communicating to the general public the dangers of alcohol consumption during pregnancy. Lupton, Burd and Harwood (2004) summarize the findings of several lifetime cost estimates, and conclude that at a $2 million lifetime cost per individual with FAS alone, funding for effective prevention programs should certainly be considered a priority.

Connoly-Ahern and Broadway (2008) conducted a review of newspaper coverage on issues relating to FASD. They explored the various frames with which FASD is presented in the media, such as "dangerous mothers" frames and "victimization" frames. They contend that the "safe levels" frame, which has been given widespread attention in recent years by two female celebrities who drank lightly during pregnancy, has undermined the message that no amount of alcohol is safe, and that future prevention campaigns need to account for this. Connoly-Ahern and Broadway (2008) also cautioned against the use of "dangerous mothers" messages because they are "other-oriented," casting mothers of FASD children as "bad," "irresponsible," "threatening," and "even evil" (p.380), and that young women are unlikely to identify themselves with these images and therefore may not make the connection of the necessity of a change to personal behaviour. Finally, the authors challenge public awareness campaign creators to step away from the unappealing, judgmental tones that have historically been associated with the total abstinence approach, and to consider message delivery agents who are equally appealing as those who have projected the "safe levels" messages.

Grant, Ernst, Streissguth and Stark (2005) took a unique approach to FASD prevention through the use of in-home support to women who have already given birth to a child exposed prenatally to drugs and/or alcohol. They found that the provision of flexible supports in a variety of areas, including connection to rehabilitation programs and employment opportunities, increased the likelihood that the women either abstained from alcohol or were using reliable means of contraception by the end of the program. The authors projected that the program prevented 15 infants from being born with high levels of prenatal exposure to alcohol and drugs.

Although these types of studies are important in order to develop knowledge about and prevent FASD, it is critical that more work be done to develop knowledge of effective intervention strategies for families of children with this devastating disorder. Issuing prevention messages may decrease the incidence of FASD, but this organic brain injury might never be completely eliminated. Many prevention messages are based on the motto that "FASD is 100% preventable," but the realities of alcohol addiction, inaccurate information about the dangers of alcohol, and barriers to accessing alcohol abuse rehabilitation programs, all point to the need for better services in order to encourage women to maintain alcohol-free pregnancies.

Further, the assumption that FASD is entirely preventable is inherently flawed, because this statement assumes that all women are aware of the fact they are pregnant prior to making the choice to consume alcohol. Research has shown that the developing child is affected by alcohol throughout all gestational stages, particularly during the first trimester (Riley & McGee, 2005), and the baby could be irreversibly harmed before a woman is even aware of the pregnancy. Floyd, O'Connor, Bertrand, and Sokol (2006) discuss a more accurate and less stigmatizing prevention message, that any sexually active [heterosexual] woman of childbearing age should either abstain completely from alcohol, or use reliable, effective means of contraception in order to eliminate the risk of having a child affected prenatally by alcohol.

The Lived Experience of Individuals with FASD

Few would argue that the impact of prenatal alcohol exposure is anything less than tragic. As one physician describes it, "from birth onward, a chain of developmental hazards starts to unfold" (Steinhausen & Spohr, 1998, p.337). In a study of 415 individuals with FASD, Streissguth et al. (2004) gathered information about the impacts of FASD. They found that 80% of individuals were not raised by their biological parents, 61% had disrupted school experiences, 60% had been in trouble with the law, 50% had experienced incarceration or had been confined to a mental health facility or an inpatient substance abuse program, 49% had repeated difficulties with sexually inappropriate behaviours, and 35% had substance abuse problems. In an important finding, the researchers determined that individuals with FASD who had a stable home environment and early diagnosis were 2-4 times less likely to encounter these difficulties. This built on earlier research by Streissguth, Barr, Kogan and Bookstein (1997, p. 35), who had reported earlier on the following protective factors, in order of their significance:

1. Living in a stable and nurturant home for over 72% of life;
2. Being diagnosed before the age of six years;
3. Never having experienced violence against oneself;
4. Staying in each living situation for an average of more than 2.8 years;
5. Experiencing a good quality home (10 or more out of 12 good qualities) from age eight to 12 years;
6. Being found eligible for DDD (Division of Developmental Disabilities) services;
7. Having a diagnosis of FAS (rather than FAE);
8. Having basic needs met for at least 13% of life.

These findings on protective factors became an important benchmark for families and service providers determined to maintain hope in spite of the staggering statistics of negative lifetime outcomes.

Streissguth (2007) subsequently published the results of a 25-year longitudinal study tracking 500 children exposed prenatally to alcohol. Even when controlled for factors such as maternal smoking, home environment and socio-demographic differences, it was consistently observed that in childhood there are difficulties with "attention, arithmetic, spatial-visual memory, speed of information processing, and lower IQ scores....during adolescence, problems with tasks involving reasoning and the manipulation of information are more prominently correlated with alcohol dose, as well as difficulty following directions and lack of persistence." (Streissguth, 2007, p.97). The author also described increased use of alcohol in the teen years and mental illness in adulthood.

Recent research has also implicated sensory integration processing problems in children with FASD as key contributors to behaviour problems such as aggression and concentration, pointing to the need for sensory testing and environmental modification in order to support these children (Franklin, Deitz, Jirikowic & Astley, 2008).

Malbin (1993, 2002) also describes some of the important "gaps" in the way individuals with FASD experience and process the world. The author identifies gaps such as difficulty acting on verbal instructions, the failure to apply rules from one environment to the next, the inability to predict the consequence of his or her actions, the inability to perceive commonalities or differences among different people or things, and the failure to distinguish fantasy from reality.

Devries and Waller (2004) describe the "moral chameleon" phenomena, where youth with FASD have a tendency to assume the norms and morals of those around them, which could result in a range of outcomes on any given day, depending on whether their current affiliation lies with a gang or a church youth group. Combined with an "exaggerated need for immediate gratification" (Devries & Waller, 2004, p.122) this can lead to a variety of delinquent behaviours.

Rasmussen, Talwar, Loomes and Andrew (2008) found that children with FASD were better at lying and concealing that lie than their non-affected peers. They go on to infer that children with FASD intentionally lie in order to hide their "transgressions" and they stress the importance of teaching children with FASD that lying has consequences. These are surprising comments considering that most caregivers and practitioners would argue that children with FASD have difficulty linking their behaviour with consequences, and that individuals with FASD generally behave impulsively, rather than in a pre-meditative manner, which one could argue would be required to make an intentional decision to lie in order to escape punishment. In any case, it was clearly demonstrated that children with FASD *do* lie and conceal their lies better than their peers, and it would be important to accurately understand the mechanisms that make this possible in order to better understand this behaviour.

Research recently conducted by McGee, Fryer, Bjorkquist, Mattson and Riley (2008) investigated social problem solving behaviour in adolescents with FASD, in comparison with non-affected peers. This study had numerous limitations due to its design and further research would need to be done in this area, but it lends preliminary support for the idea that adolescents with FASD have a tendency towards approaching problems pessimistically, and they have a lower tolerance for frustration with complex tasks. They also tend to approach everyday problems with avoidance, carelessness and impulsivity. This study helps to confirm what was already anecdotally known about the difficulties that individuals with FASD have with establishing the social skills and problem-solving abilities in order to support gainful employment and meaningful relationships in adult life.

Schonfelt, Mattson and Riley (2005) reported higher rates of delinquency in alcohol-exposed youth who were in biological and foster homes, as opposed to adoptive families. They also indicated that their finding suggests that the cause of increased delinquency in individuals with FASD is rooted in "immature moral judgment."

Unfortunately, the struggles of individuals with FASD do not end in childhood or adolescence. A preliminary study showed that adults with FASD were more likely to experience suicidal ideation than their peers, possibly due to features of FASD that overlap with typical risk factors for suicide, leading the authors to recommend that suicide risk be assessed regularly, using appropriate language that the individual would understand, and asking probing questions to confirm that the individual understands the meaning of idiosyncratic terms often used in suicide assessments such as "death", "the future", and "feeling down" (Huggins, Grant, O'Malley & Streissguth, 2008, p. 38).

Another recent study explored community integration of adults with FASD in British Columbia (Clark, Minnes, Lutke & Oullette-Kuntz, 2008). The authors categorized participants on the basis of "the degree to which his or her disability-related needs are identified and supported in a way that facilitates community involvement" (Clark et al., 2008, p.446). They found that most of the participants in the study had achieved a satisfactory degree of community integration, but it was clear that this was only made possible by the efforts of outside supports such as family members. The researchers point out a concern for what would happen to these adults with FASD if they no longer had family or friends to care for them and connect them to services. They also note that further research should explore the community integration of FASD adults with no support systems, as participation in this study required the assistance and input of a caregiver.

FASD and the Legal System

Perhaps the most embarrassing aspect of the failure of our community to rise to the challenge of supporting individuals affected by FASD, is the one and only service that *is* universally accessible to them: the prison system. As Devries and Waller (2004) describe it, "another crucial component in our research agenda is the service system that is always available for affected people. It has apparently unlimited capacity to add people to its client list. Unfortunately it is the corrections system" (p.125).

Fast and Conry (2004) point out that the legal system has failed to handle individuals with FASD justly, resulting in the overrepresentation of individual with FASD in prisons. Not only can individuals be incarcerated for crimes they *did* commit, but in some circumstances they admit to crimes they had no involvement in. To account for this, Fast and Conry (2004) point to factors such as leading questions, the desire to please the interrogator, and inconsistent memory as problems when an individual with FASD is being questioned about a crime. They suggest that it is possible that individuals may falsely confess to a crime with the hopes that they will be permitted to end the interrogation and go home. Further, the authors point out that many individuals with FASD are manipulated by others to commit the crimes. The judicial system is like quicksand to an individual with FASD: unable to anticipate the consequences of the questions being asked, incapable of deciding when it is best to answer truthfully or to remain silent, and a highly suggestible nature that often causes individuals to repeat others' stories as if their own, puts individuals with FASD at an incredibly uneven playing field when it comes to interrogation and prosecution. As a result of their inability to protect their own rights and interests, individuals with FASD often have repeated interactions with the law and imprisonment.

Literature on FASD Intervention Strategies

There is a significant gap in the research in that very little empirical work has been done to determine effective intervention strategies (Premji, Benzies, Serrett & Hayden, 2006; Zevenbergen & Ferraro, 2001). Typically, FASD interventions have focussed on curbing the child's behaviour, rather than supporting the entire family. In this study, interventions geared toward the caregiver are seen as an extension of an intervention with the child. Given the strength of having a stable, nurturing and non-abusive home environment as a correlate of positive outcomes for the child, interventions that support the caregiver from burnout are seen as having a positive trickle-down effect on the child, as caregiver interventions presumably reduce caregiver stress, increase coping strategies and set the stage for more positive parent-child interactions. Similarly, interventions that improve the experience of the child in the school setting are an encouragement to caregivers as they see their child function more positively in his or her surroundings. Given that any successful intervention has a reciprocal benefit to both child and caregiver(s), this section explores these interventions together before focussing on specific school-based and caregiver-directed interventions.

The information that exists has typically been developed by caregivers, teachers, and other professionals committed to FASD individuals in the absence of formal recommendations (Premji et al., 2006; Zevenbergen & Ferraro, 2001). Since typical behavioural modification approaches are generally unsuccessful with the FASD population, research should therefore draw from the "clinical wisdom" of caregivers and invested professionals (Premji et al., 2006), and recognize the expertise of caregivers – treating them with respect (Brown, Sigvaldason & Bednar, 2005) and as part of the intervention team rather than as clients (Brown & Bednar, 2004). Devries and Waller (2004) suggest that research should be done to investigate families who have *successfully* negotiated the demands of caring for an FASD child, in order to gain a preliminary understanding of factors that promote successful caregiving arrangements.

Several researchers have made recommendations with regard to intervention strategies. Kalberg and Buckley (2007) stress that intervention plans should include the input of caregivers, teachers, and other professionals involved in the child's life, as well as observations of the child in different environments. Zevenbergen and Ferraro (2001) note the contributions of Sparks (1993), who points out that skill-building interventions should not only focus on the skills needed in a child's current environment, but also on skills that will be needed in the future. Sadly, Kalberg and Buckley (2006) report that currently, diagnosis of FASD is rarely accompanied by an intervention plan, and that the diagnostic clinic is sometimes the last contact a family has with a professional specifically trained on the unique needs of a child with FASD.

Even when available, appropriate interventions are often delayed because of the time that elapses while doctors and service providers repeatedly insist on instituting behaviour modification programs and other interventions before they accept that the child's behaviour is neither wilful disobedience, nor due to poor parenting skills (Hess & Kenner, 1998). Unfortunately, this can lead to a worsening in the lagging skills of the child, as well as increased family stress (Hess & Kenner, 1998) and may therefore increase the chance of placement breakdown.

Existing early intervention programs (age zero to six) using public health nurses can be an excellent starting point for offering support to families caring for a child with FASD (Hess & Kenner, 1998). Not only can specifically trained nurses identify the need for an FASD assessment, but they can also assist by identifying the lagging skills rather than pathologizing the behaviour. This could help to diffuse blame away from the child and family, assist the family as they attempt to enlist appropriate services, assess and enhance the family's strengths and resiliency, and provide education, support, and referrals as needed (Carmichael Olson, Burgess & Streissguth, 1992). Hess and Kenner

(1998) also point out that the age span of early intervention programs is ideal for FASD identification because the lagging skills are starting to emerge more clearly during the preschool years, and if more time were to lapse before diagnosis, it would likely be more difficult to obtain an accurate maternal drinking history.

Once a diagnosis has been achieved, there are several researchers who have gathered anecdotal suggestions of ways to modify the school and home environments in order to enhance an FASD child's success by "circumventing" the child's disability (Kalberg & Buckley, 2007; Weiner & Morse, 1994). Effective FASD intervention strategies should also increase protective factors, decrease environmental stressors (Carmichael Olson, O'Connor & Fitzgerald, 2001), and help families determine reasonable expectations of the child's abilities (Giunta & Streissguth, 1988).

Floyd and Gallagher (1997) explored a variety of factors influencing parenting stress, and found that a child's behavioural problems were particularly associated with high levels of caregiver stress. They noted that community-based programs designed to support parents are rarely geared to include children with persistent behavioural issues, and may even *exclude* these children, resulting in the failure to provide support for caregivers with the greatest distress, and their children, who would most benefit from recreational programs that promote positive socialization.

In addition to the need for rigorous empirical studies to assert the effectiveness of different FASD interventions (Premji et al., 2006), it is imperative that research focus on contraindications for specific treatment approaches with specific problems as well. An analysis of case studies in which particular interventions were *unsuccessful* may contribute to our understanding of how lagging skills intersect with one another, and may lead to the development of new strategies to overcome the resulting barriers to learning.

Not only is there very limited research concerning FASD interventions and no research concerning FASD caregiver support groups, but the literature concerning other caregiver support groups has failed to demonstrate their value for all caregivers. The utility of support groups as a FASD intervention tool should not only be assessed, but should also consider whether or not they are useful to all caregivers regardless of age, gender, ethnicity, socio-economic status, distress level, and personality type. Gallagher and Hagen (1996) have pointed out that in their research the support group members tended to be composed of white females, and the authors call for further research to determine specific reasons why men and persons of colour are underrepresented in caregiver support groups.

Further, the research conducted concerning FASD individuals is sometimes exclusively based around those presenting with pure Fetal Alcohol Syndrome, whereas FASD is currently viewed as a continuum of disabilities and research should be conducted inclusively to account for knowledge around effective strategies for individuals with varying expressions of prenatal alcohol damage. Finally, there is a significant gap in the literature in that very few authors discuss or even consider the impact of FASD throughout the lifespan, resulting in a dearth of literature to guide our understanding of identification, diagnosis, and intervention in adult and elderly populations.

School-Based Intervention Strategies

Ryan and Ferguson (2006) point out that while FASD is "on the radar" in terms of public awareness, largely due to prevention campaigns, children with FASD and their parents are still very much "under the radar" in terms of identifying their needs in education settings and implementing effective strategies to help them learn. They suggest that this may be a result of frequent shifts in caregiver arrangements, which may involve changing schools frequently, as well as a lack of a coordinated approach within school-based special needs supports to meet their needs.

Kalberg and Buckley (2007) recommend several interventions that should be taking place within the classroom. Children with FASD are especially sensitive to changes in routine, as well as sequencing, and may benefit from external cues to help them prepare for transition throughout the day. They are also sensitive to stimulation overload and decreasing classroom decorations and clutter could be an important factor in helping children with FASD concentrate. The authors go on to suggest that an in-depth assessment should be conducted with each child over several different occasions, and in different settings, to gain insight into problematic triggers and strategies that could be developed to reduce problematic behaviour. Once this is complete, they recommend rote instruction methods, visual cues (i.e. colour-coded charts, boxes, schedules) to support the child's ability to organize his or her environment, and help the child predict what activities they can expect by using different areas of the room for different subjects, and clearly communicating steps to any task that is assigned. Green (2007) also recommends the use of the Positive Behaviour Support model developed by Bambara and Kern, which focuses on gaining an understanding of what the problem behaviour is trying to communicate, and modifying the environment to avoid problems.

Similarly, the Collaborative Problem-Solving model has been shown to be useful with children with Oppositional Defiance Disorder (Greene et al., 2004), and research should be conducted to determine if it would be useful in the case of FASD as well. This model seeks to identify which lagging skills are implicated in the problem behaviour and to develop plans together with the child to address those goal areas (Greene & Ablon, 2006). Further information concerning specific classroom interventions and modifications including picture symbols are available in an excellent publication, titled Teaching Students with Fetal Alcohol Spectrum Disorder: Building Strengths, Creating Hope (Bernstein & Clarren, 2004), the book *Fantastic Antone Succeeds* (Kleinfeld & Wescott, 1993) or from the FASD Toolkit at www.do2learn.com.

In terms of education at the secondary school level, Duquette, Stodel, Fullarton, and Hagglund (2006) performed case studies on eight adolescents who persisted with high school attendance in spite of the difficulties associated with FASD. It was disappointing that they found that none of these individuals had plans in place to transition them into a suitable vocation, in spite of the fact that legislation required this for all students. This may be indicative of the inadequate support that students with special needs are given in order to help them live productive lives post-graduation, either due to neglect or unreasonable work-load for teachers. Alternatively, it may be reflective of a perceived difficulty in helping these youths *identify* a reasonable vocational goal that would support them throughout their lifetime.

Further, this research suggested that students with FASD who remained in secondary school tended to have caregivers who were intensely involved in advocacy with the school to ensure that the academic activities were appropriately modified to accommodate their children's strengths, which increased their children's confidence in the school setting. Strong statements from parents that their child would complete high school was also observed among the participants. Duquette et al. (2006) suggested this was a protective factor, in line with the secondary disabilities studies of Streissguth et al. (1996). Although strong parental advocacy may prevent the 'secondary disability' of disrupted school attendance, I would argue this does not necessarily mean that high school completion will improve the chances of stable, long-term employment in the same way that it might for a non-affected youth.

Caring for the Caregiver: Important Considerations for Interventions in the Home

Providing full-time care for a child with FASD comes with many challenges over and above those typically experienced in a parenting role. As Giunta and Streissguth (1988) explain,

> The caretaker of a child with FAS assumes a responsibility far beyond that normally associated with parenting. The constellation of physical, intellectual, and behavioural characteristics that typifies patients with FAS can create a very demanding situation for a caretaker. These patients often require constant supervision; they are described by successful caretakers as requiring an extraordinary amount of time, energy, love, and, most of all, consistency. These caretakers need support in their efforts. (Giunta & Streissguth, 1988, p.458).

Fudyk (2003) notes that caregiver couples are further stressed when they place blame on one another for the child's misbehaviour, or when they cannot agree on appropriate disciplinary measures. Fudyk (2003) suggests that FASD caregivers are particularly in need of support because the chronic natures of the stresses of their role can lead to burnout, particularly when "natural resources" (p.80) have depleted over time. In the words of Devries and Waller (2004), "families become consumed in crisis management." (p.122).

Caregiver stress is also linked to the degree of the functional impairments of the children with FASD. The fact that caregiver stress is higher in adoptive and foster parents suggests that stress may also be linked to whether or not the caregiver was adequately prepared and informed about the child's difficulties prior to placement (Paley et al., 2006). Paley et al. (2006) go on to suggest that highly stressed caregivers may respond to their child in ways that exacerbate their child's difficulties, which highlights the importance of designing interventions for the entire family, not just for the child with FASD.

Caregiver Challenges: Loss, Grief, Self-Sacrifice and Burnout

Loss and grief are two very important experiences in a FASD caregiver's life. In the absence of specific research concerning FASD caregivers on the topic of loss and grief, parallels must be explored from the knowledge base concerning caregivers of other individuals with physical and mental disabilities, those with chronic illnesses, and the elderly. Similar to the experiences of caregivers of children with other mental health issues, FASD caregivers may experience a profound sense of loss and grief surrounding their expectations and dreams for their child that have been stripped away as a result of their disability. This can result in chronic "sorrow for what was lost and what would never be" (Pejlert, 2001, p.196), which is reawakened continually with each developmental stage that their child is never expected to reach (Burke, Hainsworth, Eakes & Lindgren, 1992), particularly in light of the progress of the child's same-aged peers and younger siblings.

Further, similarities with "ambiguous loss" (Boss, 2006) experienced by caregivers of autistic children is possible when children with FASD appear to be making progress towards "normal" functioning, only for parental hopes that their child has been misdiagnosed or cured to be shattered when they are unable to demonstrate those gains the following day (O'Brien, 2007). Boss's (2006) theory of ambiguous loss presents that families experience stress whenever there is change, but that the highest stress responses are experienced when the outcome of the situation can neither be curbed nor predicted. O'Brien (2007, p.136) applies this to caregivers of children with autism and explains that "the inconsistency in children's performance levels can keep family members feeling off-balance, never quite certain whether the child is truly unable – or just unwilling – to learn certain basic skills."

Boss and Couden (2002) also identify key factors exacerbating experiences of loss among Alzheimer caregivers, including imprecision in the diagnosis, variability in the family member's functioning from one day to the next, and an outward appearance of health that raises expectations of the family. O'Brien's work provides evidence that these aspects of ambiguous loss are certainly linked to the experience of a caregiver of a child with autism, and I would expect that research would show similar findings for caregivers of children with FASD as well.

Mohr and Regan-Kubinski (2001) speculated that in caregivers of mentally ill children "when the loss is seemingly ongoing or chronic, and when that chronicity may be punctuated by remissions that cruelly inspire hope, the experiences must be devastating for families." (p.69). This point leads me to the question of whether or not obtaining – and understanding -- the FASD diagnosis is a crucial mediator of the grief experience. Some would argue that chasing the diagnosis holds little hope for the child and may be a waste of parental resources, but perhaps diagnosis can offer the family closure, which may prevent the chronic re-experiencing of the grief process.

Mohr & Regan-Kubinski (2001) also discussed that their participants, who were caring for a child with a mental illness, described the onset of the illness as a "nightmare," characterized by a prolonged sense of foreboding that something was not right prior to diagnosis, followed by the sudden impact of the realization that their child was ill. Some caregivers quickly moved to action, and others experienced a period of questioning before finally pursuing assessment. Each caregiver described a cathartic moment when the seriousness and permanence of the situation overwhelmed them, a time of "emotional shredding" (Mohr & Regan-Kubinski, 2001, p.73), in the words of one parent. Subsequent experiences of anguish, guilt and self-blame as though they are inadequate caregivers, and a lack of closure were also described by participants.

In another study on grief in caregivers of children with a mental illness, Godress, Ozgul, Owen and Foley-Evans (2005, p.91-92) determined that these caregivers experienced "continuing emotional distress, preoccupation with the ill child, difficulties adjusting to the loss, the experience of intrusive thoughts and feelings and active attempts to avoid thoughts and feelings related to the child and his or her illness. Clearly, caregivers are significantly impacted emotionally by their child's illnesses.

Caregivers may also experience loss and grief regarding how their life has been changed since assuming the care of a child with FASD. Many disabled children are raised by their grandparents, which is certainly paralleled in the FASD caregiver population, and as a result these caregivers may have to forfeit their dreams of a responsibility-free retirement and instead assume one of the most challenging caregiving roles they would ever experience (Karash, 1999). Even among non-grandparent caregivers, there is a loss of leisure time, grief around their hopes of what parenting would be like, loss of self as they may become subsumed in the problems their child is experiencing, and a loss of self-efficacy as learned helplessness sets in with every effort to manage their child's behaviour that fails. Compounding these experiences, is the lack of understanding of service providers who tend to assume that the caregiver is simply implementing behavioural strategies incorrectly or is a poor parent, and family members who view the child as "bad".

In light of these emotional challenges, more research should be done to explore the impact of FASD interventions with regard to FASD caregivers, themselves (Burd, 2006). If living in a stable, nurturing home has such power as a protective factor against secondary disabilities, as previously discussed, then it is clear that research needs to focus on how to promote and maintain a healthy family unit, and to buffer against burnout. An understanding of the unique challenges capable of threatening a caregiver's ability to continue in their role is therefore important.

Brown and Bednar (2004) began this work by investigating the challenges of caregiving for a child with FASD, using a concept-map to gain an understanding of major caregiving struggles and how they related to one another. The results yielded eight clusters, or categories:

> Parents reported the challenges of preventing setbacks in their children's behaviour, making time for themselves, making and keeping immediate and

> longer-term plans with their child, collaborating with the school, keeping the child involved in social activities, being heard by professionals, and managing their child's behaviour problems. (Brown & Bednar, 2004, p.1).

In a similar study, Brown et al. (2005) completed a concept map with participants to gain a better understanding of the needs of foster parents caring for a child with FASD. Their findings are summarized in eight categories; foster parents need social support, "materials" such as financial resources and respite, a structured environment, the support of respectful, competent professionals, support from other foster parents, a clear understanding of FASD, certain personality traits, and strong organizational skills.

Brown, Bednar and Sigvaldason (2007) continued their work exploring interventions with FASD caregivers and explored what factors might cause foster parents to terminate a placement of child with FASD. Participants identified that although they had anticipated struggles in this role, if their efforts were taken for granted, if they lacked information about the child, if the child could not adapt to the household routines, if they could not curb serious problem behaviours in spite of repeated efforts, if the child harmed someone in the home, or unrelenting exhaustion resulted in burnout then placement breakdown might take place. The authors suggested that foster parents who are resilient and persistent might be best equipped with the personality traits needed to promote longevity in the placements of children with FASD (Brown, Bednar & Sigvaldason, 2007).

Interventions with FASD Caregivers

In the absence of helpful strategies, one could suggest that the constant self-sacrifice involved in caring for a child with FASD, coupled with the perception of there being no marked benefits to the family unit overall, nor to the child's behaviour, can result in learned helplessness, at which point family breakdown is inevitable. Thus the development of effective intervention strategies is critical to prevent caregiver burnout (Brown, Sigvaldason & Bednar, 2005; Weiner & Morse, 1994). Not only might a frustrated caregiver respond to the child in ways that exacerbate the difficulties, creating a self-perpetuating cycle (Paley et al., 2006), but an over-stressed caregiver may also struggle to bond with their child in a meaningful way, which may further impede the child's development. Carmichael Olson, O'Connor and Fitzgerald (2001) demonstrated that "cumulative risk can exacerbate problems, and [the study] extend[s] earlier data by documenting the mother-child interplay that can maintain or reduce the deleterious effects of prenatal alcohol exposure over time" (p.271). The authors therefore call for early intervention efforts that concurrently address mental health concerns in the mother as well as the child, and focus on building healthy attachments as a means of preventing the development of further mental health problems in the prenatally alcohol-exposed child.

In an effort to further understand issues that are relevant to avoiding caregiver burnout, Jones (2003) studied factors that promoted continued caregiving of children with FAS/FAE by foster parents. The author noted three critical factors affecting the likelihood of sustaining the caregiver arrangements: factors related to the personality of the child (e.g. general temperament, capacity for reciprocity of affection, behavioural problems), the ability and motivation of the family to maintain the arrangements, and the degree to whether or not the community was supporting the family. Jones (2003) discussed the "chaining of effects" (p. 212), where one impairment, such as difficulties with attachment, can lead to other risk factors such as the breakdown in the caregiving role or troubles at school, which subsequently could lead to dropping out or difficulty with the law.

Jones (2003) also described the "spider web effect" (p. 201) of caring for a child with FASD, in that many systems are involved in creating a supportive environment for these children, and a problem in service delivery in one system stresses the entire "web." As this happens, caregivers experience progressive difficulties in "holding it all together" as the child ages and supports withdraw. While the initial demand on the caregiver is to be a strong advocate, over time they become less able to intervene on their child's behalf and eventually their role becomes the sole support to their child with FASD (Jones, 2003). Clearly, competent and well-supported caregivers are a vital component of development for a child with FASD, and interventions must be developed to support them.

Current recommendations for family interventions involve the development of supports specifically geared toward FASD (Wilton & Plane, 2006) which include information about the disability, support groups, financial help, respite and advocacy (Giunta & Streissguth, 1988; Weiner & Morse, 1994). Social service agencies should also attend to the family's strengths (Brown, et al., 2005) and promote the family's resiliency (Carmichael Olson et al., 1992; Wilton & Plane, 2006). Wilton and Plane (2006) discuss a model in their community called the Family Empowerment Network (FEN) that provides education and training, support, referrals, and increased access to diagnosis and intervention resources through a parenting hotline, and parent-to-parent matching for mutual mentoring.

Devries and Waller (2004) also propose a "system of care" that involves a purposeful and sustained investment in FASD work including a national prevention and intervention strategy, regional centres responsible for diagnosis, automatic access to intervention support once diagnosis is confirmed, a uniform screening process, mandated training on FASD for all professionals likely to come into contact with affected individuals, and opportunities where FASD caregivers can be mentored by one another.

The caregiver's own social support systems may also be a valuable resource to deliver helpful interventions. Kotrla (2008) challenges church communities to become a part of the support system for pregnant women struggling with alcoholism as well as families caring for a child with FASD, by becoming a venue for disseminating information, encouraging acceptance, offering support groups, mobilizing volunteers, and providing a community of support.

In addition to caregiver support groups, some have suggested the need for group programs for teens and adults with FASD, the most neglected populations affected by FASD. Carmichael Olson (2006) specifically points to a newly developed model of a social skills and lifeskills program. Such programs would not only offer a brief period of respite to caregivers while their child is attending the group, but such a group would also be able to reinforce caregivers' efforts to teach their child important skills for the future.

Another potentially effective intervention model for caregivers of individuals with FASD could be mindfulness-based practices. Minor, Carlson, Mackenzie, Zernicke and Jones (2006) evaluated an 8-week program of a mindfulness-based stress reduction program for caregivers of children with chronic illnesses and they noted a sharp decrease in what were previously extremely high stress levels among these caregivers. Although future studies are needed involving control groups and longitudinal follow-up, this could be a valuable model for intervention, and perhaps it could be incorporated into FASD support groups already being offered.

Although caregivers do not have widespread access to specific intervention programs to support their caregiving role, there are several books and other resources that have been useful for caregivers. One such resource is the *FASD Strategies Not Solutions* (Jones & Cunningham, n.d.) booklet, a compilation of practical ideas developed by caregivers, professionals and support groups. Another excellent resource is *Fantastic Antone Succeeds* (Kleinfeld, 1993), a compilation of stories, insights, and ideas from FASD caregivers and professionals involved with children with FASD, and *Fantastic Antone Grows Up* (Kleinfeld & Wescott, 2000) a similar book geared towards the loved ones of adolescents and adults with FASD. Caregivers can also gather information and ideas from a document that has been prepared concerning the multisystemic needs of an adolescent or adult with FASD, spanning issues including housing, finances, health, education, employment, the legal system, addictions and family support, including an itemized list of special costs that families are typically forced to absorb when caring for someone with FASD (Lutke & Antrobus, 2004).

Central to several of these written resources is a concept developed by Diane Malbin, who suggests the adoption of new ways of interpreting the problem behaviours associated with FASD. Malbin (2002) describes a paradigm shift in how caregivers describe their children before and after receiving education about FASD. Malbin (2002) illustrates that caregivers can move from seeing their child as "annoying, lazy, unmotivated, lies, fussy, acting younger, babied, trying to get attention, inappropriate" to understanding their child to be "frustrated, challenged, tries hard, tired of failing, confabulates, fills in the blanks, oversensitive, being younger, needs contact, support, displays behaviour of a younger child" (p.43) when they learn to see unusual behaviours as a symptom of brain damage that means they "can't" behave, rather than "won't" behave (p.43). Interventions that model this paradigm appear to be quite useful to struggling caregivers.

There are two primary criticisms in the literature concerning FASD interventions with the family, pointing to the need for further development of these approaches in order to maximize their usefulness. First, coordination and consensus among service professionals are important aspects of developing successful interventions, but this appears to be a problem impacting FASD caregivers. As Brown and Bednar (2004) explain,

> ...Though many helpers may be well meaning, they can add to the challenges of parenting a child with a FASD if they are not taking some direction from the parents and responding in a coordinated fashion with a common agenda in mind. (Brown & Bednar, 2004, p.14-15).

Another important criticism of current interventions is that even when social service providers step outside their mandate to provide the intensive support that the family needs, as soon as things appear to stabilize they gradually withdraw services and chaos ensues for the family (Devries & Waller, 2004). Surely we can do better to support these families whose children have very specific needs in the early years that, if met, can have lifelong positive repercussions.

Demonstrated Usefulness of Support Groups in Other Caregiver Populations

In response to the need to systematically study the effectiveness of various intervention strategies, I have chosen to focus on the impact of existing support groups in providing the necessary support needed to help FASD caregivers continue in their role. Although I have not found any research to date specifically studying the effectiveness of FASD caregiver support groups, research concerning other types of support groups (e.g., for caregivers of the elderly and of children with developmental delays or medical conditions) has found that caregivers are generally satisfied with their respective groups, and have felt grateful for the social support they have experienced through these groups (Hagen & Gallagher, 1997).

Researchers found that among participants of a support group for caregivers of mentally ill adults, caregivers "reported less subjective burden, smaller social networks, and greater utilization of adaptive coping strategies than non-participants" (Mannion, Meisel, Solomon, & Draine, 1996, p.43). These findings were echoed in Cook, Heller and Pickett-Schenk's (1999) study that who explored parent burden among caregivers of adults with mental illness attending support groups versus those not attending support groups.

Slowik, Wynne Willson, Chun-Chong Loh, and Noronha (2004) reflected on the implementation of a support group in an in-patient hospital setting for caregivers of adolescents with mental health concerns. They noted that useful elements appeared to be the opportunity to talk about shared experiences, decreased feelings of isolation, and learning information about their child's disorder. They also observed that mutual aid took place and that there was reciprocal education between caregivers and practitioners at the meetings.

Participants in a study conducted by Hagen and Gallagher (1997) also identified the perceived benefits of support group participation as building awareness that they are not isolated, education about resources, challenges to irrational feelings of guilt, buffers against burnout, making use of the healing power of laughter, helping caregivers feel nurtured, offering an opportunity to vent in a confidential environment, and allowing caregivers to process their experiences of loss more fully.

Citron, Solomon, and Draine (1999) found that support groups for caregivers of an individual with mental illness had several benefits, including diminishing feelings of shame and isolation, and the formation of community and cohesiveness with other caregivers who experienced similar struggles. The authors quote a Talmudic saying, "The troubles of many is half the cure," to describe the power inherent in shared struggle (Citron et al., 1999, p.26). They also noted the potential drawbacks of support group participation among this population, including the process that new group members encounter as they hear about the struggles other group members are experiencing, and as they come to the realization that their difficulties may only increase as time goes on.

Qualitative studies of such caregiver support groups have found that factors associated with high participant satisfaction include being led by an effective facilitator who was able to handle difficult situations among group members in order to achieve an atmosphere of trust and acceptance, building in an educational component regarding the disorder and potential intervention strategies, and offering an opportunity for mutual aid and social support to take place (Hagen & Gallagher, 1997; Toseland & Rossiter, 1989).

Another study showed that among Australian cancer patients and their carers participating in support groups, there was a preference for leadership through a trained peer versus a professional; for the location to be a medical facility or community room as opposed to a member's home or a place of worship; meetings to be held monthly; to have continuous, open membership that ideally involves 9+ group members per meeting; and to be moderately structured (Butow et al., 2007). The authors note that these findings may not be generalizable to all caregiver support groups, and they recommend that a needs assessment be completed for each group.

Caregivers attending support groups seem to benefit on both educational and emotional levels. Hagen, Gallagher and Simpson (1997) found that caregivers of adults with dementia participating in support groups benefited from increased education and networking with other caregivers, and they were better able to identify and address their own personal needs. The authors argued that these factors will likely act as a buffer against caregiver burnout. Carter, Nezey, Wenzel and Foret (1999) provided specific examples of how caregiver support groups can support self-care and promote leisure activities, such as guided imagery, "mini-mental breaks" and exercises to help participants verbalize both how they feel nurtured and what their greatest needs are.

Emotional benefits to the caregiver seem to have a trickle-down effect to benefit the individual being cared for as well. Toseland, Rossiter and Lebrecque (1989) found that caregivers who were daughters of frail elderly adults and who were participating in support groups had greater social support, increased awareness of community resources, increased confidence in their caregiving abilities, a decrease in mental health issues and feelings of isolation, and subsequently experienced improved interactions with the individual in their care.

Similarly, Norris, Davey, Davey and Weiler (1995) conducted research with caregivers of the elderly and their findings showed that positive impacts were associated with support groups that equip caregivers with practical strategies for dealing with specific stressful encounters, helping them address problems that they can control, and facilitating an understanding of their needs as caregivers (Norris, Davey, Davey & Weiler, 1995). Presumably, these gains would not only prolong the caregiving role, but improve the quality of the relationship with the cared-for elder because caregivers were better equipped to deal with stressful confrontations and problem-solve more effectively.

Toseland, Rossiter, Peak and Smith (1990) also observed that daughter caregivers of frail elderly adults who attended support groups tended to experience a shift in their appraisal of their role as a caregiver and their abilities to handle challenging situations. However, they note that although caregivers learn about community resources in support groups, there did not appear to be an immediate follow-through in connecting with them. Mothers of children with autism in Taiwan also experienced increased self-efficacy and an enhanced ability to cope with challenging behaviours as a result of support groups (Shu & Lung, 2005).

Several researchers have sought to identify and categorize the specific changes in caregivers as a result of support group participation. Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) published important findings about buffers against stress amongst caregivers of children with autism. Their findings indicated that an internal locus of control did not buffer against stress; instead, coping styles had the strongest mediating effect. An escape-avoidance coping style, characterized by "hoping for miracles, having fantasies, using food or drugs, and avoiding others" (Dunn et al., 2001, p.49) was correlated with higher levels of depression, isolation and marital problems. Marital problems were also increased when low levels of social support were observed. The authors recommended that interventions should encourage caregivers towards "positive reappraisal," such as "growing as a person, finding new faith, rediscovering the important things in life, and being inspired to be creative" (Dunn et al., 2001, p.50). "Confrontive coping" was also shown to have stress-reducing benefits, which included "fighting for what is wanted, expressing anger to the cause of the problem, letting feelings out somehow, and taking chances" (Dunn et al., 2001, p.50).

Hagen and Gallagher (1996) reported on the implementation of a pilot project of Alzheimer caregiver support interventions with three primary strategies: personal care and empowerment, which included education and access to services; the implementation of mutual aid groups; and community organization involving committee work and advocacy. Several recommendations were made, including a caution regarding the difficulties in involving caregivers in planning and leadership endeavours due to the enormous stress already placed on them due to their caregiving role. The authors argued that caregiver support groups are helpful but that they should not be seen as an end unto themselves, because this would draw attention away from the greater political issues that need to be challenged and changed, namely that there are terrible inequalities in the heath-care system that should be addressed that so that caregivers are not burdened to such a degree.

One study also found that support group sessions among dementia caregivers were increasingly helpful over time and that long-term group attendance prolonged the caregiving role (Burks, Lund & Hill, 1991). These findings suggest that perceived drawbacks of group participation are likely to decrease over time, pointing to the importance of developing group content that is both relevant and helpful to long-term group members as well as newcomers.

In a study assessing utility of the Caregiver Risk Screen to explore over time how the experience of caregivers of the elderly is impacted by the involvement of a multi-faceted caregiver support program that included a caregiver support group, Huyck, Ayalon, and Yoder (2006) observed that those who appeared to benefit the most were caregivers whose family member was *least impacted* by their ailments, and those who had the highest level of distress at the onset of services.

Finally, Hagen, Gallagher, Rutman and Sandilands (2003) challenge researchers to investigate caregiver support groups in terms of their ability to promote strength and ability amongst group members, rather than a sole focus on the management of caregiver burden. This team of researchers have proposed the Caregiver Powerfulness scale as a means of gathering information about the self-sustaining messages that caregivers hold. Although more research needs to be done to assess the reliability and validity of this tool, it draws attention to an often-overlooked aspect of the caregiver experience – strength in the face of adversity.

Given the unique challenges and stressors encountered by FASD caregivers in contrast to caregivers of the elderly or children with developmental delays or medical conditions, it is necessary to determine whether or not factors associated with group satisfaction of other populations can be generalized to the FASD caregiver population. If one agrees that these findings could be generalizable to the FASD caregiver population, they shed important light on how caregiver group leaders can evaluate the appropriateness of logistical issues such as location and group composition, incorporate increased self-care strategies into group meetings, stimulate mutual support and problem-solving and model and encourage coping styles that are likely to be associated with better adjustment to the demands of caring for a child with FASD.

Gaps in the Knowledge about Support FASD Caregivers and the Purpose of this Study

Clearly there are many areas yet to be explored in relation to FASD. While research continues to be done to clarify diagnostic criterion for FAS, more needs to be done to distinguish diagnostic categories that describe other forms of prenatal alcohol exposure. Continued efforts to understand the impact that prenatal exposure to alcohol has on the developing brain may also lead to prenatal interventions to mitigate damage, and possibly lead to mechanisms for repair. Further, as awareness and acceptance of FASD increases over time, the development of effective intervention strategies that address the needs of both the individual with FASD and their caregivers should be a priority.

At the present time there is a significant gap in the literature concerning effective means of curbing problem behaviour among children with FASD. Caregivers are often isolated and experience complex challenges related to dealing with the intense behavioural challenges of their children, as well as difficulties accessing needed supports. As a result, many caregivers experience increased stress related to their caregiving role, which may subsequently lead to caregiver burnout. If maintaining consistent, long-term relationships with a nurturing caregiver is one of strongest correlates of positive outcomes for children with FASD, then a pressing priority must be to explore interventions that support FASD caregivers and prolong their caregiving role. One of the few currently available resources designed specifically to assist FASD caregivers in this way is through caregiver support groups. This study is designed to explore FASD caregivers' experience of these support groups and gain a preliminary understanding of their usefulness as an intervention with the FASD caregiver population. Central questions include:

(a) What aspects of the group's process and content are most and least helpful?

(b) What are the limitations of support groups as an intervention tool with FASD caregivers?

(c) How do the groups impact the caregivers' overall experiences of stress and burnout?

(d) What stressors remain unchanged or have increased since participation in the support group?

(e) What kinds of interventions or supports are needed to complement or replace support group participation?

CHAPTER THREE: METHODOLOGY

Paradigm

The study has been shaped by a social constructivist paradigm, which views meaning as something that is co-constructed between researcher and participants (Cresswell, 2007). Rich data is gathered through open-ended questioning and the focus is on gaining an understanding of the participants' world in order to develop accurate themes that are relevant to their experiences. This qualitative approach is preferable to a post-positivistic approach because it allows for the accumulation of large quantities of rich data so that salient factors of caregivers' experiences in FASD support groups can be uncovered and further explored. The dearth of research concerning this aspect of FASD experience provides rationale for inquiry in this manner, as it is intended to be a starting point for further exploration.

Recruitment of Participants

Seven participants were recruited through a mass-distributed email flyer (see Appendix A) to FASD caregiver support group leaders in Southern Ontario. Contact information for group leaders was gathered through internet searches and local FASD websites. Group leaders were asked to distribute the flyer as widely as possible, to both current and past group members. Respondents contacted me via phone or email and were given a description of the study and asked questions to ascertain eligibility for the study (see Appendix B). If caregivers indicated they wished to proceed with participation in the study, they were contacted at a later date to arrange an appropriate date, time and location for an interview.

Sample Selection

Purposive sampling was employed in this study in order to capture the experiences of caregivers within a relatively homogenous group. Caregivers were selected with the intent of gaining representation from participants from the greatest number of different support groups as possible. Prospective participants included individuals over the age of 18 who were full-time caregivers for a child with FASD with or without a formal diagnosis, and who had attended at least three caregiver support group sessions. An attempt was made to recruit participants with both positive and negative overall impressions of the group, as well as at least one group member with an overall negative impression of support group participation.

Respondents who had not attended a support group within the last year were excluded, in addition to those who were outside the intended geographical area or who had only participated in online support groups rather than in-person. One caregiver was excluded because the support group this person had attended only met once or twice before the group dissolved permanently. Support group leaders themselves were also excluded from the study due to the potential for bias.

Biological caregivers were not included in this study because of the possibility that FASD caregiver support group participation may be an entirely different experience for this population, and suitable interventions for this population should be studied independently from non-biological caregivers. Screening for these caregivers took place through questions in the phone/email script and non-biological caregivers were specifically targeted in the recruitment flyer. Biological caregivers may struggle to identify with non-biological caregivers in a support group setting, and they may have different emotional experiences necessary to process such as guilt, regret and shame related to the impact of prenatal alcohol exposure. Further, biological caregivers may find FASD support groups that include other types of caregivers to be oppressive and offensive if group members vent about their anger toward the biological mothers of their adopted or foster children. Biological caregivers are a special resource to a child with FASD because maintaining these caregiver relationships may support healthier attachment in these children, and biological caregivers may be more likely to maintain a longer term commitment to caring for their child with FASD. Further research should capture biological caregivers' unique intervention needs and services preferences.

Since there were no appropriate respondents with an overall negative impression, this criterion was waived, but several participants reported having "mixed experiences" in the support groups.

The Consent Form

Upon arrival for the interview caregivers were provided with a copy of the consent form (see Appendix C), which I reviewed orally with them, and the Resource List (Appendix D). The consent form secured permission for the interviews to be audiotaped and transcribed. Participants were given an opportunity to ask questions before they decided whether or not they would like to proceed with the interview. Several participants inquired about my motivation for conducting the study and how I first became interested in FASD, and these questions were answered openly and honestly. All participants agreed to proceed with the interview.

Ethical Considerations

There were several important ethical issues considered in conducting this study. Confidentiality is seen as an extremely important issue in order to treat research participants in such a way that respects their privacy. As such, all recordings and transcriptions were kept in a locked cabinet in my home and were password protected. Identifying information was removed from transcriptions and in the findings of the study. Further, the geographical location of the participants and the support groups they attended is not disclosed in this thesis, except to indicate that they took place in Southern Ontario.

It was also considered that in extreme cases it could be possible that highly stressed caregivers may provide responses that caused concern about the safety of the child in their care, given the high levels of stress involved in caring for a child with FASD and the potential absence of supports. The research consent form clearly indicated my ethical obligation to report concerns of the safety of any child under the age of 16 to child protective services, and this was reiterated with each participant at the beginning of the interview sessions.

Further, I anticipated that discussing sensitive information with caregivers about their experiences may trigger an emotional response. Participants were reminded that they were permitted to withdraw from the study at any time, and had the right not to answer questions if they wished. If it appeared that the participant was significantly distressed during the interview, I would have offered the participant a break, and then would have collaborated with the participant to determine the suitability of continuing the interview. One participant indicated at the beginning of the interview that she expected she would cry throughout the interview, but that this would not signify that she was overwhelmed and it was agreed that she would signal me if she needed a break. None of the participants appeared to be overwhelmed during the interview and it was not necessary to have breaks or terminate interviews early due to participant distress. At the conclusion of the interview, I reminded participants about the resource list of parenting support and crisis line phone numbers in case they needed emotional support, but this did not appear to be necessary after any of the interviews.

Finally, I had also considered the possibility that a conflict of interest could arise if potential participants had a prior relationship with me, and thus might feel pressured to enrol in the study. Although this was unlikely due to fact that I had no known personal or work connection to any FASD caregivers, to address this concern any participant with a coincidental prior personal or work-related relationship with me would have been excluded during the recruitment process. It was not necessary to exclude any respondents on this basis.

The Interview Process

Within days or a few weeks of initial contact with accepted participants, an interview was arranged at a mutually agreed upon location. Five interviews took place in neutral family service agencies willing to provide space, one interview took place at the Faculty of Social Work at Wilfrid Laurier University, and the last interview took place in the client's home. Each interview was 1-2 hours in length. The interview began with an opportunity to ask questions and review the Informed Consent statement. After this was signed, caregivers were given a brief optional demographic survey (Appendix E). All participants agreed to fill out the demographic survey and agreed to proceed with the interview.

The interviews followed a semi-structured format, allowing caregivers to share any aspects of their story that they saw as important (See Appendix F for Interview Schedule). Probing questions were asked to clarify information and to link responses to questions I had concerning their experiences of support groups. Audio recordings were password-protected and they were transcribed using pseudonyms and other identifying information was removed from data.

Participant Feedback

Once transcriptions were complete, participants were given the opportunity to review the documents to ensure that they had been able to communicate their ideas as clearly as they had hoped, and to ensure all identifying information had been removed. One caregiver declined to participate in this step, and other caregivers submitted only minimal revisions related to typos or identifying information. None of the participants submitted written addendums to the transcriptions.

Once data analysis had taken place, caregivers were sent a six-page summary of the preliminary findings in order to ensure that their perspectives were accurately represented in the analysis, and to offer any feedback regarding the accuracy and fairness of the interpreted findings. Participants responded in a supportive manner to the summary of the findings but declined to provide extensive feedback.

Data Analysis

The method of data analysis employed in this study is rooted in Glaser & Straus' (1967) grounded theory approach, which is known for the synergistic interactions between the data being collected and analytic interpretations, assembling meaning from the data rather than investigating an hypothesis, constant comparison, the emergence of themes as an ongoing process, "memoing" about ideas and possible connections at each stage of the research, purposive sampling, and conducting a literature review at the conclusion of the research, rather than at the outset (Charmaz, 2006).

Charmaz (2006) builds on this theoretical framework and presents a modified grounded theory approach. This author describes a two-stage coding process of the data that involves preliminary analysis, one line at a time, and a second review of the data referred to as "focussed coding," where information and ideas are pulled out and arranged into themes that represent larger sections of data. Lincoln and Guba's (1985) technique of "member-checking" is also incorporated, and this involves the participants in reviewing transcriptions to ensure that their ideas and opinions were accurately reflected in the data.

This study drew from these theoretical influences, but departed from traditional grounded theory in two significant respects, in that a literature review was conducted at the outset of the study to determine gaps in the research concerning FASD, and that the end goal of this research was not to develop a theory. Given that caregiver interventions, particularly with regard to support groups, are a relatively unstudied subject in the research, I approached this project from an inquisitive perspective aimed at co-creating meaning with participants rather than hypothesis testing. Following preliminary data analysis, a second immersion in the literature review took place, stimulating an integration of knowledge concerning findings of this study and how it relates to the overall understanding of the experience of FASD caregivers. New links and insights emerged that provided important topics for future study. However, rather than proceed with a view to construct theory as Charmaz (2006) and other grounded theorists would have done, I focussed on capturing and describing the essence of what it means to be a FASD caregiver and their related experiences in caregiver support groups, in keeping with the modified grounded theory approach of Taylor and Bogdan (1998). Taylor and Bogdan's (1998) approach requires a greater focus on gaining a thorough understanding of the people being interviewed and a comprehensive account of their subjective experiences, rather than on the development of new theories. This approach is appropriate for this study because it recognizes the fluidity and multiplicity of experiences of FASD caregivers, who are each facing different presentations of FASD behaviours, and have unique challenges within their families, schools, and communities.

Data analysis took place in a similar manner to Charmaz' two-stage coding process. Memoing created the opportunity for ongoing analysis, taking place during and after interviews, and throughout the transcription process. Questions that arose during this process were addressed with other research participants in subsequent interviews, allowing tentative interpretations to be shaped by the participants. After transcribing was complete, the data was analyzed in a line-by-line manner, looking for meaning units that might contribute to overall themes. I began to identify several main themes and related concepts that emerged from the data as a whole.

Once this was complete, I reviewed previous memoing notes to reflect on early interpretations and integrate significant ideas. Next, I recorded quotes or ideas that seemed particularly important and grouped them visually according to common themes. Larger categories were then developed, changed, re-ordered and eliminated as needed until it was felt that the data was fully and accurately represented. A summary of the preliminary results was then provided to research participants so that their feedback could be incorporated into the final analysis. Next, a return to the literature review allowed for expanding on topics that were relevant to the themes in the research, and provided some new insights into the findings.

CHAPTER FOUR: RESULTS

This chapter presents a brief description of the sample and then discusses the findings that emerged from the qualitative analysis of the interviews with the seven individuals who participated in this study.

Description of the Sample

Seven full-time caregivers of at least one child with FASD participated in this study. To protect the identity of caregiver participants within the relatively small network of FASD caregivers in Southern Ontario, a limited portrayal of sample characteristics are presented. All caregivers in this study were females between the ages of 30 and 59. Six were adoptive parents and one was a stepparent married to a biological parent. None of the respondents self-identified as visible minorities, although two participants did not respond to this item on the demographic questionnaire. All participants had completed some post-secondary training or education and three participants had graduate or post-graduate education. Annual household income varied, with all participants at the level of at least $40,000 or more, and two participants at the level of $100,000 or more.

Five out of the seven caregivers had two children with FASD in their care, and the other two participants each had one. One child represented in this study was diagnosed with full FAS, two were diagnosed with partial FAS, five were diagnosed with ARND, and three were suspected to have FASD but a diagnosis had not yet been formalized. The ages of the children with FASD ranged from 3-16 years old, with the mean age of 7.5 years. The length of care for each child with FASD with the caregiver participating in this study ranged from three years to nine years, with an average of 5.6 years. The length of time that caregivers had attended a FASD support group ranged from one year to seven years, with an average length of 3.21 years. Support group leadership styles connected to participants in this study included both peer-led and professional-led models, with a slightly increased representation of members in peer-led groups.

Five caregivers indicated they had some support services involved, but stated that they had to use a lot of energy to get them to help meet the needs of their families. One caregiver indicated that she had a few good service providers who worked outside of their mandates in order to try to meet the needs of her family. The last caregiver indicated she had no support services involved other than a family doctor, special education, and social workers.

Findings from the Qualitative Analysis

Seven categories of results emerged from the analysis of the interview transcripts, and each category had several important related themes. The seven categories of results, reviewed in order, are (1) the common challenges of being a caregiver for a child with FASD, (2) the adaptive attitudes and coping skills of caregiver participants, (3) helpful aspects of FASD group participation, (4) unhelpful aspects of FASD group participation, (5) caregivers' feedback concerning group structure/logistics, (6) caregivers' recommendations for support groups, and (7) caregivers' recommendations for supplementary supports.

Common Challenges of Being a Caregiver of a Child with FASD

Many common themes emerged concerning the impact that caring for a child with FASD has on the caregivers. These caregivers face countless challenges in meeting the needs of their children and their families, and incredible opposition from others as they work to establish the supports they need in order to create the best possible environment for their child with FASD to grow. These themes represent both the internal struggles and the external pressures experienced by these caregivers, and clarify how internal and external factors may intermingle and exacerbate one another, intensifying the challenges that FASD caregivers face and thereby increasing the potential of caregiver burnout and/or placement breakdown.

Unpredictable, Intense Behavioural Challenges

Caring for a child with FASD is unlike any other caregiving role in that the problem behaviours tend to emerge in irrational, unexpected and incredibly intense manners. Caregivers are often left emotionally depleted and stunned when a typical request or parental expectation launches the family into an entrenched battle that can last for weeks or months. One caregiver described this frustration;

> *But then he got worse. I mean, it went through a period where we just couldn't control him, he was very oppositional, so you couldn't get him to do* ***anything****. Like, even if he wanted to. It was like he preferred to cut off his own leg than do something for you. So, even if it was like putting socks on.*

This ongoing challenge to parental authority can be confusing for caregivers who are typically encouraged by physicians and service providers to use cognitive-behavioural strategies (i.e., time-outs, reward charts) to curb problem behaviours. Caregivers report that cognitive-behavioural techniques are generally ineffective strategies to curb behaviour, and that in general strategies seem to work one day, and not the next, causing the family to be in a constant state of flux. One caregiver stated that *"every time you have to find a different way to deal with it."* Many times the caregiver is at a complete loss in her ability to understand why the child is having trouble and how to create change.

This is not to say that children with FASD *always* exhibit problematic behaviours, or that they are incapable of loving relationships. But the unpredictability of the behaviour, the remarkable intensity and duration of temper tantrums, and the marked difficulty in de-escalating the child is unusual, as evidenced by the following quotes:

> *...Sometimes these [kids] really piss me off! They upset me, we get into fights, I cry, it's the truth! It can be a really...it can be a nightmare of a household. You know, when the [kids], we have calm times, and then it escalates, and then it gets totally out of control and it's--- it's horrible! I mean, the [kids] are fighting with each other, they're slamming doors, they're firing things, they're yelling at you, they're cursing and swearing.*
>
> *It's really very difficult with FAS because they're so sweet when they're sweet... ...it's like they do everything to the extreme.*
>
> *He can be quite fine for a long period of time and then we hit crisis. And every time we hit crisis it's worse than the last time."*
>
> *The behaviour is **really something else**. Like every now and then I step back and think, "I live in a **nut house**!" [laughing] You know, "How did my life get like this? Whoa!" But, you gotta laugh. [laughing]*

Another difficult factor that caregivers experience is the perceived "downward spiral" that the child experiences as they age. Each successive year can cause the effects of FASD to become more pronounced as the child lags further behind his or her peers.

> *This downward spiral, it usually lasts for about three months. So by the end of the three months, you really are at the end of your tether. And he's fairly small, he's fairly weak, actually, to be honest [laughing]. But he's not going to be small and weak forever. So, you know, we're worried about the future."*
>
> *"And then became the life of a rollercoaster."*

Frustration and Intense Emotions Associated with Behavioural Challenges

Over time, the level of supervision needed and intense dynamics take their toll on exhausted caregivers. Children with FASD may be destructive to self, property, or siblings when left unattended and so caregivers often feel they have no choice but to constantly watch their child. This alone leaves caregivers exhausted, but they still must find the wherewithal to endure intense, lengthy tantrums or "rages".

> *It is a lot of work [laughter], it's quite relentless.*
>
> *It's been such a hardship for us, we've gone through so much.*
>
> *[He is] extremely needy and clingy. Which can be really nice at times, but can be really overwhelming at times too.*
>
> *Most of the time I get through, and sometimes it's really hard, you know? So, it's exhausting......they're not* ***horrible****, they're just...very intense.*
>
> *Sometimes I was at the end of my rope because I could not ..I didn't have the energy he had and he would keep on going, keep on going, keep on going, and that was really tough.*

Pushed to the limit by the constancy of demands placed on them, and exacerbated by stress, lack of sleep, and decreased social outlets, several caregivers reflected on expressions of their anger that were unexpected and surprising after weeks and months of stifling their emotions.

> *But these guys just send me off sometimes, and I just think...where did that come from?*
>
> *And you get so* ***angry****. When I first adopted [my child], I thought, wow, I really hadn't been this angry since I stopped living with my brothers!... ...I don't know if he* ***knows*** *exactly how to push your buttons – but boy, he can get you right there. And up until that point, I prided myself on being a very calm person.*

Not only do caregivers need to deal with the fact that they experience an intense mix of emotions, but it is extremely important for them to be able to find a way to conceal their stresses as well.

> *I find kids with FASD pick up on the tiniest, tiniest things, if there's something wrong, or if you're getting anxious or what-not, and they react. They feed off that and they react...ten times more, I find, than most kids.*
>
> *He's a sponge for other people's emotions.*

Grief

Although one might expect that caregivers of any individual with a mental health diagnosis may experience some degree of loss and grief, participants explained that FASD caregivers face a unique challenge in that the issues their children face are not visible ones, such as in the case with Down's Syndrome. Widely referred to as an "invisible disability," the impact of FASD exists below the surface until crisis hits and the extent of the brain injury can no longer be denied. Grief is a built-in aspect of FASD caregiving over time, as the child lags further and further behind same-aged peers and is unable to enjoy the same freedoms and activities as others.

> *Grief is huge. For some people, the people who didn't know, it's grieving the loss of the kid that they expected to have when they adopted, and will never have. And for people who knew, or at least knew of the risks, it's...even though you know, you're still hoping. You know, that things will be different for your kid. And so it's really an ongoing grief. You know I see seven-year-olds now who can cross the street safely. They can do so many things that my son can't do, and every time it hurts, you know? He got invited to a sleepover – I can't send him to a sleepover. There's no way he can go to a sleepover. Now I have to say no, and I have to tell him no. So...sad for him. [silence]"*

Caregivers also spoke about experiencing and re-experiencing periods of time where things were going so well that they dared to hope that perhaps their child was 'okay' after all, renewing all sorts of hopes for what their child's future might become. This continues until the next crisis point hits, and caregivers described almost violent realizations that their child is indeed affected by FASD. This oscillation of acceptance of the child's diagnosis corresponds to a cycle of intensified grief, which caregivers seem to view as threatening and hurtful because of the emotional jarring that takes place as they are thrust back into their previous understanding and frame of mind as a FASD caregiver.

> *He doesn't look like he has special needs, he'll go through....like we'll have friends, like one of our best friends, we'll have them over, he'll play with their kids for three hours, without a boo, without a fight or anything, and then it's like, "Okay, maybe...maybe we're wrong. Maybe it's not okay? Or maybe he's fine! "and then BAM! Yeah, okay, he's not okay! So I think because of that, because it's not a physical thing that you can see, it's easy to forget, and it's easy...that's been one of the hardest things to adjust our expectations for him. And to remind ourselves not to get mad at him this sixth time you tell him to get his socks, because that's hard for him. But...you still get mad at him about it [laughing]...because it....because it's hard to understand that he just can't do it.*
>
> *Does it cause me to view her differently and manage her behaviours differently? Yeah, absolutely. Constantly. Maybe I'm challenged myself, but you fall in that gap* ***all the time****, and it's* ***so strange****, I think my friend does this as well, because it will escalate and escalate and escalate and you're like in crisis for two weeks solid, handling really volatile behaviours , and you know every day when you wake up, this child has FASD, and you know, you'll handle it in this way. And then they go into this little grace period where they're completely normal functioning...it's just weird [laughing].*
>
> *And I kind of feel the same thing with some illnesses, you know? Even depression, right? You take your pills and you're manic or you're...depressed, whatever, anyways, and maybe you're acute and you're taking your pills and you're really, really, and then you even out, right? And you think, "Well, maybe I'm okay!", right, and you stop taking your pills – it's the same sort of thing for me. It's like you stop applying all the FASD stuff to [my child] and [sound effect like a bomb] [laughing], and I'm like "Oh my gosh!" and there's only so many times that you can do that, right? You're picking yourself off the floor, going "What the.." [laughter] Hit by a real Mac truck, there, hit by a real Mac truck.*

One caregiver related her experiences to a poem she saw about raising a child with special needs. She described parenting a child with FASD as if you had boarded a plane heading for Italy, but you ended up in Holland instead. At first, this is unwanted, expected, and difficult, but over time she stopped wishing for Italy and can enjoy some of the beauty that Holland has to offer.

> *Somebody wrote an article about being in Holland... ...it was basically what's it like to....bring up a special needs kid.... ...you think you're going to Italy but you end up Holland.... ...and all you can think of is, "How can I be in Holland? I need to be in Italy!" But eventually you get used to being in Holland, the pain never goes away, but get used to being in Holland, and you look at the tulips, and*

> *you know all that kind of stuff. But the biggest point is that your friends are in Italy. So we have lots of friends in Italy with their perfect children.*

Fear and Immobilization

Caregivers of children with FASD have often been well-versed concerning the possibility of developing secondary disabilities such as addictions, trouble with the law, and sexually inappropriate behaviour. Many caregivers experienced fear about the possibilities for their child's uncertain future.

> *You have so much that you don't think about it... ...if you think it about it, then you're in terrible, terrible trouble!*

> *You can't let your hope go, right? Like I said, the day-to-day, you do it day-by day, because if you think of the future you start to lose your hope and you can't do that.*

> *If you begin looking into the future you just become paralysed. You do what's helpful for today. Most people kind of live in the moment. It's not like regular kids where you buy those RESP things, or plan for their university education.*

Isolation

Another factor that appears to be universally experienced by caregivers is a pronounced distancing from social contacts since caring for their child. Non-FASD caregivers tend to underestimate the toll that FASD has on caregivers, and well-meaning comments and suggestions from others tend to increase the caregivers sense that no one understands their struggle.

> *[It's] like living on another planet.*

Many caregivers are also unable to pursue and maintain friendships because of a lack of access to babysitters who are equipped to adequately supervise their children and manage problem behaviours.

> *There are very few people who are qualified and able, you can't just phone the 14-year-old down the street, and say, "Please commit" so that also needs to be sort of changed, but yeah. It is very hard to parent a FASD child, for sure, and then get supports in place, like a sitter who is able to manage those behaviours and...you know. It's taken me two years to get someone, finally, at the university level who can manage my child. And then, you know, that's limited. We call her maybe once a week, once every two weeks.*

Caregivers experience further isolation when social service providers are ill-equipped to advise them on strategies to deal with their child, often telling the family to try elsewhere, even in the absence of any other agencies to go to, rather than journeying alongside the family and designing an intervention custom-made to the needs of the family.

> *They say that it's not in the [DSM-IV], so to that – you're on your own.*

Hopelessness

Exhausted and alone, many caregivers sink into hopelessness as their emotional and physical resources deplete and challenges build.

> *Like I said, you can come in[to the group] feeling really horrible because of the sense of no hope...just all hopelessness and helplessness.*
>
> *There was no kind of light at the end of the tunnel [re:respite].*
>
> *...can't see any way out [of behaviour class ill-suited to child's needs].*

FASD caregivers need to be able to believe that if the present struggles can be endured and if all the possible protective factors are implemented, that this will have a positive impact on the long-term well-being of their child and that they will have the best chance of avoiding secondary disabilities. But on some days that hope is much less accessible.

> *For a lot of the people with older kids...their just main goals for their kids are to keep them alive and out of prison. And I look at my son, and think yeah, I can see*

> *where this is going, where I just have to keep him alive and out of prison [silence].*

Powerlessness

Caregivers are further weighed down by their powerlessness to intervene during a behavioural outburst. That innate sense to comfort and nurture a child who is clearly upset and angry is stymied by caregivers' inability to intervene successfully without escalating the situation.

> *If he's in that bad place there's nothing you can do, you just have to keep yourself safe."*

> *"When he goes, he's so....I used to describe him as the Tasmanian Devil, and it's just like [whirring noise], you just stand back, don't try and grab him because you're going to get hurt.*

Criticism and Questioning from Others

"Outsiders" display a range of unsupportive and unhelpful behaviours: from disapproving glares, to quoting one-size-fits-all parenting strategies, to challenging the caregiver's parenting abilities or even the disability itself. Coupled with caregivers' existing tendencies towards self-blame, these external negative forces can become extremely degrading to the strength of the family unit.

> *It's **horrible**! It's a constant negative kind of feedback in your life that causes you to second-guess, half the time, what you're doing, it doesn't contribute anything positive to how you're trying to...it's already hard enough, you don't need external constant criticism of "Well, you know, you know" and it's very hard making even...educated professionals don't understand FASD sometimes, even **doctors** – a lot of doctor's don't get it. So talking to my 70-year-old mother about what FASD is, is...I might as well beat my head against the wall.*

> *It depends on my mood, sometimes I think "Oh yeah, thank you for the advice" [laughing] and think "Well, it doesn't work" but whatever, and sometimes I think "Oh, please! Do we have to do this again?!" but that also depends greatly on my mood, I mean, if you're in a good place and you're in a good mood and you can laugh it off, whereas sometimes you can't...it doesn't matter what it is, it's going to irritate you anyway.*

> *Why do people keep telling me it's my parenting skills? Like you must be the worst parent in the world!*

> *They have not lived those kind of stresses and those kind of things, so everything beyond*
> *or outside of the box is weird and is...is not right, and "It must be the parent" until they live it, and they're kind of like, "Okay, I tried everything."*

> *Once we got the diagnosis it was very hard for us to convince people that this was the diagnosis.*

> *If he didn't talk so well, many people would believe me a bit more.*

> *And we told [the school] what we were thinking [regarding a FASD diagnosis] and they pretty much flat-out told us we were wrong.*

Part of the damaging impact of "outsider" statements is that they overlap and intermingle with a caregiver's own feelings of inadequacy, as well as their level of ambivalence regarding whether or not FASD is a reality for their child. As caregivers wrestle to manage their own doubts and to maintain a balance of hope and realism for the future, "outsider comments" can exacerbate this challenge. Comments that imply that FASD is curable force the caregiver to either accept this statement and expose themselves to the cycle of disappointment once again, or to correct the statement, forcing them to face the devastating nature of this disorder.

> *And that's something that I find hard and very frustrating, that people don't get it, or people say, "Well, he will get better in the future." Uhh, no probably not, and he might even get worse before it even gets a little bit better because usually when they hit puberty it will get worse.*

> *You can't really communicate the needs of the kids so well, at the educational level, because they don't seem to get it. There seems to be a...you know, I don't know what it is, but it's...an idea that it's fixable.*

Sometimes the people making challenging statements and criticisms are not "outsiders" at all, but the actual children with FASD themselves. One caregiver shared that her children with FASD do not understand the reasons for the strict household rules and constant supervision. As a result, she not only faces external criticisms about her parenting decisions, but she receives enormous resistance in her own home as well.

> *But it's really hard, no it's not really hard, it's impossible to try and get someone on the outside to understand that. It's impossible,* ***you cannot****. And we've given up. It's like, you know what? These are our boys, we're going to do what we feel is right for them, what works for them.*
>
> *And if you ask my sons that, they will tell you that there is not another person on the face of this earth that is as mean and horrible, and strict as me.*

When Caregivers Question the Diagnosis

FASD Caregivers are presented with very challenging parenting decisions related to their child's FASD diagnosis, such as the decision not to punish poor behaviour and not to utilize typical parenting strategies such as reward charts. However, the ambiguity of the diagnosis and the absence of irrefutable proof that the nature of the brain damage prevents their child from benefiting from these interventions often lead caregivers to question whether or not they are making the right choices. In their struggle to accept their child's disability, caregivers are also forced to wrestle with doubts about whether or not their parenting approach could be enabling a non-affected child to show poor behaviour.

> *Is he manipulating us? Is he just being lazy? And that's how he was labelled at school. Being lazy, being a baby, being* ***defiant*** *and manipulative. And is he truly manipulating you, or does he* ***really*** *not remember? Does he* ***really*** *not hear you? Or is he just using that as an excuse? Does he* ***really*** *not remember what happens so he doesn't get in trouble for doing it, or is he just using it as an excuse?*

This line of thinking often progresses into full-blown denial of FASD during periods of time where their child is doing well. One caregiver spoke very knowledgably about FASD and how it impacted her child's behaviour, and yet still found herself doubting the diagnosis and discontinuing needed accommodations when her child was doing well.

> *I think now I catch myself....I certainly think like a year ago I ran with it[thinking child might not have FASD] for a bit, but now, no, I try to catch myself... ... And all you have to do is step back and look at all the accommodations that happen around him, right?*

When caregivers question and blame themselves. The constant failure to create change awakens the universal fear among all parents – that they are failures as parents – and the intensity of the behaviour means that they are not only bad parents, but that they must be crazy too.

> *With FAS you get to the point where you just try and try and try and try the same things over and over again, and you never get anywhere. So you start thinking – "Is it me? Like, why isn't it working?*
>
> *Talk about how it is easy to forget sometimes, and how it is harder to convince other people sometimes, and the whole dynamic of "You're making it up, you're making it worse, it's something that you're doing."*
>
> *And that's one of the reasons why, even now, I continue to go to the support group because something will happen and I want to know -- "Did this happen to you? Like, is this, is this normal?" [laughter] Right? Because I need to know so that I don't think I'm going crazy. Because I don't think I'm a crazy person, I have an education, I used to work, I used to have a career, but you kind of second guess yourself after when so many of these things happen you start to second guess yourself, cuz you think .... "this can't be, like, how....how do they do this?" And I'm forever saying like I don't understand how they can come up with these things.*
>
> *There would be days where I would walk into the school and he'd lay into me in the hallway, and it's like...his teacher just sort of would look at me, and I'd look at her, and say, "Has he been like this all day?" And she'd say "No, not like that." And so it's...is it us? And that's what you end up going away with, and that's what my comment is, "It's always our fault, right?" But it's hard not to take it that way, it's hard not to think, "Okay, what are we doing that's creating all this stress for him?" or trying to change the way we approach things so that we're more positive. But, you know, there's only so much you can do, and they lose it when they're safe, when they feel safe.*
> *Because you really do start to wonder about your own self and your sanity.*

Secondary Losses

Caregivers of children with FASD may also naturally experience a sense of loss in their sense of self, stresses to intimate relationships, a drifting away from friendships, loss of career, and loss of leisure activities. Without intentional acts to counter these possibilities, many caregivers discover that they have experienced these secondary losses.

> *We did drift away from several of our friends because we were just so consumed, and I was upset because, I'm like, "Well why aren't you there? Can't you see that we're suffering? We're in pain, we need you. And you've gone."*
>
> *We went through a really bad patch right before his diagnosis where we...there was nothing...there was nothing about [my partner] and myself anymore, we were gone. It was all, you know, this [FASD child]-bubble.*
>
> *But then we talk about kids way more because it's so all-encompassing of our life?... ...it* ***takes over****, everything that you are, and we actually manage to do very well at work. But you know, once you have them, this is your life, you're not getting out of it.*
>
> *It's hard, because then a lot of damage is done while you think you're doing the right thing. You know? A lot of negativity, it's hard on your marriage. A lot of marriage issues in our group.*
>
> *I don't work, because I have to stay home with the kids, because we don't allow them, even now [as older teens], we never allow them to be at home alone, because I find matches in their room... things literally destroyed, broken...I can't do it...I can't do it.*
>
> *You have to change your life.*
>
> *We used to be really big campers and hikers.*
>
> *If you do try and do something, I try to play golf, and I go and play golf, and when I come back [my partner's] had a disastrous morning. And it always works that way.*
>
> *We both feel guilty leaving the other one with the kids.*

Caregivers may also experience a degree of loss concerning the unmet desire to be seen by outsiders as excellent parents. One caregiver shared about the impact it had on her when her child's fabrications caused suspicions of neglect and not only damaged her reputation as a mother but resulted in an embarrassing investigation by child protective services. Other caregivers reflected on the embarrassment and shame they felt because they could not diminish their child's temper tantrum in public.

> *... So we got dragged into the school. And I was accused of ...not looking after their nutritional needs, and we're like...the sad things is, [my child] will eventually tell you that he's made that up, but not until so much damage has been done, that a lot of times it's just too late.*
>
> *It started tearing me apart.*
>
> *One of the hardest things to deal with is the embarrassment around how your kids are, or how you are with your kids when you're in public, or at a family function.*
>
> *We've got over the embarrassment now, so anyway, that's gone, but [laughing] it was quite traumatic.*

Accessing Support: An Uphill Battle

A frequent theme arising in the data is the intense difficulty in accessing supports that are appropriate to the needs of their families. Even when supports exist, caregivers indicate that an enormous amount of time and energy goes into shaping those supports into what they are needed to be.

> *After a lot of hassling, they [the school] were not receptive at first, they thought I was overprotective and overreacting, and I should just back off and let them do their job.*
>
> *I don't know if they don't believe you, but they don't believe the disability... ... I think they don't* ***understand****. They don't get it. They don't let me talk about how he has a brain injury, he's not going to get it, you've gotta change the environment.*
>
> *So every time you go to see someone new, they do the, "Have you tried rewarding his good behaviour?" thing, which you know, I've been to several people by now, you'd think I might have tried that one!*

Few descriptives were used more often than the word "frustrated" and this was often accompanied by an emphatic tone. This frustration is compounded for families who are also experiencing the sting of bitterness stemming from the fact that they were not informed about the possibility of the kind of journey they might be embarking upon prior to adoption. Some participants described being surprised by, and unprepared for, their FASD caregiving role, indicating that they perceived their adoptions had been pushed forward by social workers who ignored, downplayed, or were oblivious to the risks FASD in spite of documented history of their child's prenatal exposure to alcohol.

> *..Being first-time parents and that being hard enough already, so we thought "No, we're not going to adopt a special needs child."*

And then caregivers described feeling abandoned by those same agencies, in a struggle that could very well continue throughout their lives. One caregiver explains her inability to access any level of support from child protective services when she could no longer deal with her child's extreme behaviours.

> *But they basically told us, "Well too bad, you adopted this child, it's in your hands now." And I'm like, "Excuse me, you're a Children's Aid Society, you're there for the children, adopted child or not, it's still a child, I need help! Do you want me to slap him in the face first before I finally get help? Is that the way you want me to do this? I don't think so! Or do you want me to drop him off at the doorstep and walk away? What is this? What is this about?" They would not do anything, really.*

For some, the salve is to fight back and demand appropriate supports, with the hopes that holding CAS's accountable will put an end to the tendency to gloss over the risks of FASD in order to improve a child's chances of adoption.

> *I try to get it there. One of the things I've gone back...it was through [other city] CAS, that's where we got the kids, that's where we went back to get our subsidy agreement. So for me, it was holding them accountable, and getting that agreement in place, and being really kind of pig-headed about it, and really being an advocate, and getting it. So, that for me was a bit of a payback, so it's like*

> *"Okay, we have these kids, we're committed...but you've gotta help us." So that's one of the things we did.*
>
> *I think that we do need to hold CAS's accountable. For future people, who actually know what they're getting into, and then for those that are in this situation. We have to be supported.*

Another source of frustration is the mounting stacks of paperwork that are part and parcel of the search for supportive interventions such as respite. In a busy household where constant supervision is required, finding the time to fill out one application form after the next is an exhausting and intimidating task. Caregivers spoke a great deal about the need for particular words or phrases that must be used in forms, or else denial of services are inevitable. Some caregivers appeared to be quite confident in filling out paperwork repeatedly until the applications were accepted, and for others the presence of an unclear question was a barrier that would cause them to give up.

> *There's certainly two or three people in every group that are very skilled at doing that, and there's all these others who... "What? I don't even know how to answer that question!" or you know, forms aren't their thing and so their kid's not going to get the service. Which is...that's not okay.*

Adaptive Attitudes and Coping Strategies of Caregiver Participants

In spite of the overwhelming challenges of caring for a child with FASD, participants possessed numerous adaptive attitudes and coping strategies that can be seen as lifelines, buffering against burnout and instilling hope. In this next section I will explore several commonalities that stood out across participant interviews, which may shed some light onto how FASD caregiver interventions can be structured in order to support and promote these positive attitudes and coping strategies.

Disentanglement from Unnecessary Battles

FASD caregivers are bombarded with parent-child interactions that present ongoing challenges to parental authority. Caregivers described being worn out and exhausted by these constant "battles" and the failure to be able to find any success in establishing "authority" as a means of creating stability and calmness in the household. The question, then, becomes how can caregivers make changes to decrease the likelihood of these battles occurring, because they neither create wellness, obedience, or happiness in the parent-child dyad? Several caregivers made statements about ways that they adjusted their lives in anticipation of potential problems and disengaged from battles that are both inevitable and unnecessary.

> *So at some point you have to decide that you can't do it [battling over non-life threatening issue]. It takes a lot of pressure off me...I don't...I hate giving up on them, I really do. But I think that [sigh] . . . the more I try and push the further I push them away from me because they think I'm picking on them, they don't understand.*
>
> *Pick your battles, it's really not worth it. [My child] cannot sit at a table to eat. Well why would we go, three times a day, through that battle, while he will sit on the couch, or with his little chair at the coffee table and eat, and he eats a good meal. If I have him at the table, we're fighting for thirty minutes, the food is all over, I'm covered, he's covered, everything is covered, there is nothing in the child [laughing], he gets grumpy because he did not eat. Right? Well, if that was reality, why would you want to deal with that? Pick your battles! I don't like it, and I don't have to, but that is just – I cannot change the child.*

Seeing Problem Behaviour as the Result of Brain Damage

A very important concept in parenting children with FASD is understanding the underlying mechanisms within the brain that contribute to behaviours that would be seen as wilful, rejecting, malicious and rude among children not affected by prenatal alcohol exposure. One caregiver indicated that she sees behaviours as symptoms of FASD, not problems, and that the task is not to change the fact that problem behaviour occurs but rather to orchestrate environmental conditions that make performance of the behaviour unlikely. One caregiver credits reading FASD resources and group participation in helping her extricate the impact of a bruised ego, indignation, and frustration from the interactions she has with her child, because children with FASD lack the capacity to understand how their behaviour affects others and caregivers who internalize the statements or actions of their child take on unnecessary hurts.

> *A lot through my group, and reading – books like Strategies not Solutions – the whole paradigm shift thing, you know "can't" and "won't".*

Adoption of a Pre-emptive Parenting Approach

Many participant caregivers assumed a pre-emptive, strategic approach to parenting that attempted to anticipate possible opportunities for temper tantrums or misbehaviour and they routinely made accommodations to the environment to prevent these things from happening.

> *And they suggest other things about* ***preventing*** *the problem from starting in the first place. If you're putting them in a bad situation and they go crazy and break things, you don't hassle them for breaking the thing, because it's your fault for putting them in that situation. So I think that has been really helpful, to look at discipline issues as, you know, as the results of previous choices, right? Not they're deciding to do something.*
>
> *You've gotta be pre-emptive.*

Rather than become immobilized because of the powerlessness to teach their child not to get into trouble, some caregivers redirect their energies into supervision and creating a supportive environment that decreases opportunities for trouble. This reflects a shift in expectations, where "normalcy" is no longer doggedly pursued, but rather there is a focus on accommodations to help things run smoothly. One caregiver spoke about how freeing it was once she reoriented herself to the ways in which parenting a child with FASD would be different from other children.

> *As long as I can protect them from getting in trouble.*
>
> *...parenting a child with FASD in the way that you think that you should parent a normal child is like trying to get through Toronto with a map of Vancouver. You see flashes of things that look familiar to you, you think you're on the right track, but you don't wind up in the right place. But once you have the right map, it's really very freeing! You can't make this kid behave! You gotta start from a different spot! And I think that once people understand that, it actually makes them feel a lot better. Like of course this wasn't working. I just wasn't doing quite the right thing. I was doing what I thought was right, but it just wasn't quite the right thing.*

Rejection of a "Magic Bullet" Solution

Caregivers also seemed to benefit when they were able to use flexibility and creativity in their parenting style, and were willing to constantly test and modify different approaches as their child's receptiveness to strategies seemed to ebb and flow. This parenting style reflects that a caregiver understands that there no "magic bullet" solutions, which seems to be of some assurance to caregivers that they're not doing anything 'wrong' and that they are not 'bad parents'.

> *I think that they're looking for that magic answer, that one key that's going to make it better. And I think that I've abandoned the idea of that one thing. And I find the conferences just, you know, it seems that everybody's got that one thing that works for them, and they're trying to impart that to the rest of the world as the solution and ...I don't know. I find that demoralizing.*
>
> *I play it by ear.*
>
> *Oh, I don't care that much, now that I know there's not one answer.*

Ability to Harness Negative Affect Towards Productive Ends

One caregiver also shared about her journey from disillusionment and bitterness regarding the fact that her child's prenatal exposure to alcohol was not more clearly discussed prior to adoption. Her initial anger, then grief, gave rise to an important period of questioning that allowed her to determine whether or not she would continue caregiving for this child, in spite of the risks and the personal impact it may have, and to emerge with a strong sense of determination to protect her child and help him reach his full potential.

> *Well, in a way you're frustrated and you're angry – you go through the grief, you go to all those steps and then you come to the point, because I thought – do I then want to parent the child? Or do I say, this is just the case, this is my child, and I followed through. And then I came to the realization that this is my child, and nobody better touch him, and I'm going to do my darned best to bring him at the utmost highest level he can get.*
>
> *Statistically we know our kids aren't going to be able to live independently, so there's that, but we don't know what level of support they're going to need. It depends on too many things, I mean they could be in prison, right? So then you don't have to worry about that part. But if they were to…best case scenario, they learn some kind of a trade and they wind up with a very supportive partner who will be their 'external brain' and make sure they go to work on time and pay the bills. That's the best case scenario.*

It is important to note, however, that caregivers' experiences do not seem to be linear, and that grief, loss, anger, acceptance, denial, and other emotions tend to overlap and interject themselves into caregivers' lives based on what is happening with their child.

> *People will be venting and whatever, and be saying, "I know, I know shouldn't be doing this anymore, or I shouldn't feel like this anymore" or "I can't believe I'm still pissed off about that happening" and it's like, you know, there's an acknowledgement that it's not a linear path, that you jump back and forth between being okay with it, to being really angry about it.*

Caregivers also appeared to be tentatively holding on to hope for a positive future for their child. Aware of the challenges their child may face in adolescence and as an adult, these caregivers look toward flexible, modified goals for the best possible future for their child. Several caregivers spoke about Streissguth's protective factors found in the literature that are associated with better outcomes for individuals with FASD, and they appear to draw hope from aligning with as many protective factors as possible. One caregiver went one step further and recognized that outcomes for children with FASD today may far exceed those of the children in Streissguth study due to early diagnosis and a better understanding of the disorder itself.

> *Well the positives for somebody with FAS is diagnosis before six, he was a couple of months over six, so we figured that would count, a support group, and I can't remember the rest because we don't have those, so we thought, "Okay, we've got to go to a support group, this is better for [my child], so that's what we do."*
>
> *...Dealing with how much change there has been in that five years, and how much more we know now, as parents of young kids, that the research is based on, and showing the secondary disabilities on kids that are in their 20's, that weren't diagnosed until they were 15, that didn't have any of the early interventions that our kids have. They didn't have the parent support that we have. You know, so I tend to read those things and think, "Wow, I really hope that we don't have to deal with that, but we're doing things differently." Because of learning from that. So when I come away from the group feeling, you know, whatever, down around what's going on with someone else, I try to...some people would say it's denial [laughing] in that I think that's not going to happen to us, but it's more of a...not a conviction...but that I'm going to try my damndest to have that not happen to us, and hoping that what we are doing is going to prevent that. And you sorta just gotta keep doing it, and in the end I think we're doing well, it's just...that crystal ball is a bit scary sometimes.*

The Use of Humour, Laughter and Forgetting

Several caregivers spoke about the use of humour and laughter to cope with their stressful daily experiences. Another caregiver spoke about "forgetting" as a coping technique, blocking the most traumatic family crises from memory, in order to be able to move forward in hope for the future.

> *I just make jokes about it [laughter].... It makes me feel better.*
>
> *So you kind of forget. Like I remember when we went to see one of the psychiatrists and he said, "Well, has he ever, you know, done anything..." – because he was describing how [my child] had said he wanted to turn into a dragon so he could burn his parents to a crisp, is what he told him – and he said, "Well, has he ever done anything like that before?" and I tell him, "No. No. Oh*

> *wait, there was the one time he described how he was going to take one of the knives out of the kitchen and come and kill me while I was sleeping." And he described it in great deal. But you forget that, what's happened, right? Once you've gone past that, because if you remembered everything, you'd be like, "Ooh!"*

Using Formal and Informal Supports

Many participants drew support from connection with others, and saw self-care through friendships as an essential aspect of maintaining well-being. Some approached this pro-actively, and would seek out support before crisis hit:

> *It's way harder to pick up the broken pieces than if you're a step ahead.*
>
> *If we go over for a swim just to realize, see there's another family doing those things, dealing with those issues, like sitting at the table – they have issues with that. You kind of feel normal again.*

Others seek out additional emotional support through professional counselling and medication in order to buffer against the chronic stresses experienced by FASD caregivers.

> *I have seen a counsellor myself and that has been very helpful.*
>
> *Our kids aren't medicated, but I am! [laughing] As is my [partner]. When they were small we used to joke, "Someone around here needs to be medicated!" [laughing] And it turned out to be us!*

Two caregivers spoke about hesitancy to use their supports as often as they would like, for fear of overusing them and subsequently losing them.

> *And I also feel like, there's times when I'd like to connect and I don't want to be a bother, so I select...so I'm probably more selective than I'd like to be. You know, for me it would be helpful if I didn't have to worry about that. Not that she's ever implied that I've been taking up too much of her time, I just try to be really respectful of that because I know she's a busy lady.*
>
> *In the summer, they have a cottage, they do their thing, we do our thing, but in the winter, she'll invite him over for weekends, and if we're both going off to a conference she'll take him, so we do have that, but you don't want to...use it up.*

Use of Respite Opportunities as a Means of Self-Care

Several caregivers were also strong proponents of the use of respite care in order to prevent burnout.

> *Because I need my own time to recharge my battery because it takes so much more to parent these children and yet that might be hard and in a way I felt like less of a parent for awhile because I couldn't care for my child 24/7, but then I thought, "No, I see the need for my family, and I know when I am a better parent", and so basically I am a better parent for getting what my family needs.*
>
> *I think a lot of them need respite. Because that gives you a break and you can regroup and start fresh again. Because I think that is the biggest problem for burnout in the parents.*
>
> *One thing I'm a big proponent of is respite. And I'm a proponent of it, having come from a place of being very resistant to it. It took...you know, a few months of being in crisis and our [agency name] worker who happens to be a friend of [my partner]'s as well, calling on the right day and asking me for the 40th time, on the right day and me finally saying "Yes!" and then two days later, having somebody at my house to say, you know, "What do you want, what has to happen?". But it shouldn't have to get to that point.*
>
> *So I'll suggest that – but always, you know, is there a camp, is there some place...anything, always looking for respite because that's what we do, we're always looking for respite, right?*

Being Determined in Seeking Resources and Seeing the "System" as Flexible Versus Fixed

Caregiver participants appeared to have above-average advocacy skills, pushing community agencies and schools to meet the needs of their family, viewing the social structures as flexible, rather than fixed, and commanding their community to make the necessary changes to help their child thrive.

> *And at first I was really upset and really* ***angry****, but then I thought this is not going to get me anywhere anyway, so I turned it around and put my anger in action and got it all myself, but I had to do it all myself. And I will – if I want it, and I need it, then I'll get it. And I did.*
>
> *I think people are afraid that if you make a fuss that, like agencies are afraid that if you make a fuss funding will be pulled, well, that's absolutely not going to*

> *happen, probably the opposite's going to happen if you raise a fuss, you'll get the additional support, you know?*

One caregiver also established healthy boundaries in her life regarding the level of involvement she is prepared to offer towards macro-level advocacy. She recognizes that caregivers of children with FASD may become overwhelmed with the added stress of coordinating awareness campaigns, becoming involved in politics to advance the FASD agenda, and so forth. While these activities are clearly important ventures, these might be better accomplished by caregivers of adult children no longer living at home or by supportive professionals working on behalf of caregivers.

> *It's the jobs of the parents to* ***rage and howl****. Not to be solving the problems, but to rage and howl...... we can't be the ones solving the problems at the same times as we're trying to get through the day.*

Celebrating Each Step in the Right Direction

Finally, another valuable adaptive attitude reflected in the interviews was the celebration of small victories. In the face of challenging life experiences, caregivers do well to reward themselves as they make each small step towards maintaining balance and good emotional health. One caregiver laughed,

> *So I'd be crying on the way to work in the bad times, right. I'm not doing that this week.*

Helpful Aspects of FASD Caregiver Support Group Participation

In general, caregivers had very positive things to say about the ways in which their lives had been improved as a result of participation in a FASD caregiver support group. Most had mixed feelings about aspects of the groups they would like to see changed, but they remained hopeful that improvements would take place over time and saw the groups as indispensable. Several participants indicated that the support they received in the groups was not available to them from anyone else in their lives and that the type of emotional support they received was vital to their survival.

> *This is a lifeline for me.*
>
> *It was like, "Wow, a life preserver!" in a pool, when you're not necessarily drowning, but you know, maybe you're struggling or thinking you could be. There could be rough weather ahead, and suddenly "Whoa! Somebody thought of this! Hello? Great!"*
>
> *No, **no way** [would I be able to manage burnout, exhaustions and fatigue without the group]. No, no way would I be able to handle. Thank heavens we have that here, a lot of people don't have that."*
>
> *I wouldn't ever want to see them stop.*

Caregivers had numerous positive things to say about the benefits of participating in the caregiver support groups. Although caregivers appeared to struggle with finding the words to capture what, in particular, had benefited them, there were clear indications that these groups *were* helpful, even if the group was not running optimally.

> *I think just, for me, it's not been anything specific, it's just knowing that there are other people out there. That we're all in the same boat, that we all have adopted kids, [crying] and that we all adopted them not knowing. I mean that's powerful.*

Caregivers indicated that support groups do not necessarily energize them because a great deal of the content can be depressing, but that there is still a clear benefit to attending. One caregiver noted that although participation in the group initially left her feeling depressed after each meeting, that over time she began to feel more positive following group sessions.

> *Usually I walk away with feeling it was valuable, not necessarily completely pumped or energized, it's more [tentatively] "Yeah, I'm glad I went.*
>
> *Now, I would say that I always feel better.*

Even in groups where there was a high level of structure, caregivers described the overall atmosphere of support group sessions as positive, fun and laid-back.

> *It's fun, we laugh a lot...it's very relaxed.*

> *It helps you to feel good.*

Participants were asked to comment on the specific ways in which support group participation was helpful to them. There were three important themes related to helpful aspects of FASD caregiver support groups: (a) emotional support, (b) practical support, and (c) supportive leadership models.

Positive Group Impact through Emotional Support.

Caregivers drew emotional support through support group participation in a variety of ways. Four sub-themes emerged under this category of results; (a) unconditional positive regard, (b) synergistic connections to other caregivers, (c) normalization, and (d) the facilitation of important emotional processes.

a) Unconditional positive regard and non-judgmentalism. Caregivers indicated that in a world where FASD caregivers are questioned, openly criticized and undermined by outsiders, a FASD support group becomes an extremely important source of unconditional acceptance and validation, where feelings that are hidden from the rest of the world can be laid bare. Caregivers are given the opportunity to verbalize their worst thoughts and fears, and discuss taboo topics.

> *Everyone is understanding... ...you can say anything you like in there... ... you can just say, "I can't stand it anymore." You could say, "I hate my child", you could say **anything** and you **know** that it's a safe environment to say it, and nobody's gonna say, [incredulously] "What do you mean you hate your child?! How could you hate your child?!" You know they'll go, "Yes, I understand." So having that is amazing, because you know that there's no judgment on you.*

Participants frequently brought up that the non-judgmentalism they find in the groups is one of the most valuable aspects of group participation. Group members are able to talk about things with one another that would be unspeakable in other contexts.

> *So I think that if a thing like that [FASD child commits terrible crime] happened, then my group is going to be the only people I would be able to talk to about something like that. Yep. Because they've been through that. And they're not going to judge me as a parent. So I think that if I had an extreme crisis, it would be them I can let my guard down to, more than anyone else.*
>
> *And there's things that I would talk about, or shoot across the email lines that I would never ever say to a friend that doesn't have kids with fetal alcohol. Because, you know,*
> *I'm afraid it would be judged, you know?*

One caregiver indicated that within this non-judgmental context they were more likely to withhold defensiveness when receiving constructive criticisms, feedback or advice from other group members, because she knew that they were offering their opinions from a place of 'knowing' what the future might hold.

> *So other people were saying that [discouraging a major life change] too, but they [group members]...yeah...I did have the sense that they knew more... ... Yeah. "You're not going to want to do that [major change]." Actually when my family said it, I was more angry with them, yeah."*
>
> *They were really able to point me in the right direction.*
>
> *I think that the FASD people, the ones who know, see the bizarre behaviours as symptoms rather than behaviours, and that is a very huge difference, because behaviours you can expect someone to change. "Well if you would just be more firm...", and that kind of thing, "...then they won't act like this" is what I get from the regular people. And the FASD community says. "Yeah, that's what they're going to do!" [laughing] And they talk about strategies, but never things that will fix it.*

In this non-judgmental setting, some people also find release in the use of humour to cope in the group with sincerely difficult emotions and situations. One caregiver described the interaction when FASD caregivers could laugh together about things that others would not find amusing.

> *A place to laugh about it.*
>
> *I have never yelled so much in my life, and that I'm* ***not*** *a yeller. And the one woman leaned over and said to me, "Welcome to the Screaming Banshee Club!" And it just...we all laughed, and it was just like, "Yeah, okay, it's okay!" And try to...you know, have some laughs over things that are horrible!" And, you know, there will be emails that will go out with "Here's a good one, of what happened today at my house", you know, and* ***it's sick****, but in some way it helps to know that somebody else's house is as chaotic, if not more so that day, than yours. So that element of not being alone is certainly...certainly accomplished.*

b) Synergistic connections to other caregivers. Caregivers often lack social support, as the fading of past friendships has been previously discussed as a secondary loss experienced by many FASD caregivers. Seeing friends with their non-affected children, who offer suggestions and ideas that reflect a complete lack of understanding of FASD, and who fail to understand that it's a disability that will not improve over time, caregivers may fall away from old friends when they do not feel understood or supported. Within the setting of the caregiver support group many caregivers find an immediate connection with others, something that has become rare over the course of their time as a caregiver: they are all in Holland.

> *...They right away picked me up and I was part of the group, which is really nice.*
>
> *The need that it fills? .... Well it's connection... ...And we're pretty disconnected, and we're pretty...right? Like it feels when you're parenting that child who does all these things like you're the only person in the world who has a kid who can be doing this all the time.*
>
> *Companionship, friendship, community...support...education...you know, safety, to be able to express both everything from anger, to grief, to celebrations, to ....laughing at things that normal people don't laugh at. [laughter]*

> *And finally nobody's looking like you've got a weird child or whatever, no they understood, right? Yeah. So there was a connection, and that's what I really liked.*
>
> *It's like being in Holland with other people in Holland [laughing].*

Caregivers are so often isolated in their experiences that they are starved for connection with someone who is intimately aware with the depth and intensity of the emotions they are experiencing. Not only is problem-solving together important, but simply "knowing" the daily struggles of one another is valuable. This normalization of experiences provides much-needed validation to the caregiver that they are not a failure as a parent, in spite of their present difficulties.

> *Last September, maybe, the first time back because we don't meet over the summer, in September you're like* ***starved*** *for somebody who [understands].*
>
> *And just to say, "Oh yeah, I'm so sorry," and you don't have to come up with a solution, but you're just listening, you're not being judgmental, yeah, that's what I need.*
>
> *I think it is a sounding ground, it does provide them with a place to come and talk about their issues when they don't have anyone else to talk to who will understand.*
>
> *The best thing about this group, is they let you finish before they answer.*
>
> *I would say normalizing it. And just the fact that even though my kids are doing those bizarre things, that it's normal there. And it's not me being a bad parent. So just a general understanding that 'we're all in the same boat' and the connection to resources. Those are the biggest things.*

This increase in social connection also seems to reduce the feelings of isolation and hopelessness brought on by the persistent nature of the problems and the absence of helpful interventions from the professional community. Caregivers described a heavy investment in the lives of one another, working with fellow group members to investigate problems, generate ideas, and be a source of support to one another during the most difficult times. Caregivers appear to shoulder the burden of 'not knowing' for one another, acting as a source of encouragement because they are not alone in the successes or failures as they forge new pathways together.

> *And we all walk in tired and we all know we're exhausted, and anything is...yeah. Great, right, like "Oh my gosh!" you all* ***know****, exactly, right, like, "I'm going to rip my hair out if I can't solve this problem!" and you don't have to say "Help!" but they can see it in your eyes. [laughing] "My daughter is doing* ***this*** *this month, and I can't take it!" Right? So somebody will come up with something fresh or something. You have to be more creative.*
>
> *It's a great opportunity for us to problem-solve together, with professionals, and when we don't have the answers or they don't have the answers, we can work on it together, and they can bring in people who...or at least point you in the right direction.*
>
> *It makes me* ***upset*** *to know, you know, that other people are going through that...it also certainly it makes me worry about "Are we headed there as well?" sometimes I can take something from that and say, "Well, when that-- if that – or when that—happens, we can try that, or we know where to go," right?*

Caregivers seem to need an outlet to vent their frustrations about FASD and the impact it has had on their child, their family, and their own well-being. A related benefit to being able to share freely is that the caregiver comes to understand that they are never alone in their experiences, because other caregivers have the opportunity to resonate with their feelings.

> *Not so much that you wanted it resolved, but that you wanted it off your chest. You want somebody that understands to listen to you, to say "Yeah, I've been there".*
>
> *I think the venting. Or the venting in the sense that this has happened, this is normal, to get the feeling like yes, you do the best you can. It is not your parenting skills in particular, but you have to change a couple of things to make it work for your family because your child is different so you have to get a different approach. And then get a handle on how they would approach a child differently, or what they do in their house different, or those kind of things.*

One caregiver talked about support group meetings as an actual benchmark of survival and hope during times of crisis. When caregivers know that others are there to help them at support group meetings it may give them the added strength to get through extremely difficult periods, knowing that the interaction that takes place when they meet with their peers is one that may offer relief and create change.

> *[Having this group is] Incredibly important, it makes the difference between sort of getting through a month, sometimes.*
>
> *If I can get through this week and I can get through this month, until the next meeting, and then maybe we can all problem-solve together.*

It also seems to be a comfort to caregivers to have someone who will actually listen to them talk and show ongoing interest in their journey of trying to access supports, whereas non-FASD caregivers seem to 'tune out' from these conversations.

> *You kind of see them [non-FASD supports] glaze over sometimes.*
>
> *Because we've gone through* ***so much*** *where people don't want to have anything to do with it, where they outright say "No, I don't want to hear about it"...I've had family members say that to me, I don't what to hear about it. That's part of my life.*
>
> *There are at least, also, maybe three or four a year where we just kind of sit and informally like, you know, back and forth... "And so, tell me what has been going on in your life this month, and how's it's going with the geneticist, are you getting any head-way with the diagnosis, and who have you gone to, who have you tried, etc."*

Even well-intentioned, supportive non-FASD caregiver family members and friends fall short from fully grasping what FASD caregivers are going through.

> *And we didn't get that from...from other people in our lives. Family didn't get how burned out we were getting.*
>
> *Understanding of the chaos! As much as my friends and family want to understand, and try to understand, it's...I don't think they have* ***any idea****, any idea.*

Caregivers described an enormous source of strength accessible to one another in the context of journeying alongside one another through the challenges of caregiving. While each caregiver has vastly different day-to-day experiences, they resonate at an emotional level with one another. They have borne the same burden, endured the same criticisms, cried out the same frustrations, and they can sense this in one another without there even needing to be words. The very discussion of this connection was an emotional experience for some caregivers.

> *I know more people that are affected – you're not isolated [emotional].*
>
> *We all deal with that, every single one of the people in that group has that common bond, that... people don't even begin to understand FASD, or parenting FASD.*
>
> *It's so frustrating talking to your family members who say 'Well, she looks like any other kid to me, and you just don't discipline them enough and consequence them enough, you're not strict enough' or 'aren't you just looking for things that are wrong with your child because you adopted her'" or something like that, and this new person went, [gasp] "Oh my God, I've heard all of those things, myself, thank you." And it's that kind of "Oh my gosh! Yeah! You have handled the exact same comments that I've handled" and so certainly has this magical bond.*

Caregivers saw the support groups as a connection to hope, and they placed hope and trust that they will draw strength from the group interaction even when the group was not functioning well. Several caregivers expressed that they missed attending the support group during times of their lives when they could not be present. One caregiver pointed to the importance of the face-to-face connection with other caregivers, indicating that the support she accessed through online support forums was valuable to her, but that meeting other caregivers in person had a more powerful effect on her.

> *It's not quite the same [online/email support], but you can still put it out there and just somehow, writing it down, putting it out there, it just...some people do respond.*

Numerous caregivers also made reference to the value of the mentorship taking place within FASD support groups. They identified that drawing on successful strategies from veteran group members was the most effective means of discovering helpful strategies for dealing with their child. Several caregivers noted that veteran group members would also extend offers of additional support outside of the group setting, which, in itself, was invaluable.

> *...Say "Yeah, you know what, [interviewee's name]? I did it 20 years ago, and mine is now 40, but he's been through it and he's doing fine." Not to diminish it, what's going on, but just to give me the opportunity, like "Yeah, we will go through this again, and we will go up and down, and up and down, there will always be a rollercoaster ride, but...".*
>
> *You want to help each other, that's a part of why you're there and... ... if their guys are in a good place then they can offer, and they do offer support to some of us younger ones, and the one couple came up to me – I'd been...I'd only been going for like 3 or 4 months, but like last spring was **horrible**, we were in crisis. And the one gentleman came up to me and said, "Look, we're on our own," their daughter lives on her own, and he said, "If you need help, if you need someone to come over, call us." And I was **floored**. Like he...I had met him three times! And he...and it was a genuine offer, and that was pretty neat.*
>
> *I get something out of both [advice from caregivers with same-aged children versus older children]. Yeah, because you're going through the same thing, so you can see that this is normal. When the kids are older, I get from...she survived, and they survived, and they've gone through it.*

Some group members also contact one another outside of group for crisis support, and this is seen as an extremely important source of support.

> *If you wait for a whole month to finally vent again, I don't think that that is healthy.*
>
> *So in a way that is nice to have a buddy or buddy system going on, especially at the beginning when you're going through so many things and you know you have to stay calm, you have to do this, and you have to do that, and you're dealing with a kid with FASD but you have not completely read the book yet and you know you have to do all those things, but "Oh, how do I do that?!" and you kind of get frustrated, and then it's nice to phone someone and say "Hey, can you quickly help me or do you have words of advice.*

> *We usually phone, and sometimes it is only ten minutes, sometimes it's an hour, but I know she's there. Even if – she said, even in the middle of the night, it doesn't matter, you can always phone. And she knows she can do that with me.*
>
> *We problem-solve together, the two of us, right? And sometimes it's just having somebody listen to you vent, like "Oh my god, you will not believe what she did today! This is not normal! [laughing]... ... It's just the sharing of your experience and knowing you're not alone, right? Because it's not a normal thing, FASD, right? It's very...incredibly challenging.*

Having a special connection to a fellow group member can also be an important resource to buffer the emotional impact of having participated in a particularly intense group meeting, and to ensure that one another maintain a positive perspective.

> *And I have that other person, as well, who's my friend, and who I can, you know, call and say "Wow, I was feeling really shitty after that meeting, frankly I felt awful" and she'll say, "You know what? I feel terrible too, but we have to remember that Ella and you know, Matthew or Johnny, are not the same has whoever, you know that, that child, you know, and it's a spectrum, and so we'll talk each other down after that meeting too.*
>
> *You can see – if you watch really closely, the body language and the facial...and you think, "Oh! I think we scared that person away for good!" [laughing] Or, you know, we do the same thing, we'd phone each other and say, "Well, did you see her face after that couple said that?" Or whatever. "I feel really bad for her." And sometimes we'll say "What can we do, to maybe" – if we have the email – "Are you okay after last night?" and then continue it on.*

Participants described the natural evolution of the role of mentee to mentor over time. Caregivers spoke warmly about the mutual impact it had to be able to 'give back' to other group members, but also spoke of the added pressure of wanting to maintain appearances of constant well-being once they begin to emerge as a leader in the group.

> *It's kind of nice, in the group that you can evolve and take on different roles over time.*
>
> *"I like to feel that I'm not just doing this for my own self [laughing] that maybe I can help somebody else through some of this.*

> *"But then sometimes I feel like I'm falling into the…I've gotta always have it all together, or at least appear like I do.*

c) Normalization. Not only are caregivers able to normalize emotional responses to chronic stress, but the sharing of their stories also allows them to conceptualize what is "normal" within a household with a child with FASD. This allows them to destigmatize their experiences and offers assurance that they are neither imagining the behaviour, creating the problems, nor losing their minds.

> *…It's basically the biggest thing [knowing that you're not alone].*
>
> *I really think that the biggest one is normalization, that it's just…it's just…that there's other people out there struggling, if not as much, then more.*
>
> *With FAS, you want to hear that, you want to hear that your kid did the same thing, you want to hear that yeah, they don't want to brush their teeth, that yeah, he stole money out of your purse. Not that you want to hear it because it's good stuff, you want to hear it because it helps you get through the next month.*
>
> *People don't understand. So it's always refreshing to come and say something like that, and they say, "Oh yeah, that happened to us". [laughing] It feels good!*

One caregiver discussed that seeing the raw, exposed emotion of another caregiver in distress during a support group meeting was an important validation for her, because she could relate to experiencing that depth of emotion. Having one's own internal thoughts echoed by another caregiver stimulates connection and lessens feelings of isolation.

> *But the support group I go to now, there was a young mom, **totally upset**, she arrived at the meeting totally upset and I have had many **many, many, many** days like that. And one of her thing was she ..uh…not being able to get the kids to brush their teeth, they're like four and six years old and I laughed and I said, "mine is [older teen] and he, we're lucky if he brushes his teeth for twenty seconds."*
>
> *It did help me to know that she was so upset because I've **been there**.*

> *A lot of them feel the same things I feel, like total frustration, and I'm doing this wrong, and no, I'm not doing this wrong, yes I am doing this wrong, and you go back and forth, right? [sigh]. It drives you crazy... it drives you crazy.*
>
> *When I do go, it's because I need to hear you say that this is exactly how you felt about your kid, because I felt like that.*

When caregivers journey alongside of one another in a support group setting over time, caregivers may be able to stem their self-deprecating thoughts because of the development of a new schema based on a collective group esteem. If caregivers view one another with respect, think positively about one another's parenting efforts, and believe others to be sane, then when they observe other caregivers experiencing distress and repeated struggles, this can lay a foundation for a new understanding of what's normal and acceptable among FASD caregivers. This, in turn, can assist them in developing a more realistic and appropriate means of self-appraisal, because they do not judge their peers as harshly as they likely would judge themselves. Caregivers may be able to use a more positive self-appraisal of their own parenting skills and capacities because the new idea of 'normal' created within the support group community allows for intense emotion, for mistakes, and validates caregivers who continue to push towards the best possible outcome for their child.

> *So a support group kind of lets you know that, you know what? They have their own kids too, and they're regular, and then they have an FAS adopted kid, and you know, they're pulling their hair out, because they are thinking "What am I doing wrong?". Well, you're not doing anything wrong, you're not doing anything wrong at all, it's how these guys are wired. So support groups are really good for that.*
>
> *That it's okay, you're doing what you can.*

Group members are also more willing to listen to one another when concerns are expressed about stress levels in one another, and can tell one another that respite is a non-negotiable aspect of self-care. In a caregiving situation where caregivers are often responsible for constant supervision in order to keep their child alive and out of trouble, accepting respite and taking time for solitude and attending to one's own needs runs against the grain of what caregivers have learned as a survival skill.

> *They really strongly encourage respite. And yeah…I think that their understanding of the value of respite is something that I don't get from the regular world too. Most of them think, you know, "My kids have tantrums from time to time, and I'm managing!". They don't get the level of intensity in parenting these kinds of kids.*
>
> *I guess I've gotta let go a little bit, that's what they encourage me. [laughter]*

Caregiver support group participation can also build confidence that there are strategies that *will* be helpful, and encouraging caregivers to keep trying to find the ones that will work best for their child.

> *It makes me feel like – at least I can do something. And I don't know if it'll work in the long run, but I try not to think about that.*
>
> *It just helps me to function on a daily basis living with a challenging child, and it helps me to be a better parent to that particular child. It helps me to be a better parent to my* ***other*** *child actually, when I'm brainstorming smarter ways of managing her sister, as well. So, it…it's…builds confidence that you're doing the best you can be doing.*

Participating in a FASD caregiver support group also provides a venue for being positive about caregiving skills and parental instincts, which is significant when outside forces are constantly challenging and questioning caregivers, particularly with regard to the implementation of 'accommodations' that restructure the environment to reduce the chances of misbehaviour, as outsiders may view this as enabling the child to maintain a pattern of poor behaviour.

> *Trying to get some semblance of "Yeah, you know, you're not crazy. Like this isn't right." And I think all along we had just been making accommodations for him without knowing that we were making accommodations. Just like, "Oh yeah, that's just Joey, yeah that's okay, that's just the way it is." But…but needing some…some validation that what we were doing was right. And…and that this*

> *wasn't a dead-end road, that there also was things to do that were going to be helpful.*

d) Facilitation of important emotional processes. In the FASD support group setting, caregivers are challenged to decide if they truly believe that their child has FASD. Often attending groups well before they ever receive diagnosis, and in the absence of irrefutable evidence of FASD, caregivers experience a degree of uncertainty concerning their child's difficulties. Listening to the stories of other caregivers in the group may help caregivers sort some of those feelings out, because either they can relate to the patterns and experiences discussed by other caregivers, or they cannot. Some caregivers refuse to accept the FASD diagnosis, and yet years later they return to the groups once the lags are more prominent and diagnosis is inevitable.

> *The* ***real*** *deal. Kind of like that it's really happening, that it's really true, not only in my family, but in other families, and what would be the consequences if we would stick our head in the sand...So it was kind of like an eye-opener. He had heard it, but now coming from another person, now it clicked.*

> *Because otherwise there's too many other forces saying, [in a nasty voice] "Oh, she doesn't have anything like that! Oh in our day we used to...you know, spank them" or "You just need to time her out" so absolutely yeah, I need to have that...I don't know how people function without their support group, their FASD support group.*

Within the context of the support group caregivers are also subsequently faced with their own experiences of grief when the stories of other group members stimulate thought in this area. Grief experiences tend to overlap with one another, and the commonality among members is rich context for connection with one another. One might assume that outside of the group context grief experiences are stifled in order for the caregiver to maintain emotional equilibrium, but the processing of these emotions are critical to long-term functioning and support groups seem to recognize the importance of bringing these emotions to the surface in a safe and healing environment.

> *Now my kids are getting older, as I am seeing – you know, my son is 7 now—and I see his friends that are "regular", in quotations, 7 year olds, being able to do so many things that my son can't do. And ...the support group is really important to me for the grieving. So even though I knew what this was going to be, you still always hope.*
>
> *And certainly [the support group is a place] to grieve about it as well.*

Another caregiver provided a powerful comment on the group experience of another member's traumatic experience. Group members not only bear witness to one another's experiences, but there seems to be a shared emotional grieving when the 'worst case scenario' becomes reality for a fellow caregiver.

> *[It's] just not something you can discuss over coffee with an average friend, but in the group you can. And then people aren't like, "Oh, your son is a menace to society, lock him up somewhere!", they really are sad for the parent, and the son, and they understand that this didn't happen because they were a bad parent and wasn't supervising them, this is just one of those things that happens.*

Aside from the normalization experience that comes from hearing about the struggles of other caregivers, support group participants also find that hearing the stories of families who are "worse off" has a significant impact because caregivers are consequently able to see the positives and strengths in their family situations that were previously obscured. Caregivers expressed a degree of guilt over the fact that they felt better to know that other families were going through worse troubles, but they recognized that there was an important element of healing in this.

> *Oh, it could have been worse, so thank God it's only this bad.*
>
> *Always going back to, okay I'm not alone in this, you know, because your son is incarcerated and mine's not, so I feel good about that. And that helps! That helps me and it helps my [partner], you know, we'll say "Well look, her kid's 19 and he's been in prison for four years". So, we're lucky, you know?*

> *Understanding, that everybody has been in that spot, and many still are. Just understanding that it's not you, it's just FASD, this is not you are a lousy parent or your kid is a lousy kid.*
>
> *It's a bad thing to feel good about, that there's other kids doing the exact same upsetting things, but it feels good.*

Even in light of the depressing aspects of hearing about the difficult struggles of families with older children, one caregiver identified that they could see hope in the fact that their fellow caregivers have *survived* in spite struggles, which helps caregivers feel hopeful about their own ability to pull through incredibly difficult situations. Caregivers become a testament to strength and survival for one another.

> *And if you want to call you can always call and we can talk about it. Not that they could really do anything, but just the understanding, the compassion, they had lived through it, so you know they survived so probably I can do it too, those kind of things I found very, very helpful.*

Conversely, caregivers also reported benefits from hearing success stories from other caregivers and seeing progress in other families.

> *[What] I **really** like about that group is that there were a couple of older foster and adoptive mom's who had done this already for twenty years, who had gone through **everything** already, and I felt that I could see their success stories.*
>
> *And an element of hope in that looking at some of those older kids, young adults, that are doing well, that are living independently with support, but you know, having jobs, and things like that. That is carrying out...carries some hope with it.*

Positive Group Impact through Practical Supports

Caregivers reported several practical benefits of support group participation as well. These include: (a) facilitation of a paradigm shift in understanding FASD; (b) an opportunity for rest/respite; (c) connection to resources; (d) advocacy; (e) innovation and education; and (f) practical tools.

a) Facilitation of a paradigm shift in understanding FASD. Caregivers repeatedly made mention to the 'paradigm shift' in how they had come to view and understand their child's disorder, as an extremely important aspect of being able to tolerate and understand the erratic and intense aspects of their child's behaviour. This appears to be a difficult shift in mind-set, and caregivers discussed the need for others to support them in maintaining this perspective. The whole concept of discipline and creating change with children with FASD is so counter-intuitive that caregivers need consistent and gentle reminders to maintain the paradigm shift that seems to buffer burn-out. This shift is even more difficult when the child has periods of time where they appear to be functioning 'normally' and the caregiver is tempted to doubt the FASD diagnosis until crisis hits again. The FASD caregiver support group can be an excellent venue to facilitate this shift in thinking.

> *And in those times it's like you think, "Wow, they're okay!" and you fall back into the old patterns and then... ...it kind of keeps you off balance all the time. So the group is there to help you go, "Okay, right, go back on that little plateau where you're understanding it as a neurological disorder and a physical disorder".*
>
> *And I said something to the other family from the support group that we were at this week, and she's like, "Well, really, that's like pretty much exactly what you* ***wanted*** *to happen, wasn't it?" And I sort of said, "Yah, I know! Because now she's seen it! And it's real! And it's not something that you're fabricating, and it's not...you know... cuz she said, "I don't know about you, but it's hard to convince people that there really is something going on."*

(b) An Opportunity for rest/respite. Caregivers also benefit from support group participation simply for the fact that it gives them a few hours away from their caregiving role, where they can benefit from social interaction without feeling guilty about it.

> *And somehow it makes it better, to have -- the chaos is still chaos, but somehow there's two adults there, and you can laugh about it, or you can try to have a coherent conversation for little thirty second snippets here and there. So that's been great.*

Five minutes away! [laughter] … …just away from here, to spend some time by myself.

> *You can justify having someone to come in to go to a meeting. Which is pretty sad [laughing ironically].*

c) Connection to resources. Another common theme among participants was that caregiver support groups were the best venue to obtain practical recommendations for ideas about needed services, helpful service providers, camps, doctors, and financial sources of support. Group members also assist one another by sharing advice concerning certain phrases or descriptions to use on application forms in order to best meet the eligibility criteria of different services.

> *The paperwork, as a whole, can be really intimidating. So they say, you need to talk to this person, or I had good success with that person, or* ***don't*** *talk to this person [laughing].*
>
> *People are able to say, "You know what? You need to call [service provider], she will hook you up with an occupational therapist fast, you tell her this-that-and-the-other", sometimes they can even say, "You know what? Use this word, use this phrase, and they will have you in." Or "You need to go to that doctor, who will possibly write you the quick referral to the geneticist, or etc." So we have a lot of really smart and useful tips that way, because there's a lot to knowing how to navigate that system, and it's kind of funny when you pick up the phone and they so "No, the phrase for that is technologically dependent, and if you don't have that, don't even bother applying."*
>
> *To gather information. You know, like it was people from the support group that said, "Hey you've gotta apply for the Disability Tax Credit, you've gotta do this, check this out, check this out," that wasn't our [agency name] worker telling us that.*
>
> *There are options, there are always options. You learn what's out there.*

d) Advocacy within caregiver support groups. Caregivers also indicated that group members empower one another to persist to obtain services and resources that may involve repeated applications, appeals, and threats of legal action. Caregivers spur one another one in this endeavour, and at times they may come alongside one another for support during meetings with the school or other services.

FASD caregiver support groups are also a means of mobilizing caregivers to participate in larger-scale advocacy efforts such as FASD-Day awareness campaigns, conferences, regional FASD Task Forces, interviews with the media, participation in research projects, and provincial Stakeholders involvement.

> *And then another thing it's been great for is connecting me with the larger FAS community.*
>
> *They bring other things to our attention like, well there's a FASD awareness day coming up, so they would mention that, there's a conference coming up, or there's this speaker over here in [city] doing, you know, x,y and z, you might want to attend that. So they're just* ***great resources****, really.*

e) Innovation and education. Some participants indicated that they had heard about groups that provided a variety of innovative educational special topic support group nights. One idea included having a night where justice issues were discussed, and police officers, probation officers, and lawyers were invited to brainstorm about ways to address the fact that group members' children were having repeated difficulties with the law. Another idea included bringing occupational therapists and paediatricians to talk about sensory problems and developmental lags and how to help children reach new milestones. Another idea centered around the education system, and bringing the teachers, vice-principals and special education department heads from the schools of group members' children to discuss successful strategies to promote learning. Caregivers expressed great interest in pursuing topics like these within the support group sessions a few times a year.

f) Practical tools. Caregiver support group are also an important venue to gain information about practical tools that can help caregivers and their families. Caregivers can share resources such as templates for calendars and picture symbols to help their children visualize daily routines and the sequencing of tasks. Resources such as books, movies, conference materials and other resources are also frequently shared within the groups.

Helpful Aspects of Support Groups Linked to Group Leadership Style

Group leaders have pivotal roles in setting the stage for whether or not a group will be perceived as helpful or unhelpful to group members. Several participants discussed qualities in their leaders that contributed to the overall well-being of their group. This section of the results will explore the approaches and leadership qualities that seemed to enhance group process and increase satisfaction among participants.

One important leadership skill that participants identified is the ability to create a safe environment for all caregivers. This enables group members to share their innermost feelings that are generally hidden from others, and to foster a constructive and non-judgmental environment of listeners.

> *It's a really safe place.*
>
> *I think that the rest of the group would not tolerate that [rude, judgmental comments]. Like I do think they are enough – there are strong, intelligent people in the group, who would say "Hey, we don't do that here." And I would consider [group leader], as a facilitator, as very sensitive to that.*
>
> *The [group leader] fairly regularly will, at the beginning of the meeting say "You know, just a reminder that we're all...adoptive parents here, we're all here to sort of not infringe on anybody's confidentiality", and sort of laying out the parameters routinely so that that...and also will say, "Just a reminder, too, that we want to remember to use adoption-friendly language," and so everybody is already kind of in a sensitive area when they say that.*

Another aspect of group process that depends on the leadership is the ability to establish and maintain structure so that each caregiver has an opportunity to share, a responsibility to listen, and a respect for the group process. The groups that caregivers spoke about most positively had a routine manner of sharing and interacting, though not regulated in militaristic manner.

> *So I would bring up my issue, and then everybody or anybody would give suggestions or you would talk about it. Either solve it, or not solve it, but you would be allowed to talk about it, and then just kind of move it around, and the mediator would make sure that people had their say, because there are – as, in any group—people that can monopolize.*
>
> *It's quite regimented, I think that's good. There's a two minute check-in around the table and everyone has two minutes to say what's been going on the last month, introduce themselves if there's new people, whether they're in crisis or not, what they need to talk about, that sort of thing. So that goes around the table, it's quick, it's kept to a time.*
>
> *They're very good at saying, okay, you know, "Have we helped you with the issue? We're going to have to move on now" and that kind of thing, and "Maybe we could talk about it next week, but we need to deal with other peoples' issues."*

Some group leaders have shown remarkable ability in their commitment to maintain the group structure, and to gently but consistently re-establish control of a meeting when a group member begins to dominate the discussion or makes inappropriate comments.

> *Once in a while, certainly there's somebody who does something [offensive or inflammatory] and you know, and then that's on the facilitator again, really, that's a good facilitator who can rein it back in, and "Okay, maybe we need to discuss this outside of the group" or "maybe you can contact me separately" and sort of take the reins back again, right?*
>
> *Just by continually saying to this one couple, "Okay, but we're going to go back to [my name]'s problem, we'll get to you in a moment. Okay, hold on... ... And she will continue to interject until the person stops. Not that the person is trying to be rude, it's just the kind of personality they are, where they keep talking. And so she has interjected, I know at one meeting, several times, probably like six*

> *times in less than two hours to tell this person, "Okay, hang on, we'll get to your situation, we'll get to your daughter, but we're going to go back to..."*
>
> *[Leader]'s really good at cutting down the side conversations.*

Group leaders must also be able to negotiate tense moments if caregivers become defensive when being given suggestions, or pushy in their manner of sharing advice. This is particularly important in the community of FASD caregivers, because one especially frustrating aspect of the disorder is that strategies may work on one day but not the next, for one caregiver, but not his or her partner, or for one child with FASD, but not the other. Leaders may be required to remind participants about the variability of the disorder and the many exacerbating factors that can lead up to an emotional outburst of the child.

> *...The mediator will say, will interject and say, "You know what? That is her side of the story, and that's how they deal with it, and we know that your side is very different, so perhaps we can address that". Like if you're the person bringing up the issue and somebody else is pushing their beliefs on you, that can be really difficult. Because every family is different, and you have to keep remembering that, we're not talking about a disability where everyone is the same.*

Participants also indicated that they appreciated when their leaders used "kid-gloves" and showed compassion for other caregivers, because there is a level of emotional fragility and vulnerability among those who gather for these meetings. Caregivers saw it as important that group leaders worked from the framework that caregivers are doing the very best they can to help their child succeed, and that they need encouragement and not judgment.

> *I think they have to feel compassion for your situation, even if they are a caregiver of an FAS...you have to feel...you can't run it like it's a board room. You have to...there's a lot of feeling and a lot of emotion going on in these rooms. And you have to remember that. [silence] I guess just...just to have compassion for the members that are there...and...I don't know, treat them with kid-gloves, you know, because nobody's to blame, nobody's at fault.*

Group leaders may also naturally become the "go-to person" for newcomers to learn how to connect to needed services. Group members spoke highly of being able to contact their leader for guidance on filling out application forms including specific wording, helpful referrals, and connections to other resources.

> *I think having a leader who is familiar, really familiar with all the available resources. And how to get through the paperwork for all age levels, I think that's huge. Someone to walk people through that, I think that's really big. Just getting people through the paperwork.*

Caregivers also identified that group leaders are most effective when they have superior knowledge about FASD and how it may impact the caregivers. They indicated that strong leaders should be able to effectively communicate basic information about FASD, facilitate a "paradigm shift" in how caregivers interpret and understand problem behaviours, and be able to stimulate brain-storming within the group to help the caregivers circumvent the disability.

> *The FASD group has...it helps me constantly reframe...cuz I think it's maybe every parent...sometimes you're just parenting them, right, and sometimes you're just in the moment and you have to stop and remind yourself, "Wait a minute, she's doing that because...her brain doesn't work that way", right? And some days you've got it, other days, she's functioning fine and she seems to be maybe not having a whole lot of...rages, or a whole lot of the...attention difficulties or whatever, right? She doesn't have a whole lot of them. So on those days you kind of forget, you fall into this lull where you think, "Okay, maybe we're going to be okay" so...and then it* ***hits*** *again, inevitably, inevitably, always. And you're gobsmacked and you go into your meeting and you're like, "Yeah" and somebody else is there to say, "Let's reframe that."*

Two participants also noted how meaningful it was to have group leaders who invested time in their families outside of the actual group sessions, both during times in crisis and when advocacy is needed.

> *And [leader's partner], he's been really helpful to us, he's come to our aid, he's advocated for us, when we've had people sit there and say there's nothing wrong with him. And [leader's partner] has come to our side and said, "Well actually there is."*

> *When I first started going and then we started to hit crisis, you know, she came over and she just said, you know, "Why don't I come over this week?" So we hung out, and so there is...availability around that kind of stuff too.*

Caregivers also indicated that it was very helpful when group leaders routinely sent out emails about relevant research, events, and resources, and when they coordinate an online forum for group members to offer support to one another in between group sessions.

> *I think it's really good... ...it's [online forum for support] more far-reaching.*

Clearly, group leadership has a significant impact on whether or not a caregiver support group is capable of reaching and maintaining a safe therapeutic space, and through artful and purposive direction of group process support groups have great promise as an effective intervention tool for FASD caregivers.

Helpful aspects of group leadership by a FASD caregiver. The greatest asset that a FASD caregiver leader possesses is an inherent understanding of the stresses, frustrations, and struggles faced by fellow caregivers of a child with FASD. Caregiver leaders may be better equipped versus professional leaders in establishing an atmosphere of trust within the support group and provide appropriate suggestions and feedback to caregivers in distress. An added benefit identified by one participant is that caregivers would not feel the need to censor their frustrations against the social work profession in the presence of their peers.

> *Oh absolutely [it helps if the group leader is a caregiver]. If she was just a social worker nobody would trust her to understand.*

> *There's a sense among the parents that the social workers don't really get it all the time. There are a few that do, and we know their names, you know? But there are a lot that think – he's fine! Because one minute he will be or she will be. So yeah, having a caregiver. Because a lot of the discussion is "How do we get these social workers to understand?" And to have one sitting in the room...*

Helpful aspects of having a non-FASD caregiver/professional group leader. Some participants also identified several positive factors in having a group with leadership through social workers or representatives from the child protective agencies that also facilitate adoptions. Some group participants commented that their non-caregiver leaders were valuable members of their group, who invested an enormous amount of time, energy and resources into creating a healthy group experience for caregivers. One caregiver indicated that although a peer-leader is preferred, she was extremely thankful for the support that the non-caregiver leader(s) provided, suggesting that this model should not be outright discarded.

> *They tried to help you solve your problems, and they didn't do it in a judgmental, "Well, you adopted the child, you oughta know" kind of way, they did it from a.. ...person who is heavily involved in helping kids who have FASD succeed, wanting to help these other families succeed as well.*

This participant went on to describe the ways in which her group leader was different from the leader of a non-FASD support group she was a part of, and how this leader's approach positively impacted the atmosphere of the group.

> *[In the FASD group it's]more laid-back, we will bring in experts to talk to you about certain things when you want to, but it's more parent-driven. Like, "What do you want? What is it **you** guys need? This is your support group, how can we help you to solve these problems?" All along, it was more, you know, seeking input from parents and, "What do you want?" you know? And the other group initially was not that way at all. It was like agency-run and they chose the topics and they just went ahead with whatever their agenda was.*

A critical factor impacting caregiver's connection to a non-caregiver leader is for the leader to assume a non-expert stance when it comes to advice for caregivers, seeing each child's caregiver as the expert, yet drawing out other members to contribute their ideas and expertise and allowing the caregiver to weigh it against his or her own experience and whether or not they feel the strategy will work for their child.

> *...understand that while they're there to help, we're the experts on FASD, in some ways, because we're the ones dealing with it.*

Participants noted that non-FASD caregiver leaders had more distance from the issues being discussed, which could be seen as a benefit because they are less likely to be brought down during tough group discussions. Further, participants in the study valued their connections to speakers, access to funds for snacks and honorariums, and willingness to do research on various topics related to FASD caregiving.

> *We like having access to their resources and having them be able to phone the expert and say, "Come in in January", you know, to the OT person. And then they do the...if there is any payment to them.*
>
> *They're willing to do the...research, they're willing to solicit parent's input.*
>
> *Definitely parent-led, I think is a much better way to go, it's just the resources are a challenge there.*

Unhelpful aspects of FASD Caregiver Support Group Participation

Overall, support groups certainly appear to have clear benefits for many caregivers, but it is important to note that within these therapeutic spaces there needs to be an acknowledgement of the responsibility to do things well. FASD caregivers are a precious resource and their well-being is fundamental to their child's ability to thrive. There is an enormous burden of emotion within the room when FASD caregivers come together, and support groups have the challenge of negotiating tough interpersonal dynamics between highly stressed peers to ensure that the group setting remains a place of a safety and hope for all caregivers. If a group fails to accomplish this task and is not meeting the needs of each of its caregivers, it runs the risk of actually feeding caregivers' sense of helplessness and inadequacy. This section of the results focuses on aspects of support groups that detract from positive experiences. Three themes emerged from the data: (a) personal factors, (b) interpersonal factors, and (c) leadership factors.

Personal Factors Influencing Perception of Support Groups as Unhelpful

Caregivers identified a variety of factors related to their experiences of support groups that were bothersome or even damaging. Many of these factors are context-dependent or specific to the situation or personality of the caregiver providing the feedback. This section will explore these aspects of the group that participants indicated impeded their enjoyment of support group participation.

A matter of timing. Participants indicated that one factor that affects whether or not a caregiver would find a FASD support group helpful is timing. Two participants reflected that group attendance is difficult for caregivers who have not yet come to the realization that their child has FASD. Hearing the stories and struggles of FASD caregivers may be a frightening experience for caregivers who desperately cling to the hope that this diagnosis is not correct for their child.

However, participants indicated that this does not preclude any benefits to attending the group on a one-time basis, because they are not only aware of the group's existence and perhaps more likely to access support in the future if their child is given a FASD diagnosis, but they gain an increased awareness of the indicators of FASD and may be more likely pursue and be able to accept that diagnosis when they are ready to.

> *They just weren't ready to hear it. So the seed is planted, but it just needs time.*
>
> *That's when we hit a real low point, and that's when we went back to the support group and actually found it supportive.*

Inability of the group to meet initial hopes. Some caregivers become disillusioned with group participation because of the failure to meet their initial hopes.

> *I thought they were going to make [my children] better.*
>
> *I had no fears, lots of hopes around getting support [crying] and just getting information about getting ideas for services. Respite ideas, where the services are available, how do we fight for them, how to be political as a political group, all that sort of stuff. I'd hoped that we would do all that sort of stuff. And we haven't done any of that. You know, we'd leave – I'd leave at the end of the night and think, "I'm not sure I'm coming back!*

One caregiver spoke about the emotional impact it had when support group participation not only failed to meet her initial hopes and expectations, but poor group functioning expectedly resulted in many negative emotional experiences for her. Caregivers do not seem to anticipate the possibility of any negative outcomes of group participation.

> *No, I was thinking it was all going to be positive for me [laughter].*

When the stories are too heavy to bear. Although the healing power of listening to the stories of fellow caregivers has great potential for healing, caregivers consistently made reference to their dialectical power to become harmful and worsen the caregiver's distress, even if only for a time-limited period. One caregiver pointed out that the depressing impact of the stories seemed to be more prominent in the beginning, but that as time went on they were not affected by those stories in the same way.

> ***Oh yeah** [attending the group was depressing]! Yeah, in the beginning, sure!*
>
> *It helped, but mostly it made me really sad because I always – part of you always wants something to be better, and you have to hope for something to be better, but we'd go to these meetings, and I'd leave and look at my [partner] and go... "They're talking about ...., you know, her son's been incarcerated for the fourth time, her daughter's pregnant for the third time and she's only 19 years old", and you hear these absolute horror stories – their horror stories—you have to...one family had to buy a safe because the son keeps stealing from them, we can relate*

> *to that, our sons are thieves, they've stolen from us. So most of the time I left feeling really depressed, really depressed, because I thought ... you know... [sigh] we were lucky in -- and still are in a lot of ways – our [children] have never been in trouble with the law.*
>
> *And when we went to the meetings, we found them very discouraging and depressing because here's all these people and their kids are – you know—in prison, or kicked out of school, and all the, you know the mental health issues, and all the secondary disabilities that you would expect. So we found it really discouraging and we just went – "No! I mean look, that's them, but this is ours! And he's so perfect!*
>
> *It's quite depressing, because they've been struggling with this throughout the* ***whole*** *of their lives.*

Hearing the "horror-stories" of what has happened for older teens and adults with FASD also has a significant impact on the caregivers of young children. These caregivers are left to balance the need for hope that their interventions will produce a better outcome for their child, and yet at the same time manage a realistic concept of the finality of FASD and prepare themselves for what that may mean for their child's future. Caregivers appeared to vary from one meeting to the next regarding their ability to listen to the difficult stories of their peers, and still maintain hope, attributing this variation to their emotional state coming into the meetings based on how their day had been.

> *... And you're leaving that kind of meeting, going "Ugh! Shit! Is that, you know, the end result of my..." [laughing] So certainly, yeah, there's definitely those meetings when I felt worse, when you're sort of 'crystal-balling' and you're seeing "Wow, this is what happened with this child...is that my future?" I don't know how I'm gonna cope with that, right? And you're just thinking "Oh, I think I could cry! [laughter] or "Why did we do this again?!?"*
>
> *...There's been a couple of times where I've almost left because of that [depressing stories], because I can feel I'm getting pulled down instead of ...getting pulled up, and I try to maintain that perspective, but it can be hard depending on where I'm at that day.*
>
> *It's the lack of* ***hope*** *when you hear the adult stories. So, and I come home from the group and I say, [distraught tone] "Oh God, I'm so depressed!" and [my partner]'s like "Well, stop going to the group", "No, but I like going to the group! [laughter] So yeah, if you get one of those weeks where it's*

> *all...everybody's got some very big problems with their kids, and one of their adult kids, you just – you see your future, and you think, "Oh, crap!" Excuse the expression. [laughter] And you know, but when you – you have to live – when you have an FAS kid you have to live day-by-day so you have to go, "Oh, we're having a good day today!" And not spoil it.*

> *There were a couple that were grandparents...which became a horrible thought for me, thinking that [sigh] these guys could easily get someone pregnant....And we could be raising kids in our sixties, in our seventies.*

Caregivers have few fears concerning FASD support groups outside of the possibility that they might become drawn into one another's helplessness or hopelessness. This seems to be a particular issue when an immobilized caregiver brings the same problems forward week after week, without ever implementing strategies to create change and without having any success.

> *Fears...[long pause]. Maybe getting sucked in to other peoples' problems. And I think that that's probably partly why my [partner] doesn't go.*

This points to the need for containment in the manner in which stories are shared in the group. Lengthy accounts of tragic stories, with no regard for the impact this has on other group members and the need to balance these stories with messages of encouragement could be an unhealthy way for a group to operate. Caregiver group leaders can facilitate movement away from traumatic stories in a manner that is both respectful and gentle, but the failure to do so on a regular basis can detract from the helpfulness of the group.

> *That just...[sigh]* ***rocked*** *a lot of us, I guess... ... And that was really hard to take in and walk away from, and not [sigh]...it's easy to get into thinking, "That won't be my kid" but that's what they thought a month ago too, so it's really hard not to sorta...umm...get caught up in that.*

> *I've talked to others about that dynamic and we'll just sort of exchange a few looks across the table, and you know...yeah, sort of, we need to move on cuz we can't keep hearing about this.*

> *That's that balance...giving people what they need and also knowing when it's time to move on.*

> *I haven't found it helpful to come and to listen to, you know, because it's been...it's not been...I don't think it's been facilitated properly in terms of saying too much, or take it and don't go some place with it.*

Interpersonal Factors Contributing to Group Dissatisfaction

Negative or unhelpful interactions with other group members. At times, participants found that certain interactions with other caregivers were unhelpful and affected their enjoyment of the groups. One caregiver indicated experiencing irritation with a group member who exuded an air of superiority as she talked about how successful her strategies for dealing the FASD had been.

> *There was this one woman who's got it all sorted out, and good luck to her, right? "Well, I give him money, so he doesn't steal money, and you know, I do his shopping for him, so that he has food," and she's* ***really*** *got it figured out but the way she says things sometimes a can be...well it's not offensive, but it can get your back up a little bit because it's like, "Oh, well, are you saying that I don't have it sorted out?*

Caregivers are also triggered when their peers offer one-size-fits-all solutions to their caregiving problems. It is important to caregivers to be given credit as the expert regarding strategies that are likely or unlikely to work with their child, and for fellow caregivers to be able to accept it when their suggestions are not implemented for a variety of reasons.

> *It's hard for me, but I just have to think, "you know what, that's their opinion...she may have an FAS child but she does not live in our house. And I have to keep telling myself that...that's all fine and dandy for you, but it doesn't work in our house.*

Similarly, another caregiver spoke about the tendency for fellow group members to proselytize one another. Certainly, drawing strength from one's faith will be an enormous benefit to individuals who are a part of a religious community, but caregivers who do not identify with any particular faith group do not necessarily benefit from hearing at length about the religious convictions of other group members.

> *Their religious view are...completely, you know, beyond anything that our main group...[laughing] so every now and then they go off on one of those...sometimes you just have to kind of let them run with it, and you know, whatever. But I would say more often the facilitator is able to say, "Okay, sounds like that works for you.".*

Another caregiver found that non-specific advice concerning appropriate interventions and advocacy tasks were fairly unhelpful because she was unclear on how to implement the advice.

> *So they'll say, "Well, you should get him...made a physical exception." Okay, well, how do I do that?*
>
> *[Support group members would say] Oh, he's in the worst class", "Okay, well tell me what to do!*

In another situation, a caregiver was surprised by the advice being shared in the support group meetings, which seemed to be contrary to what she understood to be common knowledge concerning inappropriate pharmacological interventions.

> *But, you know, my first meeting there...everyone was like, "Oh, you should have him on Ritalin" and I'm like, he's...you know, like, I thought it was only people that didn't know about FAS which tell you to have him on Ritalin.*

Caregivers are also very sensitive to direct or implied criticisms of their parenting skills or dedication to their child, particularly from another caregiver. Criticisms from other caregivers have an added impact because there is an assumption that the groups should be a non-judgemental space for all caregivers, and group members come to expect that fellow group members would be especially cognizant of the impact of hurtful messages.

> *When they suggest that ...suggest that you don't love your child enough. And for me, how much is enough? My health has suffered from this, it has, I don't have a career anymore – I was the head [career title]...no more—I can't even imagine going back to work now because the stress is always there and I'm always....[sigh]... So yeah, yeah, I left – with that person—feeling a few times that you know, why do I even bother to go because they don't understand, and I feel that she should understand because she's a caregiver.*

Another factor that led one caregiver to feel disappointed with the group interactions was created by the failure of the group to be divided by the age of the group members' FASD child. This created a situation where she could neither contribute, nor benefit, from the exchange of concrete strategies and intervention ideas that were relevant to her child. Being able to "give back" by sharing strategies with other caregivers seemed to be very important to this participant, and she expressed a sense of profound loss that this could not take place.

> *One time I was kind of giving some, you know, just saying some of my experiences and somebody who had a 17-year-old went [haughty tone] "Well obviously it's not going to work for a 17-year-old, is it?"*
>
> *[Because their children are] a lot older it's all about getting their kids money because they can't hold down a job. So, you know, which is, will be quite useful for us one day, but right now... I won't remember in ten years time about it.*
>
> *When we talked about the school, it wasn't as helpful as usual, because there wasn't anything concrete we could gain. So the online support group, we got help that way.*

Although caregivers did not say so explicitly, another possible unhelpful outcome of group participation could be the inadvertent placement of undue emphasis on the protective factors (e.g. FAS diagnosis before age six, living in a stable and nurturant home for over 72% of life) against secondary disabilities. While an awareness of these factors is certainly useful, caregivers in a support group may share inaccurate information with one another concerning protective factors, which may lead them to take on responsibility for the child's future behaviours and actions, and blame themselves if those secondary disabilities become a reality for their children. Support group leaders have a valuable opportunity to help caregivers understand that while the protective are *correlated* with better outcomes, they are not causal and do not necessarily guarantee one outcome or another.

> *I don't know what I'll do if we get to that road, I don't know what I'll do, because I'm gonna wonder, what should I have done the last ten years to stop this.*

One caregiver spoke about how unhelpful it was to have to repeatedly go over the basics of FASD for new caregivers who may join the group without a strong understanding of the disorder. Although caregivers understand the benefits to doing this, group leaders should work to contain the time spent on this as well, to ensure that the group's time together is benefiting all who are present. Alternative means of sharing information, such as brochures or booklets, or possibly a connection to a 1:1 mentor to facilitate the sharing of basic information about FASD might be another option to assist new members.

> *...Go over the whole spiel again, like what it is, and this what it is about and sometimes you get tired of it, like "Okay, here we go again." Yeah, that would be one of the things that I could do without, but then again, they did it when I came in, so that was helpful for me, so. If I would know ahead of time, I would skip that session then.*

One caregiver also shared her intense disappointment when the support group failed to provide her with allies for advocacy, which was an important part of her journey in dealing with FASD. This unshared vision regarding what the support group can accomplish was very frustrating for this caregiver. Although the caregiver acknowledged that not all group members would wish to be involved, advocacy is an important endeavour for many caregivers and should be encouraged within support groups.

> *We need a vision, in terms of what our group is about.*
>
> *I would like to see us have a support group that has kind of different prongs. So, sometimes, some nights are just strictly informal chit-chat where people share what's going on. I've had to see us have formal, some nights are formal education, where we have somebody come in and talk about—okay, so let's talk about every resource that's available, which are income based and which ones are not, how do you access them. So, evenings that are educational, and then some evenings that look on the political aspect in terms of so what do we do about this, how to we move this along? So that's what I would like to see, is kind of to have a three-pronged process.*
>
> *But I think that there is a place for...for that group to be advocating* ***as a group****.*

Jealousy over resources of others. Another factor that can impact a caregiver's satisfaction with the group process is when distinct disparities exist among group members concerning access to much-needed resources. Even if one caregiver is attempting to motivate and mobilize other caregivers into accessing those services, defensiveness and frustration can surface over the perceived inequalities in how applications for government funding are often indiscriminately approved or denied.

> *...Maybe a little defensive, but they're thinking 'Well why do* ***you*** *have that, and I don't have that?'*
>
> *Sometimes at the Ministry level and everything, sometimes you get to think, well they have guidelines, but that's a little bit of a crap-shoot depending on who is doing the application and which doctor signs it and which words you put in there, and how effective you were at describing your child's situation and what-not. So yeah, sure sometimes there's hard feeling, like "What the hell? She got that and I didn't?!" [laughing] "My child deserves that too!".*

This disparity in access to resources also has an impact on how the group interacts with one another. The members who are not strong advocates for themselves may begin to feel increasingly frustrated, isolated and rejected in a community that is so unresponsive to his or her needs. They may have difficulty listening to others talk about the supports that they have secured, and struggle to celebrate the victories that others have in this regard.

Conversely, several participants in this study also described feeling disheartened, saddened and frustrated when their fellow caregivers give up on the suggestions they have made.

> *I find that frustrating, particularly for this one individual, she...ugh! She could have had subsidy, she could have had support, she could have had respite, she could have had...if she had just gone to the **right person** and followed through, used the **right phrases**, and you know? It's unfortunate, some people get what they need and others just...equally worthy, get nothing.. ...it frustrates me to no end.*
>
> *But not everybody is like that, some parents -- I know enough parents who sit at home, frustrated, crying and what-not and cannot deal with the child and do not get the services they need. And the adoptions will be disrupted, which I think is even way worse.*

Although each of the research participants in this study could be considered to be excellent advocates for themselves, they were asked to speculate about whether or not the caregivers they knew who lacked those skills enjoyed the same benefits from support group participation.

> *When I've talked about some of the advocacy issues that we've done at the school, parents look at me, sometimes, and go "I could never do that." And I'm like "Well, you've gotta do that," and that's the problem.".*
>
> *So she went to that person and gave up. And myself and this other person would say, "That's not okay, you need to go above" but she doesn't want to play that, you know what I mean? There are people who don't want to play that game so they essentially fall by the wayside sometimes, and you need to say to them this-that-or-the-other, and maybe they will and maybe they won't. But there's almost a job for a full-time advocate in that arena as well.*
>
> *I don't think they get all of the same gains [of support group participation], but they get some of it.*

One caregiver was visibly upset at the thought of what happens to her peers who cannot or do not advocate for themselves long enough to see success. She noted a fear that in her own efforts to secure resources that her success might be taking away something from a peer who is less assertive.

Those other parents don't get anything for their kids. Because we fight!

Unhelpful Aspects of Participation Related to Group Leadership

Caregivers were consistent in pointing to the need for group leaders, regardless of caregiving status versus outside profession, to possess excellent group facilitation skills.

I think we need a skilled group leader, ***absolutely****.*

Numerous caregivers mentioned how unhelpful it is when fellow caregivers offer a play-by-play verbatim account of meetings with the school or other service providers. However, several caregivers noted that strong leaders of their groups were able to minimize the length of time taken up by these accounts through firm group structure.

> *And some people's ability to share information is like...instead of just giving the big picture they get into details and he said and she said, you know? And that's not for me, personally, that's not helpful. Cuz I don't need to have, verbatim, the conversations with the staff and the doctors, and so that, to me, is a real not good use of time.*

Unhelpful aspects of group leadership from a FASD caregiver. There are many benefits to having FASD caregiver support groups facilitated by a FASD caregiver. However, one participant pointed out that caregiver leaders may need to discontinue leadership for periods of time if family crises arise.

Another caution from one participant concerning peer leadership was the possibility of group leaders becoming over-involved in sharing during the group meetings. Caregiver leaders have a wealth of experiences to draw from in order to help group members feel less isolated, but rather than relating the accounts of each group member back to the leader's own experiences, the leader should engage *other* group members in relating similar stories and sharing how they overcame obstacles.

> *I think that it's a hard line to draw, to not always throw in your own personal experiences, because sometimes it gets a little bit...like okay, I really don't...it feels like she's gotta put her own 2 cents worth on everything.*
>
> *Say that [group member] tells a story of what's going on with her, well [caregiver leader]'s gotta one-up that, or has a similar experience to share. And then the next person has their time, well, [caregiver leader]'s gotta throw in... so it's like...we hear a lot about what, you know, what's gone on with her. And they're in a good place right now, so that's good, but...*

Unhelpful aspects of professional group leadership from a non-FASD caregiver. Some participants expressed dubiousness about support group leadership from a non FASD caregiver. First, a non-FASD caregiver would likely struggle to have the same level of understanding of the FASD caregiving experience as a peer leader might. Caregivers may have also had negative experiences with a professional, causing them to withdraw from group participation. Further, participants pointed to the ways in which a non-FASD caregiver leader's very presence may impede the development of trust within the group, may lead to censoring in the sharing of certain information, and may exacerbate experiences of bitterness and powerlessness.

> *Some parents didn't want to come out because you don't always want to deal with the social workers from the agency.*
>
> *That certainly makes it harder. And particularly with the other group we've seen, because many of the workers that manage the other group are workers that have finalized our own adoptions, so they're very, very up-to-speed on all of our personal information so really ideally, both groups should not be occurring either with Children's Aid workers there, they should be parent-run, parent-led and you know, happening in a neutral location.*

Participants seemed to be resistant to non-FASD caregiver leaders when they appeared to be present only as a "representative" of a connected agency, and when they failed to provide any useful contributions to the group.

> *Is there a role for CAS in a support group? ... I don't know. I struggle with that one, I like to see them connected because I want them to see our issues, but if it's just that, a token "I hear your issues" then that's not helpful.*

Several participants made reference to enormous frustration when non-FASD caregiver group leaders failed to use their skills to teach caregivers to powerfully advocate for themselves and mobilize for collective change. Caregivers identified a variety of contributing factors to explain this dynamic, but several participants perceived a conflict of interest when the non-FASD caregiver group leaders were employed by the child protective service agency that brokered the adoptions of the children with FASD and was refusing to assist the family with support such as respite money.

> *I would say that at times the worker's hands are* ***completely*** *tied because they're hearing things and they want to say "Good for you, go for it!" but they know that if somebody comes back and it gets to the E.D. level, that they're the ones that made that happen or suggested it, then they're in trouble, in terms of their job performance.*
>
> *They basically say, yeah we hear you, we tell your concerns, but we don't know – it's out of our hands. And it's not really that they were really advocating. Because it was "Yeah, we know you need money, or we know you need this resource, but sorry we don't have it."*
>
> *The Children's Aid doesn't want to publicize that they have any money for that, of course, they would prefer that you took your child and adopted him and went away, really, and that you lived your life and never [laughter] darkened their door again!*
> *CAS really doesn't want too much to do with FASD, because they're very much afraid that if parents find out they don't want to adopt anymore.*
>
> *It's a* ***total*** *conflict of interest.*

When issues exist like leaders with conflicts of interest, this may cause the support group meeting to shut down and cease to involve meaningful discussion of resources and how to obtain them. Several caregivers discussed the outcome of this, which is that there is a noticeable discomfort and tension around discussions concerning one of the most needed intervention resources -- namely respite funding -- and that conversations of this nature are deferred outside of the group setting, such as in the parking lot during break or after the meeting. This shift in focus during group sessions away from opportunities for empowerment, and the likelihood for less connected group members to miss out on post-group discussions about resources, can result in an awkward, unhelpful dynamic during group sessions.

> *So we also have to be, sort of, a little bit sensitive to the fact that we're sitting in that room, and that there are social workers in that room, and that she can't actually speak of this topic while they're sitting there. So you know, afterwards or outside when we're at break you would discuss that, and also sort of things like subsidy.*

One caregiver suggested that perhaps conflicts-of-interest could be handled through overt acknowledgment of competing interests, and for those leaders to leave the room for periods of time during a group session so that the group members can share how they accessed resources, and brainstorm or collaborate on a plan of action.

> *What would be ideal is if we knew the social workers were a little more sensitive to what was going on, and you know, give us the room, give us the guidance, give us some of the resources, and then sensitively leave the room for awhile.*

Each community and their respective FASD caregiver support group needs to carefully weigh the type and style of leadership that is most helpful at a given time, and should work to decrease any limitations experienced by the groups based on the type of leader. In any case, it is important to note that if there is to be any transition of leadership, that it should take place in a planned and supported manner, such that group members are not left feeling abandoned in the absence of a well-trained and willing group member to assume that role.

> *[The former leader] stepped back and basically threw it back in our lap. That's not what we expected.*

Ambiguous co-leadership. Some caregiver groups appear to have poor role differentiation in their leadership structure, particularly in co-leadership models involving a FASD caregiver and a community professional. If neither leader assumes responsibility for understanding and promoting healthy process the group may begin to encounter difficulties, such as members beginning to dominate group discussions to the exclusion of others. The very presence of the co-leader may cause both individuals to maintain silence on these issues for fear that they would be 'stepping on the toes' of the other.

> *See I am, I just am really torn from the present structure. [A local agency] has lent support for it, yet to a certain extent they distance themselves, they say we'll set the room up, we'll supply the coffee and the snacks, but it's your group. But yet they're physically there and kind of act as a leader, but don't. I think part of the problem is that [fellow caregiver] doesn't necessarily have the skills to take over and run the group, but to be fair to her it's also hard to do that when you have [an agency] worker here too. And part of the upset is at them. So that's where it gets kind of convoluted.*

These comments articulate the difficulty with arms-length, "juice-and-cookies" leadership, where the presence of a relatively uninvolved professional actually disrupts group process even though the intent is to be supportive. The very presence of an individual who is not a caregiver of a child with FASD can create a significant shift in the atmosphere in the group; caregivers may no longer feel assured that they will be understood non-judgmentally, choosing then to withhold sharing of the most intimate nature as a means of self-protection. Caregivers may also be particularly aware of a social worker's reporting obligations to child protective services, and an individual who is not in a caregiving role may have a vastly different understanding of expected levels of stress and emotional intensity in a FASD caregiver, which may result in unnecessary and unhelpful reports to child protection agencies concerning parenting capacity.

Lack of structure/control over group processes. Caregivers spoke at length about how the structure of the group session impacts their experience of it as helpful or not helpful. Leaders have the challenging task of establishing and maintaining the right balance of consistency and routine. One caregiver points to lack of structure as the key factor when she feel experiences the group in a negative way.

> *More structure. If it's a little bit more organized.*

However, leaders must exercise good judgement and not allow structure to interrupt or prevent intimacy within the group. Clearly, this is a delicate balance and group members need to be willing to provide feedback when the group process borders on being too structured.

> *...That the conversation of the group isn't always respected. It becomes more directed by her.*

Caregivers also expressed dissatisfaction concerning instances when group leaders failed to adequately address group members who dominated group discussions to the exclusion of others.

> *If you've got one person monopolizing the other people will just tend to sit back, and that happens, and we've left and it's like... "Okay, well, that didn't get resolved..."*
>
> *And people who don't have strong advocacy skills, the venting might be really helpful, and I get that piece, so I would wanna...and I don't want them to stop, I*

> *just want it to be different, or to share the floor, or to only be part of what we're about.*
>
> *In terms of people's styles in the sharing of stories they've gotta do a 'he said, she said' and' then I did this, and then I said that', and like something that I could probably do in five minutes has taken three quarters of an hour, and I'm like "Oh, God, I'm gonna die!" [laughter]*
>
> *It is really a mess. But she cannot even hear for five minutes somebody else's story. Or she will bump in with her own story and put it all back, and that is really, really hard, and our facilitator cannot even stop her either. So that's really hard, because people get frustrated then, because they want to share, or they have questions, and then they do that afterwards at the parking lot.*

One participant shared a particularly painful account of her frustration at having to hear an immobilized caregiver vent for the majority of the meetings without any constructive resolution of the issues month after month. As a result, she experienced and re-experienced increased distress because of the lack of hope in the stories being shared.

> *Because all we've done is heard people's experiences, and some people...from my perspective are immobilized. And so all they talk about is their immobility and being stuck, and not being able to move on and the challenges they're having and the difficulties they're having with their kids. And they're not open to support from each other, in terms of when you provide ideas, "We tried that, that's not working" and that's real difficult.*
>
> *And so then one family can really bring the group down because of the lack of facilitation skills.*

However, participants in these situations indicated that they did not feel prepared to verbalize these concerns or address these issues with the group.

> *I'm afraid of confrontation, so I won't say it.*
>
> *We're a very polite group [laughter]. Probably too polite at times. No, we're very polite. I think people have gone out of the room and have been like "Ugh!" and frustrated...*
> *Some other parents they won't say anything, or they would say it out in the parking lot, but they didn't want to say it in front of them because you never know what's going to be reported back or how it's going to be taken, right?*

As a result of conflict that went unresolved, group members formed sub-groups that met outside of regular support group times in order to address their needs. This highlights the importance of leaders who are sensitive to the issues that may impede intimacy within the group, and capable and willing to take whatever steps necessary to ensure that small conflicts are addressed satisfactorily and in a timely manner, such that they do not become pervasive struggles that are damaging to the group's ability to function on a regular basis. Sometimes this is a challenging task and leaders may be understandably apprehensive due to fear of hurting the feelings of a caregiver.

> *And so instead of when people start getting...over-taking and too negative, taking it away from there and say "Okay let's hear from other people, let's talk about this" it just keeps going, they let people vent, it becomes a venting session.*

Leaders must be capable of attending to the needs of each group member in the room and be aware of the impact of what is being shared on each listener. This is true in cases where there *is* unresolved conflict among members, but it is true in the opposite scenario, where the caregiver is being prodded to share some level of distress when they do not feel the need to do so.

> *If I were to say that I don't need support, that's not always ...not always...respected. Like sometimes...instead of...instead of going to people that really do need support, she'll sort of turn...turn things around and sort of go back to somebody who has said that they're okay.*

Leader is out of synch with group members. Finally, one participant noted the irritation that can occur when the group leader appears to be working according to his or her own agenda, rather than allowing the group to make decisions on a variety of aspects such as location, structure, and topics of support group meetings. Group leaders who are marching to a different drummer are likely failing to harness the full investment from caregivers in the group process.

> *And the other group initially was not that way at all. It was like agency-run and they chose the topics and they just went ahead with whatever their agenda was.*

General Feedback Concerning Group Structure/Logistics

There are several logistical aspects of support groups that participants commented on during the course of the interviews. The first aspect to be discussed is clarity in public communications concerning the purpose and target participant group. One caregiver noted that she had heard about a support group in her area, but could not find contact information for the group in spite of numerous attempts. This is a frustrating waste of time for caregivers and group leaders should ensure that clear contact information easily accessible for all groups running, even if the group is not open to the general public.

> *...But the number was disconnected, but I googled it and I phoned 411, I couldn't get a number with it, so that was too bad.*

Another confusing aspect can be a lack of information concerning who is welcome to attend support group meetings. One caregiver indicated that during the lengthy process of having her child assessed and diagnosed for FASD that:

> *I always needed assurance that I could* ***attend*** *the group if I didn't have a diagnosis.*

Caregivers had mixed feedback concerning the frequency of the group. Some indicated that monthly meetings were sufficient, and that it would be difficult to find the time to attend the group more often. Others felt that meetings twice monthly would better meet their needs, even though it might be a struggle to find the time and arrange an alternate caregiver. Caregivers spoke favourably of having a formal web-based forum for communication with other group members between groups in the event that difficulties arise between meetings, although this was not seen as preferable or as powerful as face-to-face support. Numerous caregivers also had one or more fellow caregivers whom they contacted for support between groups, which might also account for satisfaction with the monthly meetings.

Caregivers indicated that it was important for the meetings to take place in a neutral location (i.e. community centre, publicly accessible buildings, church) and specifically mentioned that groups that ran in the buildings of child protection agencies were not comfortable.

Caregivers expressed concern and resentment when FASD support groups were accessible only to caregivers who had adopted though the local child protective agency. This appears to be an unreasonable restriction, marginalizing and cruelly isolating non-adoptive parents, biological parents, and adoptive parents who moved into the area from other communities.

> *So I called CAS [other city name] and I was not allowed to go because I did not adopt through them, or care for a child through them, it was restricted only to parents from their CAS, which was quite frustrating and upsetting.*

It is important to note, however, that the composition of the group, in terms of foster parents, adoptive parents, kincare arrangements, and biological parents can create unique dynamics and possible sources of conflict. Some caregivers were hesitant about recruiting biological parents to be a part of their group because there were times when they needed to "vent" against the biological parent of their adopted child, and they recognized that this would likely be hurtful for other biological parents to hear.

For similar reasons, another caregiver expressed concerns about the presence of individuals diagnosed with FASD at caregiver support group meetings. Although this participant appreciated the opportunity to interact with one of the caregivers' children on an occasional, pre-planned basis, the participant expressed discomfort about sharing her innermost frustrations about FASD when someone affected by the disorder was in the room. Caregiver support groups who divide into age groups should also be very careful in how they label groups, such that misunderstandings do not occur if newcomers arrive and interpret signs such as "FASD Adults" to mean that this is a sub-group for adults with FASD, rather than a sub-group of caregivers and supports for adults with FASD.

> *You want to be able to say, 'You know what? Sometimes this FAS just really pisses me off', but I can't do that if there's a table of FAS adults sitting there. How do I say this disability just pisses me off so much because I'm sick and tired of the lying, I'm sick and tired of the stealing.*
>
> *But yeah, I think something like that would be helpful [to occasionally have individuals with FASD present], have them come in and let you know that they're going to be there, and talk to them, have people ask them questions.*

Further, the inclusion of foster parents in the support can create some interesting dynamics, because of the disparity in the level of agency supports they receive, and a subsequent disinterest that foster parent members have in discussing systemic issues such as how to gain access to respite care and other forms of support.

> *"Oh, I get the support from CAS because I've got a* ***foster*** *child'" and they do, I mean if they phone and they need support they get it. Right? But then when you're adoptive parents, you're on your own.*
>
> *The agency does not want to help us or give funding or whatever, and they [foster parents] get credit – training credits for attending.*

Further, the absence of on-site child care is a significant barrier that may prevent single parents from ever being able to attend these groups. Although there would be many logistical challenges in arranging on-site child care, this leaves a particularly vulnerable population – lone mothers and fathers—unsupported when they may also have additional financial stressors and increased difficulties in accessing and coordinating supports for their child. Alternative interventions such as online support groups have been suggested for this population, but research should be done to investigate the effectiveness of this type of intervention.

Another consideration in the absence of on-site child care is that caregiving couples are faced with the decision to decide which partner gets to attend the groups regularly, or for each partner to attend on alternating months. In several participant situations it seemed that the non-attending partner did not have interest in attending for a variety of reasons.

> *I've read her book, I don't know how many times, my husband will* ***not*** *read the book. So. And it's not that he denies that they have ARND... ...He just doesn't want to think about it.*
>
> *I love talking about it. [laughing] Because I can't talk about it at home because my [partner] doesn't want to talk about it because it upsets [my partner].*
>
> *And, it's funny because [my partner] doesn't* ***get*** *a lot of what I do. And so when we're talking and I say, and I say to [my partner], "I can't do this, I can't carry this amount of anxiety, and stress" and [my partner]'s like, "But what? Like what are you anxious about?*
>
> *It's mostly females that participate in these groups, which is a downfall, for sure, because the husbands, who are dealing the behaviours as well, don't get the same sort of support. Which is not to say that they don't need the same sort of support, because I think they do and there's a way to involve them as well, so maybe the online thing*
>
> *[My partner] is more laid back and a little bit more shy as well, so [my partner] doesn't like it.*

One group member also mentioned a concern about the heterogeneity of her support group, and her suspicions that newcomers who did not share the same socioeconomic status might feel unwelcome. This points to the need for group members to be conscious and aware of the types of group discussions and how that might marginalize others within their group.

> *Cuz that's an entirely different thing. My group is mostly people who are quite affluent and educated and adopted children. And it's not that we don't run into*

> *the same problems, but we just have a different level of support and ...I think that specialists and people take us more seriously than if we are somebody in subsidized housing, a single mom with four kids, you know, I don't think you get the kind of resources.*
>
> *I think they [newcomers with less financial resources and less education] would notice it right away, I think they would feel intimidated. And I think that they wouldn't feel welcome. And I ...So you know, I don't think that one group can meet every need. So I don't think it's necessarily a bad thing, since there is another group, but I'm a little uncomfortable. I sense it to be a little more elitist than I would have noticed before.*
>
> *Again it's all people who own homes, and who can afford to send their kids to camp. And can afford to get tutors for their kids, and therapists.*

As previously discussed, a predictable structure to group sessions, possibly even including time limits for each member, is seen as necessary and favourable. Further, numerous caregivers made statements pointing to the importance of separating the caregivers into different groups based on the age of their child with FASD. In cases where this was not taking place, caregivers noted that it was extremely difficult to repeatedly hear the "horror stories" of older caregivers, and not to be able to benefit from an exchange of information concerning resources in the same way they would with the caregiver of a similar-aged child.

> *It needs to be split up into two. I think you need the kids one and the adult one, for sure.*
>
> *If there's enough people, they will split the group into two, so the...what ends up being the older parents and the younger parents, so [one leader] will take the older parents and [another leader] will take the younger parents. And what's great is that some of the older ones...like if two people come, if a couple comes, then one of them will sit in with us, so that they put their little two cents in when they've got something to add.*
>
> *The scary part for me is the ones with adult children – they're still going to these groups, and they're still dealing with these adult children and I'm sorry, but I don't want to deal with them when they're out [laughing]. Because I will feel I have put my time in.*

> *Being with people who have kids at a very early age, we've gone through that and I can certainly relate to all of that, but our troubles are* ***totally different*** *now. Same amount of troubles, if not more, but totally different.*

Caregivers also seemed to struggle with achieving adequate supports when the groups were not in session. Several participants commented on wishing that support groups would continue during the summer, although they recognized that it would be very difficult to coordinate due to vacation schedules.

Caregivers' Recommendations to Enhance FASD Support Groups

Participants were able to identify several key priorities to reduce the likelihood of negative experiences within FASD caregiver support groups. First, caregivers identified the need to work towards greater empowerment in caregiver support groups including the training of internal leaders, independence from social service agencies, where appropriate, and neutral meeting locations. They also suggested that it would beneficial to have more caregiver groups operating, pointing to the need on a provincial level to identify communities that may benefit from their own regional support group due to travel considerations.

There were mixed feelings concerning whether monthly meetings were sufficient to meet the needs of caregivers. It is possible that this could be ameliorated with a combination of the implementation of online forums for support between group members, as well as a formalized 1:1 mentorship system within the groups. Mentorship could also be offered to caregivers who do not attend caregiver groups for a variety of reasons. Caregivers also hoped for more social activities with fellow group members and their families, such as potlucks and dinners, particularly during the summer months when many support groups stop meeting.

Participants were also concerned with the need for *all* FASD caregivers to have access to an appropriate means of support, including caregivers who cannot attend groups or who may be less likely to benefit from support groups (i.e., single parents, biological parents and non-adopting/foster parents, non-attending caregivers). Further inquiry should be done to determine appropriate interventions for these caregiver groups. Where possible, some caregivers hoped that on-site child care would be made available, particularly for families with no access to respite care.

In terms of the group content, if it was not already taking place, participants saw it as important to make improvements to group structure including establishing and maintaining a flow to group meetings that allows each group member an opportunity to speak about his or her experiences, to balance difficult stories with ones about successes and to press for sufficient attendance to make dividing into separate age groups possible. Having sufficient numbers in the group in order to divide the group in this way might require increased advertising of the support group and ensuring recruitment information includes up-to-date contact information that clearly indicates who may attend group meetings.

Caregivers also hoped that support groups would continue to work towards enhancing caregivers' knowledge on more advanced subjects concerning FASD through incorporating stimulating educational topics and bringing in speakers periodically throughout the year. Several participants also voiced the desire to build opportunities for FASD advocacy *as a group*, and one caregiver hoped that groups would continue to lobby for funding in order to ensure the continuance of support groups.

Other recommendations include that groups should have a clearly defined leadership structure and in co-leadership models both leaders should be fulfilling compatible roles within the group, complementing one another, and providing united leadership.

Caregivers Recommendations for Key Priorities to Support the Family in Addition to Support Groups

Caregivers also noted several key priorities that should be pursued as complementary interventions alongside caregiver support groups. Most participants endorsed the need for funding for respite care as one of the most critical services for their families. This should be seen as the primary focus of advocacy campaigns in Ontario at the present time.

Several caregivers also voiced the need for FASD-specific summer camps. This is a beneficial service because these camps would not only offer a form respite to caregivers during the summer months, but specific training on FASD for camp staff would also give caregivers the peace of mind needed to "let go" enough to entrust their child to the care of a stranger, particularly due to the need for constant supervision of their children.

Most participants argued that difficulties with the school system needed to be a top priority. Ideally, caregivers indicated that their child would benefit from a 1:1 educational assistant to assist them with both school work and social interactions on the playground. Caregivers also indicated a desire for there to be training for teachers concerning FASD within Teacher's College curriculum, and one participant also noted the same for Social Work programs.

Further, caregivers hope to see increased access to multi-disciplinary teams for diagnosis and intervention, and access to developmental assessments, psychometric testing, and other tools to assess their child's needs. Caregivers also discussed the enormous financial costs associated with caring for a child with FASD. One participant identified the need for access to extended health care coverage for FASD-related medical complications not covered by OHIP and typical employee benefit programs.

Caregivers also hoped that resources would be uniformly distributed, rather than being contingent on a caregiver's ability to excessively self-advocate. One pointed specifically to the value of support from a case manager to work directly with families to coordinate services, provide referrals, and advocate within the schools and other systems that might be putting up barriers. On a larger scale, caregivers hoped to see increased advocacy on a provincial level, including increased communication between support groups and the sharing of resources, speakers, and other useful information.

Finally, several caregivers felt that their children with FASD would benefit from interventions, such as a support or a life skills group to help older and teens and adults succeed. Others felt that mentors and tutors, in the words of another caregiver "a bodyguard," would be useful supports for their children.

CHAPTER FIVE: DISCUSSION

Summary and Interpretation of Findings

This study was designed to gain a preliminary understanding of the strengths and limitations of FASD caregiver support groups as an intervention tool for non-biological caregivers. Individual, semi-structured interviews with caregivers who had attended such groups were conducted to explore their perceptions of the strengths and weaknesses of the groups, in what ways the groups were helpful or not, and how the groups might be improved upon or supplemented with other interventions.

This study provides strong support for continued investment of resources in FASD caregiver support groups. Caregivers clearly identified the benefits of mutual aid arising from these groups and a resultant positive shift in their approaches toward caring for their child with FASD. It was evident that the level of understanding, acceptance, and non-judgmentalism found within the groups was not found anywhere else among caregivers' informal or formal support networks. Caregivers clearly indicated a desire for these groups to continue and to work towards continual improvement of the groups in order that they are optimally effective in helping them cope with their difficult situations and emotions.

While this study clarifies that caregiver support groups are a fruitful intervention for many caregiver populations, it cannot be concluded that they are appropriate interventions for all caregivers. Participants identified that some of the aspects they found most helpful, such as ideas and support for caregivers as they advocate for needed resources, may not be as helpful to and even increase the frustration of peers who are less inclined to fight relentlessly for needed services. Participants also pointed out the inaccessibility of support groups for single parents who have no access to child care, and the absence of biological parents in their support groups. This is extremely important because it points to the need for interventions that are designed specifically for these populations and others who may not find support groups welcoming or accessible. This study also reveals important implications for caregivers considering joining a group. The results suggest that prospective participants should curtail expectations away from seeing the groups as a means of "fixing their child," and establish a more realistic understanding of the gains that can be accomplished through group participation.

It is not feasible to discuss each of the many categories and themes presented in the results in this chapter. Thus, for the purposes of discussion, I have chosen to discuss the overall results concerning positive and negative aspects of FASD caregiver support group participation as dialectical aspects of four main issues: (a) aspects that give voice to or silence caregivers (b) aspects that reduce or exacerbate isolation and marginalization, (c) aspects that promote empowerment or advance learned helplessness, and (d) aspects that promote or inhibit positive framing and the adoption of a paradigm. Although these issues do not encompass all of the results, they capture the most important aspects of the findings.

Aspects that Give Voice to or Silence Caregivers

In discussing their everyday experiences outside of the groups, caregivers spoke about numerous ways that they were silenced in unhelpful ways that depleted their emotional resources. One such means of silencing takes place within a resource allocation system where FASD is poorly understood and almost universally underfunded. This system is set up in ways that ignores the very existence of FASD and punishes caregivers who look for supports by labelling them as inadequate parents. FASD is not a recognized disability in the DSM-IV and thus there are no community resources specifically mandated to provide tailored interventions and support to these individuals or their families.

Typically, the families who have been able to access services have either successfully advocated for themselves over many months or years, possibly with the backing of legal counsel, or else they have been granted access to services through a "back door" by sympathetic service providers working outside of their mandates with or without the knowledge of their superiors. Other caregivers have been able to secure supports by accepting a misdiagnosis of autism, which is a diagnosis more commonly supported in applications for respite and other intervention services.

However, not all caregivers have the natural abilities, assertive personality, or emotional strength to persist with such efforts in order to secure supports. Their applications for different services are repeatedly denied because certain phrases and terms have not been used, regardless of the family's level of need. Some caregivers stop asking for supports because of the perceived futility of those efforts and the emotional impact of being rejected for a needed service. It is possible that some caregivers retreat into silence as a coping strategy for dealing with this oppressive system.

Caregivers also discussed being silenced in their interactions with family and friends who fail to understand FASD and the behavioural consequences. One caregiver discussed the outright refusal of family members to allow her to speak about her experiences as a FASD caregiver, and others assumed silence because those in their social circles persistently questioned the diagnosis, challenged parenting decisions, and made unhelpful suggestions. One caregiver even described being silenced by her partner who was in denial about FASD and did not wish to hear anything about the disorder. Caregivers expressed extreme frustration at the lack of understanding from those in their intimate circles and the inability to access appropriate support from these sources.

On a personal level, caregivers may also silence themselves from expressing the full range of emotions tied to FASD caregiving. Some caregivers spoke about being irritated by their child, questioning their desire to continue parenting their child, and embarrassment about how they were perceived as parents. Caregivers appeared to feel a degree of shame for these emotions, and indicated that the support group is the only place they can discuss these feelings because they know that fellow group members who share these sentiments will not judge them. Caregivers appear to shield themselves from talking about these emotional experiences until they are in the presence of other FASD caregivers again.

However, even within groups it appears that silencing can continue to be a pervasive and damaging force. Caregivers spoke with intense emotion about times when the support group was unable to meet their needs because a dominating member had taken too much of the group's time, and they were unable to share their experiences or solicit feedback. For caregivers who have been waiting to 'unload' at a support group, only to be silenced by poor group process, this was an extremely disappointing and disillusioning event.

Unresolved conflict and frustration with poor group process also seemed to be an important factor related to the silencing of caregivers' needs. One can understand the reticence of group members to address conflict in *any* group, but this tendency may be more pronounced among FASD caregivers. This population faces such enormous isolation even among family, friends, and community, that the thought of potentially losing their connection to one another, either by a massive group clash, division, or the dissolution of the group results in silence becoming preferable to taking any sort of risk. Further, there may be some level of fear concerning what the outcome might be of addressing conflict within a group of emotionally depleted caregivers, with the potential of unexpected outbursts of emotion or the possibility of causing further harm to caregivers already in distress.

Caregivers also spoke very clearly about their frustration when group leaders had conflicts of interest that created a silencing effect in the support group. The presence of non-FASD caregiver leaders may prevent group members from discussing issues such as advocacy for respite funding from child protective service agencies, or may cause them to censor what they share for fear that those group leaders would report sensitive information back to their professional colleagues. If caregivers cannot discuss things openly in a group session, it adds one more place in their lives where they have to stifle their own needs.

In a caregiver's experience, the multiple sources that silence them create an enormous stress that needs an outlet. Perhaps this is why caregivers speak so highly of the value of support group attendance when they *are* able to freely express any emotion in a support group and not fear judgment or reprisal. Support groups that are able to maintain an atmosphere of unconditional acceptance and promote opportunities for every caregiver to be heard at every meeting are invaluable outlets for stressors that have no other forum to be shared.

Aspects that Reduce or Exacerbate Isolation and Marginalization

Caregivers also repeatedly made mention of the value of meeting other caregivers struggling with many of the same issues they had experienced. Caregivers expressed that support group members were often encouraging and that they journeyed alongside one another in difficult times. This is particularly important considering the distancing from their friends and friends and family previously discussed.

Conversely, when caregivers did not perceive their fellow group members to be in similar circumstances, either due to age of the child, caregiver status, parenting styles, or the types of problem behaviours they were encountering, caregivers seemed to feel like an outsider even among peers, which threatened their enjoyment of the group. One participant identified that dividing the group by the age of each caregivers' child made a significant impact to allow for mutual aid and increase connection among group members.

Caregivers also appeared to feel more confident about their parenting decisions because they had the support of their fellow group members as they tried new parenting strategies. Caregivers seemed to have developed new concepts about 'normalcy' for families affected by FASD, and seemed to accept their own struggles more readily when they observed respected group members with similar difficulties. This normalization allows caregivers to feel less marginalized and combat feelings of being a "bad parent" and being "crazy".

On the contrary, group members who perceived criticism from their peers in the support group appeared to find this highly offensive and it reinforced their fears about poor parenting skills. Caregivers have high expectations of one another in the group setting and judgmentalism appears to be one of the cardinal sins in FASD support groups. Several caregivers discussed how their leaders firmly redirected judgmental comments to maintain an atmosphere of safety and acceptance in the group setting.

Aspects that Promote Empowerment or Advance Learned Helplessness

Caregivers who start attending groups usually seem to be at a crisis point in their lives, unable to achieve the behavioural changes in their child that they had expected to accomplish. With each parenting strategy suggested by physicians and service providers failing to produce the desired outcome, FASD caregivers may experience a form of learned helplessness, where they become disillusioned with the continual failure of their parenting efforts and see no reason to continue trying to create a healthy family dynamic.

Within the support group context, however, caregivers are able to hear success stories from other FASD caregivers and are able to gain strategies, new ideas, and resources that offer renewed hope. Several caregivers also discussed the value of having their fellow group members come alongside them to strategize, and that even if they did not come up with successful solutions, they felt less isolated and knew that others would continue to work with them towards strategies that might work. This synergistic dynamic among caregivers at support group meetings was an extremely important aspect to participants, and allowed caregivers to invest new energies and confidence in their abilities to parent their FASD child.

In contrast, other caregivers submitted that at times they perceived they were being given "one-size-fits-all" suggestions from their peers, or that fellow group members were pressing to find a solution when the caregiver just desired to share their story and vent their emotions. Group members and leaders should be sensitive to the needs of one another and when their reason for sharing is motivated by a desire for management of the *emotions* of caring for their child, as opposed to management of the child's behaviours. When group members fail to sense this difference, caregivers appeared to feel less hopeful about the ability of the support group or any other support to understand and respond to their needs.

Aspects that Promote or Inhibit Positive Framing and the Adoption of a Paradigm Shift

Several caregivers mentioned how they had been positively influenced within the group setting through education about a paradigm shift in how they understood and subsequently responded to problem behaviours from their FASD child. This idea has been discussed by Malbin (1999) and it centres on reframing the interpretation of behaviour such as "won't" behave, to "can't" behave as a result of irreversible brain damage. This is an important shift, because caregivers no longer blame themselves for the behaviour nor see it as wilful manipulation, which allows them to gain distance from the problem and evaluate lagging skills without so much emotion attached. Participants identified learning about the more helpful paradigm at their group, at FASD conferences and through books and other written materials.

However, participants who discussed this paradigm shift also indicated that they oscillated in their mastery of this shift. They indicated that when their child improved for a period of time, they would stop making accommodations in the hopes that their child did not actually have FASD, and then the family would hit a crisis point when this illusion was shattered. Participants indicated that fellow group members were able to constantly challenge them to reframe problem behaviour, and re-establish Malbin's helpful framework for understanding FASD. Groups that are able to consistently move caregivers towards an understanding of their child in this manner appeared to be most effective.

On the other hand, several participants described the upsetting impact when groups did nothing constructive with one another's depressing stories about their struggles. The failure to reframe the child's behaviour as a symptom of their disability seemed to result in the group becoming "stuck," as constructive discussions concerning how to identify the 'gaps' or lagging skills, and how to restructure to circumvent the disability or avoid the possibility of problem behaviour from occurring were absent. One caregiver appeared to experience significant negative affect as she spoke about the powerlessness of the group to assist her peer, and as a result the same problems and issues were brought forward month after month with no resolution, which became an emotional drain on other group members. Since Malbin's paradigm shift appears to be one of the few intervention strategies that is experienced by caregivers as helpful, it is critical to incorporate this into support sessions in order to promote reframing of behaviours, rather than reinforcing the use of behaviour management skills that are unhelpful to FASD caregivers.

Moving Forward to Enhance Group Effectiveness

This study also provides concrete suggestions for ways that caregiver support groups can be improved and pinpoints key targets for groups to evaluate their success at mediating critical emotional factors that may lead to caregiver burnout. Caregiver group leaders can ask themselves: Does our present structure allow each group member to share at every group meeting? How am I modelling containment through group structure? Am

I afraid of hurting the feelings of someone who is dominating the meeting? Have I allowed this fear to become a priority over the needs and feelings of other group members who have become silenced as a result? How can I share leadership with other caregivers so that we can be as effective as possible? Does my presence silence any members of the group, and what kinds of solutions can we come up with together to resolve that struggle?

Further, this study reflects that there is great inequality in the distribution of resources to FASD caregivers even with their own community, and it reveals the oppressive nature of a system that only serves those with the most powerful voices. Caregivers have to fight for many of the resources they need, which causes unnecessary strain and exacerbates emotional resource depletion. Advocacy for immediate change in this regard should be a priority.

Relationship of Results to Previous Research

This research builds on the scant literature concerning the experiences of FASD caregivers. No studies concerning FASD caregiver support groups specifically could be found, and only a few studies explored other interventions that focussed on the FASD caregiver rather than the child. This study departs from the primary focus in the literature, which is prevention and diagnosis of FASD, and focuses on practical interventions for isolated caregivers, particularly FASD support groups.

The findings of this study are consistent with the benefits of support group participation as described in Shulman's (1992) discussion on "mutual aid" and Yalom's (1995) presentation of "therapeutic factors." While a comprehensive review of the literature on group process is beyond the scope of this study, several important connections should be pointed out.

Participants were clear about the importance of the group leaders establishing predictable structure and being able to intervene with challenging members in order to promote safety and constructive use of time within the group. Doel and Sawdon (1999) and Wayne and Gitterman (2003) each present useful insights into the issue of problematic interactions in the group and provide direction for leaders on how to address these situations. Berman-Rossi (1993) discussed the stages of group development, and the necessity of addressing these conflicts within the group as a pre-cursor to establishing true intimacy. Several participants described situations where unresolved conflict led to tension in the groups on a week-to-week basis, and in one instance the impact on the group was so destructive it impacted on a participant's desire to continue attending. Doel and Sawdon (1999, p.189) provided a colourful analogy for this dynamic, describing it as "the elephant shit in the middle of the group." They describe this as follows: "No-one is acknowledging it. It won't go away on its own; indeed, it will continue to grow and to smell, and to become even more powerfully foul because no-one is able to deal with it. Only when the group acknowledges its existence can it be swept up and dealt with." It is clear that group leaders must be willing and able to address sources of conflict in the group in order to maintain their potential as a therapeutic tool.

Kurland and Salmon (2005) also provide an interesting framework for distinguishing two different approaches that might be present in different support groups: "casework in a group" and "group work," the latter of which promotes a stronger identification with the emotions connecting each group member, and highlights the overlapping nature of members' difficulties. Several participants seemed to allude to this and pointed out the need for FASD group leader training in order to enhance group effectiveness. What is important for optimum group functioning is that group facilitators stimulate discussion among group members rather than simply responding themselves to what group members share.

Several researchers have specifically made mention of the value of caregiver support groups for FASD caregiver population (Carmichael-Olson, 2006; Giunta & Streissguth, 1988; Weiner & Morse, 1994), and this research expands on these anecdotal suggestions that support groups are an effective intervention tool. The findings of this study suggest similar gains can be expected for FASD caregivers in relation to what previous research has found in other caregiver populations.

For example, the findings of the present study are consistent with the findings of Citron, Solomon and Draine (1999), who reported that caregiver support groups benefit caregivers of adults with mental illness by decreasing shame and isolation by creating an opportunity for community among caregivers who share similar struggles. However, the potential negative impact of group participation described by Citron, Solomon and Draine (1999) was also strongly supported in this study, which refers to the initial depressing impact group participation can have as caregivers hear the stories of one another's difficulties and come to realize that their future may involve similar struggles.

Further, Dunn, Burbine, Bowers, and Tantleff-Dunn (2001) reviewed coping attitudes that seemed to buffer against stress in autism caregivers. Participants in this study who seemed to be coping well appeared to share many of these perspectives such as positive appraisal and confrontive coping, which indicates that this might be a helpful framework to explore protective factors against burnout in FASD caregivers as well.

One point of interest to note is that caregivers' descriptions of their struggles to access support and the emotional impact of being a FASD caregiver were very similar to what was described by other researchers (Brown & Bednar, 2004; Brown, Sigvaldason & Bednar, 2005). This suggests that in spite of the significant increase in awareness about FASD in medical and helping professions, interventions developed in the past 4-5 years have not ameliorated these difficulties.

The data in this study also did not indicate that FASD caregiver support groups incorporate specific self-care activities, with the exception of general group participation and respite care. Carter, Nezey, Wenzel and Foret (1999) described several easily implemented activities to promote stress reduction and improve coping which could be incorporated into FASD support group sessions. These include leisure activities, guided imagery, and exercises designed to help caregivers identify their needs and how they can be satisfied.

Implications for Practice

This study points to several recommendations for practice that would improve services to FASD caregivers and the effectiveness of support groups. First, support groups should assess the leadership needs of their individual group, develop a reasonable timeline for any needed changes and identify needed resources in order to reassign leadership if this is desired. A particular area of debate concerning group leadership revolves around whether or not leaders should be FASD caregivers themselves, or if groups can effectively be lead by non-FASD caregivers such as social workers.

Both group leadership models were represented among the support groups attended by participants in this study, and a variety of perspectives emerged when participants were questioned about preferred leadership. Many service providers are involved at the level of caregiver group facilitation, but the data reflects that even in the best case scenarios where there is solid leadership and the group is running very well, caregivers still view internal leadership as the best model. That said, in some communities having professional leaders continue in the support group leader role might be important for a period time or even on a permanent basis depending on the needs and desires of group participants, so it is important not to make sweeping conclusions on the basis of these findings about the imminent need for leadership transition when some of the higher-functioning groups were, indeed, led by non-FASD caregivers.

In communities where a FASD caregiver leadership model is desired, an important task will be the development of training tools to help those caregivers develop necessary positive leadership qualities and skills to become strong facilitators of FASD support groups. An effective caregiver-led group will likely need a leader whose family is relatively stable, so that the leader can provide adequate support for group members. Further, if a situation arises whereby the caregiver leader has an unexpected family crisis, it is critical that there is an atmosphere within the group that permits the leader to step out of his or her role for a period of time, as necessary, and the group needs to accept new leadership during this time.

Finally, many caregiver group leaders appear to be saddled with enormous responsibilities related to their leadership roles including crisis support, mentorship, research, developing connections to resources, finding speakers, fundraising, task force membership, advocacy, and so on. If FASD caregiver leaders are to take on these roles, appropriate changes to the leadership model may be necessary, such as establishing co-leadership with a clear division of tasks.

If this shift in leadership results in the displacement of valued professionals formerly in leadership positions, then these social workers or service providers should thoughtfully consider their roles in relation to FASD support groups, and ask caregivers how they might be more helpful in their communities. Service providers should be willing to respectfully shift away from support group attendance, if deemed appropriate, and with consideration for the importance of proper timing for this shift. Social workers could consider assuming different responsibilities such as providing training and support to group leaders outside of sessions, teaching principles of community development, micro and macro level advocacy, and providing assistance with practical aspects such as assisting with paperwork, developing connections to help caregivers access more resources, and the development of tools such as charts and calendars using picture symbols, when needed by individual caregivers. If long-term leadership by a non-FASD caregiver is preferred, then discussions should take place to reduce any conflicts-of-interest and prevent silencing. Both models are valuable and sustainable but are highly dependent on the group leader in question and the needs of group members.

In either leadership model group leaders should consider ways to improve conflict resolution within the groups and create a predictable structure for group sessions in order to prevent caregivers from experiencing ongoing distress as a result of hurtful or unhelpful group interactions. In addition, mentorship stood out as one of the most powerful helpful interventions that caregivers spoke about in this study. As such, FASD support groups should explore ways of increasing mentorship opportunities both within and outside support group sessions. Further, group leaders may benefit from sharing resources with leaders in neighbouring communities and developing a Speakers Bureau in order to make it easier to incorporate educational aspects into support group sessions. Taping or telecasting of speakers could even be considered.

The data collected in this study also illustrates the fragmentation of services and the discontinuity across systems concerning an understanding of FASD and an unwillingness of community agencies to provide supports. Caregivers face an ongoing battle to educate teachers, physicians and service providers about FASD and why cognitive-behavioural strategies will not work in order to garner their support for creating a modified environment more suitable for their child. One strategy that appeared to be successful was to have a FASD expert, namely the group leader, to attend a meeting at the school alongside the caregiver in order to lend support to their position and requests. It may be beneficial to seek funding for localized case managers where a social worker comes alongside caregivers as they work to connect with needed resources and ensure proper accommodations take place. This advocacy role has an additional supportive element in that caregivers who struggle with self-advocacy would have access to someone who will do this on their behalf and push for the removal of barriers to service.

Support groups could also be a venue to create material to disseminate to family members and others supporting FASD caregivers about ways they can be most helpful. This might include information about the impact of questioning the FASD diagnosis, criticizing caregivers, and pushing strategies that the caregivers have found unhelpful. Several caregivers in this study also appeared to be restraining their use of needed supports out of fear of overusing them and subsequently losing them. Thus, materials developed for external caregiver supports may also be able to communicate that external supports can be most effective if they provide clear indications of the degree of involvement they are willing and able to offer, perhaps planning regular dates for respite, social activities or other forms of support at pre-determined intervals so that caregivers can anticipate and count on these opportunities for stress release and not have to "save" the support opportunity for a crisis point.

Finally, the results of this study identified several priorities from FASD caregivers about the types of supports that would be beneficial in addition to FASD caregiver support groups. Ideas included access to respite care options and respite funding, incorporation of FASD education in the training of teachers and social workers, increased educational supports for their children, 1:1 mentors for both caregivers and FASD children, improved access to diagnostic teams, increased awareness of FASD among the general public as well as professionals, and advocacy for increased access to resources.

Implications for Future Research

There are several areas that emerged as important areas for future research as a result of this study. In order to further assess the effectiveness of support groups, future quantitative research should examine specific outcomes concerning factors such as stress relief and promotion of long-tem caregiving commitment among support group participants versus non-participants. However, caution should be exercised when conducting research with caregivers not accessing support groups, because if this leads them to be isolated and if they lack opportunities to process the complex emotions created by their caregiver role, it is possible that engaging in intense discussions about such intimate aspects of their lives may lead them into further distress. The well-being of the caregiver is clearly a priority over conducting research, and studies should be carefully designed in ways that benefit caregivers rather than create situations that might increase distress.

Similarly, future researchers should weigh the benefits and drawbacks of incorporating participatory action research methods with the FASD population. The community of FASD caregivers is very welcoming to allies in the research field. A researcher who has an ongoing investment in FASD research or advocacy is more beneficial than a researcher who is only invested in the issue for the purpose of a time-limited study or for publication. Although elements of participatory action research were incorporated in this study, including several member-checks, shared ownership of the results, and my continued involvement in FASD initiatives outside of this study, a full participatory action model was not incorporated in this study due to time constraints. In any case, caregivers appeared to struggle to provide feedback at the various stages of research because of the ebb and flow of family crises that arose. Researchers need to be respectful of FASD caregivers who may not be able to provide any further input beyond the initial interview. Caregiver feedback regarding the design of the study spoke positively of the semi-structured interview format that allowed them to freely speak about issues they needed to talk about and did not limit discussion to the researcher's questions. One caregiver indicated a preference for the interview to be shorter than the 66 minute duration of her interview.

Further research could also be conducted to explore the utility of non-support group based mentorship models and online forums for support and assess whether or not they are more effective intervention tools for certain caregivers based on factors such as geographic considerations, caregiver status, and so forth. Some have suggested that the anonymity of online forums allow biological and non-biological caregivers to access support without experiencing the same level of stigma. This may be a more suitable intervention tool for biological caregivers, which is a specific caregiver population that should be given special attention in future research. Also, northern and rural caregivers may not have the same access to caregiver support groups, and therefore web-based support groups may be a preference among this population.

Further study could also explore the effectiveness of FASD caregiver leaders versus professional leaders in more depth. Researchers could also explore if there is a risk of vicarious trauma taking place within these groups if a caregiver leader experiences a particularly traumatic family event, and how it impacts group functioning and attendance when the leader is struggling.

To build on the findings of the present study, further research should also be designed to engage participants who chose to never attend a support group, and also to solicit input from those who attended a support but chose not to return. This might provide important information about the needs of different caregivers and offer suggestions on how all caregivers can better be supported. Further inquiry could also explore the impact on families when only one partner attends a FASD support group (e.g. whether this contributes to relationship struggles). Special efforts could also be employed to access the voices of male caregivers in relation to their experiences of FASD caregiver support groups.

In this study it was also surprising that no extended family caregivers responded to recruitment flyers, which might be reflective of the fact that extended family members who enter into kinship care or intermittent care of FASD children either do not know about FASD support groups, do not feel welcome to attend, or possibly do not feel the need to attend due to the temporal nature of their caregiving role. However, it could be an indication that these caregivers need an explicit invitation to attend support groups and participate in research, and recruitment materials should include this information.

Finally, in the context of this study, numerous caregivers made reference to changes in their thinking patterns concerning their child's behaviour as a result of conferences, books, and guidance from fellow caregiver support group members. The adoption of this 'paradigm shift' appears to be a critical turning point for caregivers, although ongoing mentorship seems important to help caregivers continue to reframe problem behaviours as symptoms of FASD. Researchers should consider developing a tool to assess the degree to which a 'paradigm shift' acts as a protective factor against caregiver burnout.

Limitations

This study has several limitations that impact the generalizability of the findings. The small sample size of seven participants is sufficient for a qualitative study to uncover general themes and ideas, but future research should target a larger population. Further, all caregivers in this study were adoptive parents and were women who were well-educated, enjoyed middle or upper-class lifestyles, and identified themselves as Caucasian. Future research may wish to specifically target a mixture of other demographic populations, particularly men, who may have had different experiences within support groups. It is possible that this demographic is representative of those who actually attend support groups, but this cannot be inferred from the current study.

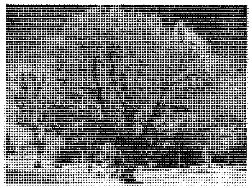
Finally, the recruitment strategy used in this study was not successful in securing participation from FASD caregivers with a predominantly negative view of support groups and/or the decision not to continue attending these groups. It is possible that these caregivers saw recruitment information but decided not to respond because they wanted support groups to be seen in a positive light, in spite of their experiences. Further research should consider means of disseminating research recruitment flyers that focus on gaining constructive criticisms from this target population, and that flyers should also be distributed through diagnostic clinics, hospitals, family physicians, online FASD websites and list-servs.

Conclusions and Summary

In conclusion, FASD support groups are a highly valuable resource for some caregivers. Although non-biological caregiver impressions of the usefulness of FASD support groups in this study are generally quite positive, it should be acknowledged that such groups also have the power to reinforce negative self-talk, isolate caregivers and induce silence among caregivers who had hoped for more from these groups. Finally, even though participants expressed the view that FASD caregiver support groups should be continued and expanded, they were also clear that groups are not adequate as a stand-alone intervention for caregivers, and that other supplementary supports such as respite care are critical.

Appendix A

"When we long for life without difficulties,
remind us that oaks grow strong in contrary winds
and diamonds are made under pressure". -- Peter Marshall



CAREGIVERS' EXPERIENCES OF FASD SUPPORT GROUPS

Principal Investigator: Sharon Porty -- Member of the Hamilton FASD Task Force
and MSW student, Wilfrid Laurier University

Research Supervisor: Dr. Nick Coady
Professor, Faculty of Social Work at Wilfrid Laurier University

**Are you caring for a child affected prenatally by alcohol?
Have you ever participated in an FASD caregiver support group?**

If so, **you** are the expert on FASD interventions, and we hope you will consider joining our study on your experiences in these groups.

For this study, you will be asked to participate in a private and confidential interview to talk about your experiences as a caregiver, your perceptions about the strengths & and limitations of FASD support group participation, and your thoughts about the personal impact these groups have made on you and your family. For research purposes, this study will be focusing on the experiences of caregivers who are **not biological parents** to the child with FASD.

The first interview will take place privately and will be 1-2 hours in length. An optional follow-up conversation will be offered at a later date to discuss the results of this study, debrief about this research project, and talk about future research directions. Participants will be provided with a $45 honourarium for his/her time.

Please note that support group participants are not required to participate in this study, nor will their access to support group services be impacted by their involvement. Support group leaders will not be given information about whether or not any caregivers in their group are a part of this study, nor will any identifying information about you be shared in the findings.

For more information, or if you are interested in participating in this study, please contact Sharon Porty, the Principal Investigator, at (519) 884-0710 ext.5268 or port3770@wlu.ca.

Appendix B

Caregivers' Experience of FASD Support Groups

TELEPHONE/EMAIL SCRIPT

Hello. My name is Sharon Porty. I am a graduate student at Wilfrid Laurier University in Social Work, and I am conducting research for my Master's thesis. Thank you for your interest in this research project. In this research, I want to learn more about the impact that support groups have on caregivers of young person's with diagnosed or suspected Fetal Alcohol Spectrum Disorder. There is little information available on successful interventions and supports for families affected by FASD, and it is my hope that your experiences will help us have a better understanding of how to offer the best support to families like yours.

Before I tell you more about the project, I want you to know the no one other than me will be informed that you are talking to me today, and no one will be told whether or not you agree to take part in the study. The choice to be involved in this project is completely up to you and it will not affect your ability to take part in a caregiver support group, nor will any support group leader be informed that one of their caregivers is involved in this study.

If you agree to participate in this study, you will be one of 6-12 men or women who have been caregivers for a young person up to the age of 21 who has suspected or confirmed FASD, and who have attended at least three sessions of a caregiver support group. No information that would identify you or your child will be shared in the findings of this study.

I am meeting participants in various locations in Southern Ontario that will be mutually agreed upon and accessible to you. If you agree to be a part of this study, we will meet privately for a 1-2 hour interview where we will discuss your experiences in participating in a caregiver support group, what you appreciated about the group and what could be improved, and we will explore if participating in the group has helped you deal with any feelings of frustration, hopelessness, and loss. Our meeting will be audio-taped, and transcribed, and you will have the opportunity to provide a written submission to clarify or expand on areas if you see fit. I will later offer an opportunity for an additional conversation to debrief about the study, go over the findings, and discuss recommendations for future research.

I would like to tell you a bit more about the study, but before I do, do you have any questions?

If you agree to participate, you will not be required to answer any questions that you do not wish to answer. You can end the interview at any time, and may discontinue your participation in the study if desired.

If you do agree to participate in the study, the information you share with me will not be used in any way that will identify you, your family, or the caregiver support group you had participated in. Your name will not be used in any reports or submissions.

Do you have any questions?

Do you think you would like to take part in the project?

If they agree:
Ok, I have a couple of questions for you, just to make sure that you are eligible to participate in this study.

First, are you 18 years of age or older?
This study is about caregivers of a young person with suspected or confirmed FASD, who have participated in a caregiver support group specific to FASD issues. Have you provided care for a someone who fits these criteria?
Do they have a diagnosis? If so, what are they diagnosed with?
If they have not been diagnosed, what indications are there of FASD? Is a physician investigating a diagnosis of FASD?

Are you the caregiver for more than one individual affected by FASD at any one given time?
Have you participated in an FASD support group? How many times?

The experiences of a biological parent may be different in some ways from other caregivers. Are you the biological parent of an individual with FASD?

Can we set up a time to meet together?
What city is most convenient for us to meet? Kitchener, Milton, Burlington, Hamilton, or elsewhere?
What is the best time of day for you to find a couple of hours for an interview?

This study has been approved by the Wilfrid Laurier University Research Ethics Board. I can provide you with contact information for the Chair of the REB if you have any questions about the ethics of this project.

If they decline participation:

That's fine. Once again, I want to reassure you that I will not be telling anyone that you contacted me about the study. Thank you for your time and interest in the study.

Appendix C

INFORMED CONSENT STATEMENT

Caregivers' Experience of FASD Support Groups – Sharon Porty, Dr. Nick Coady

You are invited to participate in a research study. The purpose of this study is to determine the how caregivers of a young person with FASD experience support groups, and the impact it has on their family life. This study is being conducted by Sharon Porty, a graduate student in the Masters of Social Work program at Wilfrid Laurier University. This research is being supervised by Dr. Nick Coady, a professor in the Faculty of Social Work at Wilfrid Laurier University.

INFORMATION

You are invited to participate in this study as the caregiver of a child or young adult with confirmed or suspected Fetal Alcohol Spectrum Disorder who has participated in a caregiver support group. This study will involve an 1-2 hour interview where we will discuss your initial impressions of participating in a parent support group, strengths and weaknesses of the group(s) you have attended, and ways in which your attitudes may have changed since attending a group. Topics covered may also include feelings of hope, frustration, grief and loss, and your relationship with your FASD child. This interview will take place with a trained interviewer who is sensitive to the struggles you may face as a caregiver of a child with FASD, and will take place in a private location that is mutually agreed upon. Prior to the interview you will also be asked to fill out a brief demographics questionnaire.

For research purposes, your interview will be audio-recorded and later transcribed. Your identifying information will be removed from the transcription, in order to protect your privacy. The transcription will be provided to you and you will have an opportunity to attach a written submission in the event that you feel you were unable to fully express your thoughts in the verbal interview, or if you feel further clarification is needed. You are under no obligation to provide this feedback, and can participate fully in the study without agreeing to provide later feedback.

The researcher will then analyze all the information collected in the study, and draw up a summary of the preliminary findings. This summary will be mailed or emailed to you, and you will have the option to provide me with your feedback on the findings, to debrief about what it was like to participate in this study, to offer your input about how the findings should be shared within the FASD community, and to talk about future research directions. This discussion will take place in the most convenient format for you, whether that be via email, telephone, a letter, or another in-person meeting.

The audio recordings from the interviews will be assigned a code number and stored in a locked filing cabinet or secured information system in the researcher's home, and will be preserved for two years after the publication of results from this study. After those two years, the audio recordings and transcripts will be destroyed.

There will be a total of six to twelve caregivers participating in this study, who are each a caregiver for a child with FASD, and have participated in a support group. If you agree, it is possible that direct quotes from your interview may be used in publications. To maintain confidentiality, identifying information will be removed from the quotations. If specific personal information is contained in the quote, it will be changed in order to protect your privacy. Please indicate your preference below regarding the use of your quotations:

☐ Yes, I can be quoted.

☐ No, Please do not quote me.

RISKS

It is possible that during the interview you may wish to discuss sensitive personal information about your experiences, which may cause you to feel a variety of emotions. If the interviewer senses that you are experiencing emotional distress, you will be reminded that you may stop the interview at any time, and that you have the right to "pass" on questions you are not comfortable with. If necessary, the interviewer will refer you to appropriate services to ensure your support needs are met.

BENEFITS

This benefits of this research project is that it will provide insights into whether or not caregiver support groups are effective, including strengths and weaknesses. It will also offer preliminary insights into whether or not participating in such a group improves your experience as a caregiver for a young person with FASD, and acts as a buffer to prevent burnout. This information could be very valuable to other caregivers who are considering joining a support group, and could be used to pursue funding for caregiver support groups.

You may also feel that participation in this study is beneficial in that you will have an opportunity to share your experiences, whether positive or negative, in a non-judgmental environment, and that it will be used in a constructive manner to benefit other caregivers and support group leaders.

CONFIDENTIALITY

Every effort to protect the anonymity of yourself and your family in this research will be made in order to respect your privacy. Your support group leader will not be aware of your participation in this study unless you choose to inform them of that information.

By law, the interviewer is required to report any disclosures of emotional, verbal, or physical abuse or neglect of a child under the age of 16 to child protective services. The interviewer is also obligated to report any concerns if you are at risk of causing harm to yourself or others. Outside of these circumstances, all interview information will remain confidential, and identifying information will be removed from the data. All documents and audio recordings will be identified with a number and will be

____
participant's initials

stored in a locked filing cabinet in the researcher's home. All information stored by computer will be protected by a password. Identifying information will not be mailed to anyone at any time. You will not be identified by name in any reports of the completed study. The interviewer, Sharon Porty, and her research supervisor, Dr. Nick Coady, are the only people who will have access to the data.

COMPENSATION

For participating in this study you will receive compensation in the amount of $45 upon completion of the interview.

CONTACT

If you have questions at any time about the study or the procedures, (or you experience adverse effects as a result of participating in this study) you may contact the researcher, Sharon Porty, at port3770@wlu.ca or the Research Supervisor, Dr. Nick Coady, at 1(519)884-0710, ext. 5238. This project has been reviewed and approved by the University Research Ethics Board at Wilfrid Laurier University. If you feel you have not been treated according to the descriptions in this form, or your rights as a participant in research have been violated during the course of this project, you may contact Dr. Bill Marr, Chair, University Research Ethics Board, Wilfrid Laurier University, (519) 884-0710, extension 2468.

PARTICIPATION

Your participation in this study is voluntary; you may decline to participate without penalty. If you decide to participate, you may withdraw from the study at any time without penalty and without loss of benefits to which you are otherwise entitled. If you withdraw from the study before data collection is completed your data will be returned to you or destroyed. You have the right to omit any question(s)/procedure(s) you choose.

FEEDBACK AND PUBLICATION

It is expected that the results of this study will be submitted as a thesis, and may be published in a journal. Further, the information may be shared in the form of a presentation or written form at conferences or workshops. The findings may also be disseminated in the form of an email or on a website. The findings will be available by summer, 2009.

CONTACT INFORMATION

The researcher will send the transcriptions of your interview and, at a later date, a summary of the preliminary findings to you, to enable you to provide feedback if you choose to do so. Please provide the email address and/or mailing address where this information can be sent:

Email Address: ______________________________

Mailing Address: ______________________________

____

____

CONSENT

I have read and understand the above information. I have received a copy of this form. I agree to participate in this study.

Participant's signature__________________________________ Date
____

Investigator's signature_________________________________ Date
____

Appendix D

Resource List

DISTRESS LINES

Community Torchlight Distress Centre (Wellington-Dufferin) 1(877) 822-0140
Oakville Distress Centre (905) 849-4541
Telecare Distress Line (Halton, Hamilton, Haldimand-Norfolk) (905) 681-1488
Distress Centre of Peel (905) 278-7208 or 1(800) 363-0971 for Caledon residents
Distress Centre of Toronto (416) 408-4357 or 416-408-HELP
Distress Centre of Niagara Inc (905) 688-3711, (905) 734-1212, (905) 382-0689,

PARENT SUPPORT GROUPS

Association of Parent Support Groups In Ontario Incorporated (APSGO)
1-800-488-5666

FAMILY COUNSELING

Hamilton
Catholic Family Services (Individual and Family Counseling Services, Walk In Counseling Clinic) 905-527-3823
Halton
Reach Out Centre for Kids (ROCK) (905) 634-2347 ext 239
    Parenting Crisis Line: (905) 878-9785

Peel
Family Services of Peel Individual, Couple and Family Counseling (905) 453-5775
Peel Children's Centre (905) 795-3500
    Parenting Crisis Line: (416) 410-8615
Associated Youth Services of Peel 1(800) 762-8377

Toronto
Family Service Association of Toronto (416) 595-9618
Numerous other Toronto services: 211Toronto.ca

Waterloo and Wellington
Family Counseling and Support Services for Guelph /Wellington 1(800) 307-7078
Catholic Family Counseling Centre (Waterloo and Wellington County) 1(800) 743-4140
Kitchener-Waterloo Counseling Services (519) 884-0000

Niagara
Family Counseling Centre Ext 3345 1(800) 937-7731

Appendix E

Demographics Questionnaire

Please check the box that is most appropriate:

I am:

- ☐ An adoptive parent
- ☐ A foster parent
- ☐ Grandparent
- ☐ Other extended family member
- ☐ Other:___________________

I identify as:

- ☐ Female
- ☐ Male
- ☐ Other

My ethnic background (if known): ___________

The ethnic background of my child with FASD (if known): ______________

I would identify myself as a visible minority: yes/no/unsure

The last time I was in school I was in:

- ☐ Elementary school
- ☐ High School/Equivalency program
- ☐ College or Trade program
- ☐ University
- ☐ Graduate School/PhD program

My annual household income (before taxes) is:

- ☐ Under $20,000
- ☐ $20,000 to $39,000
- ☐ $40,000 to $59,000
- ☐ $60,000 to $79,000
- ☐ $80,000 to $99,000
- ☐ over $100,000

My Age:

- ☐ 20's
- ☐ 30's
- ☐ 40's
- ☐ 50's
- ☐ 60's
- ☐ 70's
- ☐ 80's and up

The age of my child affected by FASD: ______

Ages and gender of other adults and children living in the home:

____

____

My child with FASD lives with me:

- ☐ full-time, on a permanent basis
- ☐ full-time, permanently, with some formal or informal respite care
- ☐ full-time, but this is likely a temporary living arrangement (i.e. foster care)
- ☐ around 50% of the time
- ☐ for the summers and other special occasions
- ☐ on occasion
- ☐ Other:____________________

How long has your child with FASD been in your care? ___________

How long have you participated in an FASD support group? ______________

Please list the kinds of service providers (**other than a caregiver support group**) that have been involved with your child with FASD (including doctors, specialists, special education, occupational therapist, probation, social workers, programs, respite, etc.)

____

____

____

Please indicate your experience with the services provided:

- ☐ I am well connected that services that are mandated to meet the needs of my family
- ☐ I have a few good service providers who work outside of their mandate in order to try to meet the needs of my family
- ☐ I have some services involved, but I have to use a lot of energy to get them to meet the needs of my family
- ☐ I have some services involved, but they only marginally meet the needs of my family
- ☐ I have no services involved
- ☐ Other: _______________________

Appendix F

Interview Schedule

Before we begin with the interview, I wanted to give you a quick snapshot of my motivation for doing this research. I am not a caregiver of a child with FASD myself, nor have I ever led a support group. However, I have worked with youth whom I have suspected to have FASD, and I have experienced some of the frustrations and struggles related that. This has led me to seek out more training on FASD, join my local FASD task force, and create this research project, in order to learn how caregivers like yourself can best be supported.

Now I would like to talk with you about your experiences with the FASD caregivers' support group. After talking about your experiences with the group, including your views on its strengths, limitations, impact, and suggestions to make it better, I'll also ask you about your views on what other types of resources and supports should be made available to caregivers. I have a number of questions to help guide our discussion, but please remember that you have the right not to answer any question and that you may stop the interview at any point. Do you have any questions?

1) Can you help me understand how you came to be a caregiver of the child with FASD and how that led you to come to a support group?
    - How did you hear about the group?
    - What had you heard about the group, if anything?
    - What were your thoughts and feelings about becoming involved?
    - What were your hopes and fears about the group prior to becoming involved?
    - How long have you been (were you) involved in the group?

2) Can you please describe the support group to me.
    - Who is the leader of the group and what is her/his background?
    - Do you know how long the group has been running and how it got started?
    - How many people typically attend the group?
    - How often does the group meet?
    - Where does the group meet?
    - Can new group members join at any time?
    - How long are the meetings?
    - Can you describe a typical group meeting?
    - How do the group meetings start? How do they end?
    - Is there a topic or theme for each group meeting (if so, how are these determined and what are some of the topics/themes)?

3) Please tell me about your experiences in the FASD caregiver support group. Probes for positive aspects:
    - What are (were) the best aspects of the group?

- In what ways is (was) the group helpful to you?
- What aspects of the group are (were) most helpful to you?
- What topics or themes addressed in the group were most helpful to you?
- In what ways does (did) the leader contribute to the group?
- In what ways do (did) the members contribute to the group?
- What needs does the group meet for its members? How?
- How has (did) the group help with your ability to cope as a caregiver?
- How has (did) the group help with your ability to deal with stress as a caregiver?
- Can you describe a particular group session or part of a group session that had a particularly positive impact on you or another group member?
- Can you describe any ways your life has changed for the better as a result of your group involvement?

Probes for negative aspects/suggestions for improvement:

- What are (were) the worst aspects of the group?
- Are (were) there any negative aspects to the leadership of the group?
- Are (were) there any negative aspects to the membership of the group?
- What things about the group would you change?
- Was there a time when you felt that you left the group feeling worse than when you came? Can you tell me about this?
- Have there been (were there) times when there was a noticeable tension in the group? Can you describe this and how it was handled?
- What would you like to see more/less of in the group's time together?
- Are there any stressors or needs related to your experience as a caregiver of an FASD child, that you felt have *not* been addressed by the support group?
- In what ways could the support group change, in order to better meet your needs?
- Can you describe any ways your life has changed for the worse as a result of your group involvement?
- Do you have any suggestions for support group leaders that would improve the effectiveness of the group?

4) Beyond your involvement in the group, what other types of services for caregivers do you or have you had access to?
    - What (are) were the best aspects of these services?
    - What are (were) the worst aspects of these services?
    - If you could have access to unlimited resources and finances to support the needs of your family in caring for your child affected by FASD, what sorts of interventions would you put in place?

5) Is there anything else you would like to share about your experiences as a caregiver, of the support groups, or of FASD services in general?

Sometimes talking about personal things like what we have talked about today can be a bit uncomfortable or even upsetting. If talking to me today has upset you, or if you have experienced added stress or discomfort as a result of taking part in this study, please refer to the resource list I provided to you at the start of our conversation today.

Also, if you have any questions or concerns regarding the study itself, you can contact me, my thesis supervisor, or the Ethics Committee chair at any time. The numbers can be found on the Informed Consent Statement.

Thank you for taking the time to meet with me today. I appreciate your honesty and openness and wish you and your family all the best in the future. I will send you the transcriptions of our interview when they are complete, and you may submit any additional thoughts or comments if you did not feel you communicated what you wished to say. I will also be in touch with you at a later date to invite you to participate in the follow-up group meeting with other participants if you like.
Thanks again!

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