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Burden Experienced by Caregivers of Youth with
Fetal Alcohol Spectrum Disorder: An Exploratory Study

by

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Abstract

Caregivers of youth with Fetal Alcohol Spectrum Disorder (FASD) experience burden in the form of objective responsibilities, subjective strain, along with oppression and stigma. Caregiver burden has been linked to three distinct areas in the literature: 1) specific demographic characteristics of the caregiver; 2) perceived social support of the caregiver; and 3) symptom severity of the individual with the disability. The participants ($n = 9$) completed four self-report questionnaires aimed at identifying correlates of strain in this sample. In comparison with prior studies, this sample reported higher levels of strain, less perceived social support, and equivalent levels of symptom severity of the youth. Correlational analysis revealed numerous statistically significant associations with strain including: lower income (caregiver); lower education level (caregiver and youth); fewer children in the home; lower age (youth); higher number of prescribed medications (youth); and poor social and emotional skills (youth). More research is needed in order to better understand the problem of caregiver burden in this population in order to improve outcomes for both youth with FASD and their caregivers.

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List of Symbols, Abbreviations and Nomenclature

Symbol	Definition
4DDC	Four Digit Diagnostic Code
ASPD	Antisocial Personality Disorder
β	Beta: standardized multiple regression coefficient
CGSQ	Caregiver Strain Questionnaire
CNS	Central nervous system
FABS	Fetal Alcohol Behavior Scale
FAM	Family subscale on MSPSS
FASD	Fetal Alcohol Spectrum Disorder
FRI	Friend subscale on MSPSS
M	Mean (arithmetic average)
Mdn	Median
MSPSS	Multidimensional Scale of Perceived Social Support
n	Number in a subsample
OS	Objective Strain subscale on CGSQ
PBCL	Personal Behavior Checklist
r_s	Spearman rank correlation coefficient
SD	Standard Deviation
SES	Subjective Externalized Strain subscale on CGSQ
SIS	Subjective Internalized Strain subscale on CGSQ
SO	Significant Other subscale on MSPSS

CHAPTER ONE: INTRODUCTION

Fetal Alcohol Spectrum Disorder (FASD) is the leading known cause of mental retardation (Eustace, Kang, & Coombs, 2003). Individuals with FASD experience numerous secondary disabilities (psychosocial problems) consequent to the primary disability of neurocognitive dysfunction. Caregivers of individuals with this disorder experience higher levels of burden as a result of these secondary disabilities. However, little is known about caregiver strain with this population.

Caregiver burden has been given attention in the social science literature in relation to other physical and mental health conditions; however there are virtually no studies that examine the burden experienced by caregivers of youth with FASD. This is in spite of the fact that much is known about the condition of FASD and the factors that influence outcomes for youth both positively and negatively. Clinical wisdom and anecdotal information about caregiver burden with this population have emerged; however a more rich and structured understanding of the caregiver experience is required. In addition, this is a critical issue of social justice that, if it was better understood, would impact positive outcomes for both youth and caregivers. Burden experienced by caregivers has been shown in the literature to be related to specific demographic characteristics of the caregiver, their perceived social support, and symptom severity of the individual with the disability.

With the above points in mind, the three purposes of this study are: 1) to develop better comprehension of the demographic characteristics of caregivers associated with burden; 2) to understand the relationship between the caregiver's perception of social

support and burden; and 3) to improve comprehension of the relationship between symptom severity of the individual with FASD and caregiver burden. This study will provide an introductory knowledge of the caregiver experience and offer clinical direction for agencies and practitioners working with this population. In addition, increased awareness of the issues related to caregiver burden may provide a stronger basis for resource allocation on a government and policy level.

Theoretical underpinnings

Positivism and Constructivism

This study was designed with both positivist and constructivist assumptions. Positivism impacted the method, in that it is scientific and empirical. The research design focuses on testing a hypothesis, making it hypothetico-deductive (Ponterotto, 2005). With positivist research there is a quest for truth, certainty, universal laws, and credibility (Patton, 2002). The design of this study, being quantitative in nature, began with a hypothesis: caregiver burden may be related to specific demographic characteristics of the caregiver, their perceived social support, and symptom severity of the youth.

This project also has constructivist assumptions. Axiologically, the constructivist researcher does not consider him- or her-self as a neutral observer of human behaviour. Instead, the researcher is as engaged and integral to the research process as the participant. Indeed, the researcher's lived experiences and values should be overt and bracketed, not eliminated (Ponerotto, 2005). Even in a quantitative, scientifically designed study, the researcher's lived experiences impact the process from the research

questions to the study's design to the interpretation of the data. Therefore, this writer has indexed below the major factors in her lived experience that have impacted this study.

Writer's lived experience

The caregiver experience has been an integral part of this writer's personal and professional development. For more than 30 years, her family has provided foster and group care to over 200 adolescent males. Professional caregiving has been a family vocation and has directly impacted her beliefs, values, and perspectives. For most children, their parents' chosen area of work is away from the family home and does not include direct involvement on the part of the child. In contrast, this writer's unique home environment endowed each child with a role in the family profession. In this context, caregiving was considered a highly valued line of work with spiritual, emotional, cognitive, and physical implications. Indeed, caregiver burdens were experienced in the family in the form of fiscal constraints, restricted freedom, and increased responsibilities. In addition, oppression was experienced as a result of the perception of social degradation and the low status of caregiving in society. The extraordinary significance of the social justice needs of caregivers was conceived in this context and had a direct impact on the pursuit of this topic for this thesis project in the Master of Social Work program.

Social justice for Caregivers

This project is grounded on social justice principles that will be elaborated in chapter three of this document. In particular, the capabilities approach (Nussbaum, 2000) formed the theoretical underpinnings and motivation for this study. The approach was first proposed by Amartya Sen (1999) and further developed from a feminist perspective

by Nussbaum (2000). She asserted that human processes and relationships are central to well-being and identified 10 central human capabilities that make someone “truly human” (Nussbaum, 2000, p. 231). These capabilities are: 1) life; 2) bodily health; 3) bodily integrity; 4) senses, imagination, and thought; 5) emotions; 6) practical reason; 7) affiliation; 8) other species; 9) play; and 10) control over one’s environment (ibid, pp. 231-233). This approach is built on the assumption that there is a “threshold level of each capability” that each person must have available to them for full human functioning (ibid, p. 223). Capabilities, she argued, are not equivalent to functioning and should not be confused. Each person should be apportioned the 10 capabilities but may choose for themselves how they will function within those capabilities. Caregivers and issues of dependency were given special attention in her approach:

Care must be provided in such a way that the capability for self-respect of the receiver is not injured, and also in such a way that the care-giver is not exploited and discriminated against on account of performing that role. In other words, a good society must arrange to provide care for those in a condition of extreme dependency, without exploiting women as they have traditionally been exploited, and thus depriving them of other important capabilities (ibid, p. 236).

In addition to burden experienced by caregivers in general, caregivers of youth with FASD experience added burden due to the higher psychosocial problems, called secondary disabilities, inherent to the condition of FASD. Furthermore, biological

mothers who remain caregivers for youth with FASD have shame and stigma assigned to them for having “caused” their child’s disability.

This document will unfold in the following format: chapter two is a review of the literature and includes 1) primary and secondary disabilities of FASD; 2) caregiver burden which includes: a) demographic characteristics caregivers associated with burden; b) perceived social support of the caregiver; and c) symptom severity of the youth. Chapter three analyzes the social justice issues associated with this population that formed the foundation and motivation for this study. The following chapter (four) includes the methods section, which describes the participants, instruments used, research methods, and data analysis. The results of the study follow in chapter five and the discussion is found in chapter six. Appendix A includes a copy of the demographic questionnaire developed by this researcher for this study. Appendix B includes the Caregiver Strain Questionnaire (Brannan & Heflinger, 1997) and permission to use the instrument. Appendix C includes the Multidimensional Scale of Perceived Social Support developed by Zimet, Dahlem, Zimet, & Farley, (1988). Appendix D includes the Personal Behavior Checklist (or the Fetal Alcohol Behavior Scale) developed by Streissguth, Bookstein, Barr, Press, & Sampson (1998) and permission to use the instrument. Appendix E is a copy of ethics approval from the University of Alberta Health Ethics Research Board (Panel B) and re-approval. Appendix F is a copy of ethics approval from the University of Calgary Conjoint Faculties Research Ethics Board and annual renewal.

CHAPTER TWO: LITERATURE REVIEW

This literature review will begin with a look at the primary and secondary disabilities of Fetal Alcohol Spectrum Disorder (FASD). Next, the relevant literature that corresponds with the three guiding questions of the present study will be described starting with demographic characteristics of caregivers, perceived social support, and symptom severity of the youth.

Fetal Alcohol Spectrum Disorder (FASD)

FASD is known to be the “single most preventable cause of congenital neurobehavioral dysfunction in the Western world” (Nash et al., 2006, p. 181) and in Canada the annual cost to care for individuals with FASD from birth to age 21 totalled \$3.44 (Stade, Ungar, Stevens, Beyen, & Koren, 2007). FASD is caused by prenatal alcohol exposure and is characterized by cognitive deficits, facial dysmorphology and growth impairment. The condition was first identified by French researchers Lemoine and Rouquette around 1960 (Lemoine, 2003). The scientific community did not take much notice of these results until American researchers Jones, Smith, and Ulleland published similar findings in 1973. The University of Washington, where the American researchers conducted their research, quickly became the centre for research excellence in this area. In 1997 the 4-Digit Diagnostic Code (4DDC) was developed as a systematic method for assessing and diagnosing FASD (Astley & Clarren, 2000). Although other diagnostic tools have been developed since that time, the 4DDC will be referred to in this paper and throughout this study for a variety of reasons. First, this writer received in-depth training at the University of Washington Diagnostic and Prevention Network in

2003 to conduct multidisciplinary assessment and diagnosis of FASD using the 4DDC. Second, the research conducted for this project occurred at the Centerpoint Program, where the multidisciplinary team uses the 4DDC as the standard for assessment and diagnosis of FASD. Third, although it is only one of the diagnostic codes available it continues to be the most commonly used diagnostic tools and is systemized in a way that makes it highly utilitarian for research purposes (Astley, 2006).

Terms and vocabulary

There has been much debate in the literature and in clinical environments about the most appropriate nomenclature for FASD. Originally, Jones, Smith, and Ulleland (1973) identified the condition as Fetal Alcohol Syndrome (FAS) and later the terminology of Fetal Alcohol Effects (FAE) was added by Rosett (1980). Eventually, the field began to develop more terms such as Partial FAS (pFAS), Alcohol Related Birth Defects (ARBD), Alcohol Related Neurodevelopmental Defects (ARND) and finally FASD. This document will not attempt to enter this debate. Instead, the nomenclature adopted by the University of Washington DPN and the 4DDC will be used here. In some instances different vocabulary has been used in literature by other authors. In those cases, whatever term was included in that particular document will be used in this one for the sake of consistency.

Primary disability

The primary disability resulting from prenatal alcohol exposure is central nervous system (CNS) damage. The University of Washington Diagnostic and Prevention Network developed four diagnostic categories used to assess and diagnose FASD. Table

1 shows the 4DDC with the four diagnostic categories: FAS facial features, growth deficiency, CNS damage, and prenatal alcohol exposure. Three of the four digits (growth deficiency, FAS facial features, and prenatal alcohol) vary in severity from a rank of one (none or no risk) to a rank of four (severe or high risk). The Central Nervous System (CNS) digit varies in terms of certainty of CNS damage from one (unlikely) to four (definite). Each digit has specific guidelines for diagnosis based on extensive research primarily conducted by the University of Washington DPN.

Table 1

The 4-Digit Diagnostic Code, University of Washington Diagnostic and Prevention Network (Astley & Clarren, 2000)

	FAS facial features	Growth deficiency	CNS damage	Prenatal Alcohol Exposure
4	Severe	Severe	Definite	High Risk
3	Moderate	Moderate	Probable	Some Risk
2	Mild	Mild	Possible	Unknown
1	None	None	Unlikely	No Risk

Secondary disabilities

Subsequent to CNS damage from prenatal alcohol exposure, individuals with FASD also exhibit psychosocial and behavioural deficits, which Streissguth (1997a) referred to as “secondary disabilities”. They “arise after birth and presumably could be ameliorated through better understanding and appropriate interventions” (Streissguth,

Barr, Kogan, & Bookstein, 1997b, p. 27). Secondary disabilities consist of mental health problems, disrupted school experiences, trouble with the law, inappropriate sexual behaviour, confinement, and substance abuse. Although these secondary disabilities are also known psychosocial problems, these problems occur more often in samples of individuals with FASD than in non-affected populations. Streissguth et al. (1997b) found that of the 415 children, adolescents, and adults, over 90% experienced mental health problems, in particular Attention Deficit Hyperactivity Disorder (children and adolescents) and Depression (adults). Barr et al. (2006) also found that psychiatric problems are more prevalent in patients with FASD and O'Connor et al. (2002) similarly noted a high proportion of individuals with FASD had psychiatric problems (87% of their sample). Streissguth et al. (1997b) also found that more than 60% had disrupted school experiences including early drop-out, learning, social, and behaviour problems. More than half (60%) of the adolescents and adults had come to the attention of criminal justice authorities and half (50%) had also experienced confinement (involuntary inpatient mental health, addictions treatment, or jail). Forensic involvement of individuals with FASD will be elaborated on below. Sexually inappropriate behaviours were higher than in a non-affected population across all age ranges (49% of adolescents and adults and 39% of children). This category included sexual advances, sexual touching, and promiscuity. Finally, individuals with FASD had a high probability of experiencing problems with drugs and alcohol (35%). Due to the incumbent secondary disabilities, caregivers of individuals with FASD have more intense caregiving demands and responsibilities over a long term (Giunta & Streissguth, 1988).

In contrast, protective factors have been identified that reduce the risk of developing secondary disabilities. Protective factors indicate an opportunity for intervention and prevention. They are: 1) living in a stable and nurturing home of good quality; 2) not having frequent changes of household; 3) not being a victim of violence; 4) having received developmental disabilities services; and 5) having been diagnosed before six years of age (Streissguth et al., 2004). Three intrinsic factors were also identified: a diagnosis of FAS instead of FAE, a higher Fetal Alcohol Behaviour Scale score (also called the Personal Behavior Checklist; used in the current study), and an IQ above 70. Streissguth (1997a) posited that protective factors “point to specific community and family advocacy” (p. 111). Of the eight protective factors identified, four are dynamic and four are static. The dynamic factors relate to home environment and caregiving. Although the scope of this study does not include data collection about protective factors, the current study was designed to better understand environmental factors such as a positive home environment that may reduce caregiver strain.

Relevance to forensic populations

Further elaboration of the relevance of FASD and secondary disabilities in a forensic population is critical, given the current study occurs in this context. Researchers have found that FASD is more prevalent in forensic samples (Fast, Conry, & Loock, 1999) as are the attendant secondary disabilities. Antisocial Personality Disorder (ASPD) is a behavioural diagnosis that is most often found in criminal populations and includes criteria such as aggression, impulsivity, and failure to conform to social norms (American Psychiatric Association, *DSM IV-TR*, 2000). In an adoption study with a criminal

population aimed to understand the genetic and environmental influences that predict ASPD, Langbehn and Cadoret (2001) found prenatal alcohol exposure to be a statistically significant risk factor. The risk factor remained significant even after controlling for the environmental influence of parental addictions. Schonfeld, Mattson, and Riley (2005) likewise found that children with a history of prenatal exposure to alcohol were found to have lower moral maturity (meaning delayed moral development) in comparison to a control group. In addition, individuals prenatally exposed to alcohol engaged in significantly more delinquent behaviours than the control group. In that study, home placement was also related to delinquency: participants who were prenatally exposed to alcohol and lived in adoptive homes had lower rates of delinquency than those in foster or biological homes. Regardless of home placement, individuals who are prenatally exposed to alcohol have been shown in the literature to be overrepresented in the criminal justice system. These findings provide relevance to the motivation for this study.

Caregiver burden

Caregiver burden is a concept that has been studied in a variety of populations of individuals with mental and physical conditions (Baldwin, Brown, & Milan, 1995; Baronet, 1999; Chronister & Chan, 2006; Chwalisz, 1992; Kalra, Kamath, Trivedi, & Janca, 2008). Caregiver burden has been defined as “the demands, responsibilities, difficulties, and negative psychic consequences of caring for relatives with special needs” (Brannan & Heflinger, 1997, p. 214). It developed as a construct that explored the correlates of stress experienced by caregivers. Chwalisz (1992) incorporated the perceived stress of the caregiver and grounded her theory on Lazarus’ transaction theory

of stress, which stated “stress reaction occurs in situations in which the demands of the environment are perceived to tax or exceed the individual’s resources” (p. 193). In this conceptualization, if the caregiver perceives the environmental demands (such as their child’s symptoms) as exceeding their resources, they would experience greater burden.

Conceptually, it has been split into two key components: objective and subjective burden (Baronet, 1999). Objective burden refers to observable events and occurrences that are the direct result of caregiving needs. These may include increased financial burdens or caregiving responsibilities such as attending counselling appointments, medical consultations, or school meetings. Subjective burden conveys the strain experienced by caregivers that is emotional or psychological. This may be further subdivided into externalized or internalized subjective strain. These terms describe caregiver strain as negative feelings outwardly expressed (such as anger and resentment) and inwardly (such as sadness, worry, and guilt; Brannan & Heflinger, 2006).

Three broad areas have been shown in the literature to either reduce or increase caregiver burden in samples of individuals with various cognitive, emotional, physical, and behavioural disorders. They are certain demographic characteristics of the caregiver, the caregiver’s perceived social support, and severity of the youth’s disability. Each of these variables and the relevant literature will be elaborated on below.

Caregiver demographic characteristics

The following demographic variables of caregivers were shown in the literature to be related to burden: age; ethnicity; gender; increased responsibilities outside of the

home; relationship of the caregiver to the ill or disabled individual; income; number of children in the home; and marital status of the caregiver.

Caregiver's age

Younger caregivers have been found to experience higher levels of burden in numerous studies (Baldwin, Brown, & Milan, 1995; Baronet, 1999; Boyce & Behl, 1991; Chwalisz, 1996; Schoeder & Remer, 2007). One study that is particularly critical to this review was Schoeder and Remer (2007), as that sample had numerous parallels to the present study. In both studies the sample included caregivers of youth with significant cognitive and behavioural deficits. Schoeder and Remer (2007) found that caregiver age was a significant predictor of caregiver strain. Baronet (1999) also found younger caregivers experienced more burden in two of three studies in her meta-analysis of the caregiver burden literature. In contrast, Ostberg and Hagekull (2000) found older parents reported more stress than their younger counterparts. The participants were parents of children aged six months to three years and lived in Sweden. According to the authors, this sample was fairly homogenous and not particularly clinical. Both the young age of cared for children and the less acute needs of those children may explain this divergent finding. Baronet's (1999) explanation for disparate results on the variable of caregiver age relates to the nature of the individual's disability that is being cared for. If the ill or disabled relative was in a crisis situation younger caregivers experienced more burden; whereas in the study where no relationship was found the illness was considered stable. This fits with both Hobfall and Lerman (1988) and Quittner, Glueckauf, and Jackson's (1990), who found that women with children with chronic illness found social support to

be perceived as less helpful than those with children who had an acute illness, perhaps because it magnifies feelings of inadequacy when they are in a more chronic need of support.

Another explanation for differences in age as a variable in caregiver burden was offered by Cook, Lefley, Pickett, and Cohler (1994) who suggested caregivers of various ages may be burdened by different aspects of caregiving. Younger caregivers were noted to have more subjective burden regarding the management of symptomatic behaviours. Whereas older caregivers were more burdened by their ongoing responsibilities for the child (such as who would care for the ill child if they were unable to fulfill this task). Fitting and Rabins (as cited in Chwalisz, 1992) likewise found younger caregivers to be more resentful and unhappy with their caregiving role and reported more psychological distress.

Caregivers of youth with FASD who have experienced conflict with the law have features of both chronic and acute stress. The nature of the primary disability of FASD is static, and therefore chronic. On the one hand, this may result in no demonstrable difference in burden in a sample of caregivers of youth with FASD. On the other hand, caregivers of youth involved in the criminal justice system may have more acute caregiving needs due to that immediate crisis. In either case, a better understanding of whether age is a significant correlate of caregiver burden in a sample of youth with FASD in conflict with the law would be beneficial.

Caregiver's ethnicity

Another significant correlate of caregiver burden that has been demonstrated in the literature is the ethnicity of the caregiver (Baronet, 1999; Boyce & Behl, 1991; Bussing et al., 2003; Dal Santo, Scharlach, Nielsen, & Fox, 2007; Haley et al., 1996; Kang, Brannan, & Heflinger, 2005; McCabe et al., 2003; McDonald, Pertner & Pierpont, 1999). In those studies, Caucasian caregivers experienced higher levels of burden than non-Caucasians. In contrast, Chwalisz (1996) and Schoeder and Remer (2007) did not find ethnicity to be a significant caregiver characteristic correlated with burden. Several theories have been proposed to understand these discrepant findings. Differences may be related to diversity of time periods, ethnic groups studied, conceptualization of the construct of caregiver burden, and methodological differences. The studies cited here are quite diverse, ranging from 1990 to 2007 and ethnic groups studied (Black, Latino, Asian, American Indian, and other). They also differ in the conceptualization of caregiver burden. For example, Haley et al. (1990) studied appraisal, coping, and social supports of caregivers of patients with Alzheimer's disease. Schoeder and Remer (2007) studied perceived social support and caregiver strain in caregivers of children with Tourette's disorder. Other methodological considerations such as sample size and diversity of methods used in the studies differ considerably. For example, Schoeder and Remer (2007) had a relatively small non-Caucasian population in their sample (5.7% of the 140 participants). The ethnic groups included in the non-Caucasian sample were highly diverse. It is possible for these reasons that the variable of caregiver ethnicity was not found to be a significant correlate of caregiver burden. The construct of caregiver

burden is complex and related to so many different variables that it would be remiss to generalize the findings of caregiver burden and ethnicity. Each of these studies had ethnically diverse participants and their findings reflected that diversity. It is prudent to include this variable in the current study in order to better understand how ethnicity of caregivers relates to burden.

Caregiver's gender

The gender of the caregiver has been identified in the literature as related to caregiver burden (Chwalisz, 1992; Chronister & Chan, 2006; McDonald et al., 1999; Webster-Stratton, 1990). In these studies, female caregivers experienced more subjective burden than males and had a lower quality of life. These findings suggest women may have different coping strategies and social supports than men (both known mediators in caregiver burden). Chronister and Chan (2006) found, contrary to Chwalisz (1996), that women had more problem-focused coping efforts and therefore experienced more burden. This discrepancy may be explained by differences in assessment, methods, and conceptualization. Baronet (1999) found none of the 10 studies included in her meta-analysis noted a significant relationship between caregiver burden and gender of the caregiver. However, she noted two other studies that found isolated associations between these variables. Recently, Bonner, Hardy, Willard, and Hutchinson (2007) found both mothers and fathers experienced greater psychological distress in their care of children diagnosed with cancer. In addition, more fathers had elevated rates of depression than mothers. This study had a small sample size ($n = 33$) and addressed an acute illness. The authors also speculated that the fathers' rates of depression in the study may have been

linked to marital status (all were unmarried). In sum, in spite of discrepant findings in the literature regarding gender and caregiver burden, the relationship between these two variables may prove to explain the construct better with the proposed population, and therefore requires further analysis.

Caregiver's increased responsibilities

More responsibilities outside the home, such as part- or full-time employment, have been demonstrated to increase burden to caregivers (Brannan & Heflinger, 2006; McDonald et al., 1999). In Brannan and Heflinger (2006) caregivers with location and time barriers to support services experienced more burden. Caregivers in general are known to have significantly less time for recreation or socialization due to their caregiving responsibilities (Statistics Canada, 2008). According to that study, caregivers (over the age of 45) average 11.6 hours of caregiving responsibilities in a typical week. They had 33.8% less time to spend on social activities and 18.7% had to cancel their holiday plans. On top of that, they had less time with their spouse (18.7%) and less time with their children (16.3%). From a social justice perspective, Nussbaum (2000) would indicate this violates the capability to play, which she described as “being able to laugh, to play, to enjoy recreational activities” (p. 232). They also have other responsibilities, often a double-day (unpaid labour following a workday of paid labour), potentially more than one child in the home to care for, and their own social, psychological, and physical needs. Increased responsibilities away from home also take away time and opportunity to access social supports, which is a known mediating factor in caregiver burden (see below).

Subjectively, caregivers also experience stress as a result of their caregiving responsibilities. Statistics Canada (2008) reported 62% of caregivers self-rated stress in caregiving from “a bit stressful” to “extremely stressful” and 4.2% had only fair or poor mental health. Therefore, caregiving responsibilities increase strain due to the objective and subjective demands placed on them. The consequences of caregiving significantly disadvantage this population from having full human capabilities, especially to play and laugh.

Caregiver's relationship to disabled person

The relationship of the caregiver to the ill or disabled individual has been demonstrated to be related to caregiver burden (Chronister & Chan, 2006; Heflinger & Brannan, 2006; Paley, O'Connor, Frankel, & Marquardt, 2006). In contrast, Baronet's meta-analysis (1999) found no relationship between type of caregiver and burden in four studies. However, the literature provides far less insight about how this variable impacts burden in this sample. Most of the available literature on caregiver burden is based on samples of caregivers of parents or spouses with dementia, or parents of children with mental health or behavioural conditions. The closest approximation to a study that may have a parallel sample in regards to this variable is Heflinger and Brannan's (2006) study of adolescents with mental health or substance abuse problems. In that study, the authors found that being a biological parent increased subjective internalized strain of the caregiver. The caregiver had more negative feelings such as worry, guilt, sadness, and fatigue in regards to their child with a mental health or substance abuse problem. The reason this study may best approximate a sample of caregivers of youth with FASD is

that the problems experienced by the youth in both studies are similar. There is a significant overlap between youth with mental health problems, substance abuse problems, and FASD. In fact, the former two are considered secondary disabilities of FASD. Caregivers of the two groups studied in Heflinger and Brannan (2006) may experience social stigma and guilt from having a child identified with social problems, as with FASD. However, in other studies the parallels between the characteristics of the participants and caregivers of youth with FASD are limited in regards to this variable.

In addition, most children and youth identified as having FASD are not living with their biological parent (Streissguth, Barr, Kogan, & Bookstein, 1997b). This is due to the fact that children with FASD are born to mothers with substance abuse problems, which are exacerbated by the child or youth's increased needs due to the primary and secondary disabilities of FASD. In addition, Gardner (2000) reported 69% of biological mothers included in Streissguth et al.'s study (1997b) were deceased due to alcohol-related illnesses or causes. In Paley et al. (2006) only a small proportion of the caregivers of children with FASD resided with one or both biological parent (23%). The rest lived with an adoptive or foster parent. In that study, custodial arrangement was a significant predictor of parental stress. Specifically, biological parents, single parents, and parents with fewer resources reported higher levels of parental stress. The participants in the present study most closely resemble the sample in Paley et al. (2006). Relationship to the youth in this sample may include biological parents, kinship care (e.g., grandparent), adoptive parents, foster parents, or other. All of these relationships have differences in the availability of formal social supports. For example, a biological mother of a child

with FASD may continue to struggle with addictions and other psychosocial problems. She is more likely to be older, have more children born to her, smoke cigarettes, and live in poverty (Olson, Morse, & Huffine, 1998). In addition, she is likely to have higher rates of childhood maltreatment, serious psychological distress and mental health problems. These women are likely to have fewer and less diverse social supports, which is a known factor in caregiver burden. In contrast, caregivers who are adoptive or foster parents are likely to have more resources (including financial supports from the government). Given that, it is critical to understand how the relationship of the caregiver in this sample correlates with caregiver burden.

Caregiver's income

Lower socio-economic status has been linked to increased caregiver burden in numerous studies (Baldwin et al., 1995; Barnett, 2008; Boyce & Behl, 1991; Brannan & Heflinger, 2001; Paley, O'Connor, Kogan, & Findlay, 2005; Paley et al., 2006; Webster-Stratton, 1990). Paradoxically, Baronet (1999) found no relationship between income and caregiver burden in her meta-analysis. Other studies demonstrated similar counter-intuitive findings such as Heflinger and Brannan (2006) and Kang, Brannan, and Heflinger (2005) who found caregivers with the lowest family income had less objective caregiver burden. These findings may indicate overlap with other caregiver characteristics such as ethnicity and social support. As indicated above, ethnicity is a complex variable that significantly overlaps with social support (access and type). These are both known correlates of caregiver burden. In either case, this variable remains important to be included in this study to determine if it is related to caregiver burden.

Number of children in the home

Ostberg and Hagekull (2000) studied the relationship between number of children in the home and parenting stress. They found a statistically significant but weak relationship ($\beta = 0.09$) between parity (number of children born to a woman) and parenting stress. This variable was intercorrelated with another variable that measured child irregularity ($\beta = 0.24$), which referred to the ease or difficulty of the child to parent. A child that demonstrated more regularity would be easier to parent, especially in the case of more than one child in the home. It follows, then, that parity would have an even stronger relationship to parenting stress if the irregularity variable were removed. Conceptually, more children living in the home may interact with caregiver burden similar to a caregiver's increased responsibilities outside of the home. The caregiver may experience more strain due to their available resources being dissipated amongst more children. This fits with Chwalisz' (1992) model of parental stress identified above. A caregiver with more children in the home may perceive his or her environmental demands as outweighing the caregiver's resources.

Marital status

The relationship status of the caregiver has been demonstrated to impact caregiver burden (Boyce & Behl, 1991; Paley et al., 2006). Many other studies have not included this variable. However, there is a conceptual overlap between perceived social support and availability of parental support in the form of a significant other or marital partner. The relationship between this variable and the other demographic variables along with

perceived social support would illustrate more clearly how these concepts contribute to or mitigate caregiver burden.

Perceived social support

Social support has been linked to decreased burden for caregivers in numerous studies (Baker et al., 2005; Baldwin et al., 1995; Baronet, 1999; Boyce & Behl, 1991; Brannan & Heflinger, 2001, 2006; Chronister & Chan, 2006; Chwalisz, 1992; Gardner, 2000; Haley et al., 1996; McDonald et al., 1999; Ostberg & Hagekull, 2000; Quittner et al., 1990; Schoeder & Remer, 2007; Webster-Stratton, 1990). In many of these studies social support accounted for the greatest variance in caregiver strain. Formal social supports were defined by Kenny and McGilloway (2007) as professional support services (e.g., family physician or social worker) and informal supports were social networks (e.g., spouse or friends). Both formal and informal social supports are known to assist people in coping with difficult experiences (ibid).

In addition to the direct relationship between perceived social support and caregiver strain, symptom severity of the individual was less in families with more social support (Baldwin et al., 1995; Schoeder & Remer, 2007). Similarly, Dubow, Tisak, Causey, Hryshko, and Reid (1991) noted the importance of social support on symptom severity and also found enhanced academic performance of the children who had family support.

Caregivers of children with chronic conditions have been found to access social supports less frequently (Quittner et al., 1990). In their study they reported smaller social networks and less use of informal social supports in families of children with chronic

conditions. Interestingly, they also found no statistical difference between caregivers of children with chronic and acute conditions on a measure of perceived social supports, although the sources of support differed. These findings may appear to conflict with Chwalisz's theoretical integration in that if the perceived level of social support outweighs the demands of the environment, the level of caregiver burden will be less. On the contrary, Quittner et al. (1990) explained the caregiver's perception of the support differs when the child's condition was acute or chronic. In the case of an acute condition, the caregiver may perceive an infusion of social support as helpful. On the other hand, a caregiver of a child with a chronic condition may perceive an infusion of support as intrusive or suggestive of their incompetence.

The nature of the primary disability of FASD is chronic. The primary disability of brain damage occurred in utero and cannot be reversed. In fact, some researchers have speculated that as individuals with FASD progress in age, they will need more supports (Streissguth, 1997a). This may be due in part to a societal expectation that with age cognitive and adaptive functioning increases. In contrast, individuals with FASD may reach an intellectual ceiling and as their peers mature, they maintain their need for supports into adulthood. Similarly, caregivers of individuals with FASD will need supports for the life course of their child. However, according to Quittner et al. (1990) they may be less likely to access social supports and when supports are offered to them they may perceive the support as intrusive.

The caregiver's perception of social supports is a critical variable in caregiver burden as demonstrated by prior research findings. A better understanding of how this

variable relates to a sample of caregivers of youth with FASD could inform clinicians and policy makers.

Symptom severity

Symptom severity is the most highly correlated and commonly cited variable in caregiver burden research (Baker et al., 2005; Baldwin et al., 1995; Baronet, 1999; Boyce & Behl, 1991; Brannan & Heflinger, 2001, 2006; Bussing et al., 2003; Heflinger & Brannan, 2006; Kenny & McGilloway, 2007; McDonald et al., 1999; O'Connor, Sigman, & Kasari, 1993; Ohaeri, 2003; Ostberg & Hagekull, 2000; Paley et al., 2005, 2006; Schoeder & Remer, 2007; Williford, Calkins, & Keane, 2006). In particular, Paley et al. (2006), found impaired child executive functioning, poorer adaptive functioning, and higher levels of internalizing and externalizing behaviour to have independent and significant contributions to the prediction of child-related stress in parents of children with FASD. Interestingly, Kenny and McGilloway (2007) found “carers of children with learning disabilities – when compared with carers of adults - tend to experience less strain from problem behavior and more from how they feel about the caring experience” (p. 226). Baronet (1999) established caregiver burden was related to symptomatic behaviour of the ill relative but not to the specific diagnosis. This finding is relevant to determining how to best measure symptom severity in a youth with FASD. As noted above, Streissguth et al. (2004) found that having a higher Fetal Alcohol Behavior Scale (or Personal Behavior Checklist) score was a protective factor. In contrast, Paley et al. (2006) found no association between the severity of the child’s FASD diagnosis and parenting stress. This seems counter-intuitive; however, this finding may be related to

the visibility of the disability. People are more likely to provide supports for an individual who is easily recognized as having impairments (such as a noticeable physical disability) than a youth who exhibits behaviour problems in the absence of physical markers. Therefore, the youth who has a more visible disability may be provided more supports, which may reduce the secondary disabilities. Youth without the physical markers of FASD, growth impairment and facial dysmorphology, would not qualify for a more severe diagnosis in the FASD spectrum. However, this group by far constitutes the majority of individuals diagnosed within the spectrum (Olson et al., 1998). In fact, the diagnostic facial features of FASD are known to arise only when the biological mother consumes alcohol in the third week of the gestation (Sulik, Johnston, & Webb, 1981). In contrast, the Central Nervous System (CNS) develops throughout the entire course of gestation (Olson et al., 1998), making CNS damage much more likely to be present than facial dysmorphology. Furthermore, it has been consistently documented that individuals without the physical markers of FASD function at or below those that have the physical markers (Streissguth et al., 2004; Mattson & Riley, 2000; Paley et al., 2006).

As already outlined in this paper, youth with FASD are at significant risk for the development of secondary disabilities. Although many researchers have attempted to delineate a behavioural phenotype of FASD, a clear pattern has not been established. This is likely due to the random and diverse impacts of alcohol exposure in utero. “Like that of other teratogens, the impact of alcohol on the ‘maternal-fetoplacental unit’ depends on the amount, timing, pattern, and conditions of prenatal exposure (Olson et al., 1998, p. 269). Each person with FASD has different constellation of deficits and

strengths. Similarly, measuring the symptom severity of the youth with FASD would provide a stronger understanding of how it relates to caregiver burden.

Symptom severity has also been found to impact the frequency of access to mental health services amongst caregivers of youth with emotional and behavioural problems (Angold et al., 1998). As noted above, perceived social support of the caregiver interacts with symptom severity, which may explain this finding. Symptom severity is a complex variable that interacts with both genetic and environmental factors, especially in a sample of youth in conflict with the law. Given that, it is of particular importance to include this variable.

Conclusion

There is consensus amongst researchers that individuals caring for children or youth with emotional, cognitive, and/or behavioural disorders creates significant burden for caregivers and affects their well-being (Schoeder & Remer, 2007). Caregiver burden has been studied in other populations (such as traumatic brain injury, psychiatric disorders, and patients with dementia) but there remains a glaring gap in the literature for caregivers of individuals with FASD. This condition has been demonstrated to increase the risk of psychosocial difficulties (Barr et al., 2006; Streissguth, et al., 1998; O'Connor et al., 2002), which could increase burden on the caregivers. Cousins and Wells (2005) suggested caregivers of individuals with FASD do indeed have increased burden but did not study the affect, and recommended further research be done with this population. Many variables are known to be correlated with levels of caregiver burden in a diversity of samples. They correspond to several specific demographic characteristics of the

caregiver, perceived social supports of the caregiver, and symptom severity of the youth with FASD. Demographic characteristics of the caregiver explored in other studies in relation to caregiver burden included: age, ethnicity, gender, increased responsibilities outside of the home, the relationship of the caregiver to the ill or disabled individual, income, number of children in the home, and marital status. A better understanding of the variables related to caregiver burden and how they interact in a sample of caregivers of youth with FASD in a criminal justice population could provide directions for further research and program development. In addition, this is a critical area of social justice that demands special attention. This topic will be covered in the following chapter.

CHAPTER THREE: SOCIAL JUSTICE FOR CAREGIVERS

The motivation for this project firmly rests on a social justice theory termed the ethics of care. This area of study in social justice has its roots in feminist and post-modernist thought that challenged the dominant discourses prevalent in earlier social justice theories. This reflective and contextual perspective grounds the present study and demonstrates the importance of broader understanding of the social justice issues faced by caregivers.

Philosophically, the ethics of care emerged as a feminist response to John Rawl's ethics of justice. Tronto (1987) suggested the ethics of care differed from the ethics of justice in three ways: 1) relationships and responsibilities are emphasized rather than rights; 2) it is contextual and concrete, as opposed to abstract and informal; 3) the ethics of care is a moral activity rather than a set of principles. The ethics of justice was based on a modernist framework which emphasized fairness, equality, rationalism, universality, and autonomy (Botes, 2000). On the other hand, the ethics of care is based on a post-modern, feminist conceptualization of care, extended communicative rationality, holism, and contextuality (ibid). Nussbaum (2000) criticized Rawl's social contract approach in particular because it assumed the hypothetical contract in which all participants are "fully cooperating members of society over a complete life" (Rawls as cited in Nussbaum, 2000, p. 236). She argued that this assumption completely distorts the principles of justice by "effacing the issue of extreme dependency and care for the agenda of the contracting parties, when they choose the principles that shape society's basic structure" (ibid, pp. 236 - 237). In attempting to better understand the experience of caregivers of

youth with FASD, it is necessary to ground this work in the theoretical constructs of the ethics of care. These notions carefully consider diverse frameworks and power imbalances that encumber human relationships. One such relationship is the care-giving and care-receiving relationship. This relationship identifies power imbalances, oppression, and stigma that impact a unique subset of the population.

The Canadian Charter of Rights and Freedoms guarantees each Canadian freedom from discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability (Canadian Charter of Rights and Freedoms, 1982).

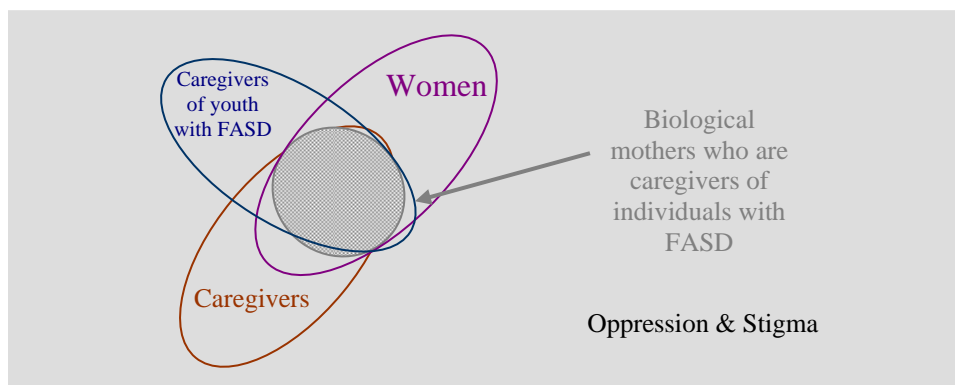
However, many groups of people continue to experience oppression on a daily basis.

Oppression is experienced by the unique group of primarily female caregivers of youth with FASD on multiple layers. These layers include caregivers (in general), women, caregivers of youth with FASD, and biological mothers of youth with FASD. Gender discrimination is a common experience for women across the world. When these women are caregivers, as they most often are, they experience an added level of oppression.

Caregivers in general experience oppression in the form of everyday and extraordinary burden that have been identified in the literature under the terms caregiver burden and caregiver strain. In addition to the burdens experienced as the result of their caregiving role, caregivers of youth with FASD experience added levels of burden based on the higher levels of psychosocial difficulties, called secondary disabilities, experienced by this population. An even more heavily burdened group imbedded in the larger cluster of caregivers of youth with FASD, are the biological mothers that remain caregivers to this population. They experience stigma and shame, given that the medical community and

media have identified them as the “cause” of their child’s disabilities. This writer created a Venn diagram (Rusky & Weston, 2005) to visually describe the overlapping and compounding oppression experienced by this unique subset of caregivers (Figure 1).

Figure 1. Oppression experienced by caregivers of youth with FASD (not a proportionate representation)



Care and power

Meyers (1998) defined caring as “a way of appropriating – making your own, making use of – the practical fact of dependence” (p. 144). The ethics of justice, the antithesis of the ethics of care, focused on equality and fairness. On the contrary, the ethics of care stipulated that relationships exist in the context of power and there is “conflict between compassion and autonomy, between virtue and power” (Gilligan as cited in Meyers, 1998, p. 148). Meyers (1998) asserts that “all ethical questions refer to dependence. They either acknowledge or deny it” (p. 145). He goes on to stipulate that denial of dependence creates silent suffering and removes ethical issues from the realm of the political. Gilligan, however, shied away from the concept of dependence in care

relationships; instead she discussed the notion of interdependence. Tronto (1987) agreed in part with Gilligan, however she noted the ethics of justice promotes a simplistic evaluation of the public and private split, which creates an “implicit devaluation of the female” (p. 654). This distinction fit with Meyer’s ideas of power and dependence in care. She discerned that the boundaries of the private realm are indeed defined in the public arena. Later she wrote:

Care helps us rethink humans as interdependent beings. It can serve as a political concept to prescribe an ideal for a more democratic, more pluralistic politics in the United States in which power is more evenly distributed... care can serve as a strategic concept to involve the relatively disenfranchised in the political world (Tronto as cited in Williams, 2001, p. 477).

The language of dependence is hotly contested in the literature, especially with the Disabled People’s Movement (DPM). Given its post-modern roots, the criticisms of language are poignant. Hughes et al. (2005) wrote, “care is associated with institutional confinement, limited social engagement, partial citizenship, disempowerment and exclusion... disabled recipients of care – be they male or female – live ‘tragic lives’, ontologically doomed to a deficit of agency” (p. 261). This position does not dispute the nature of power inherent in the caring process. Indeed, it supports the notion of a power imbalance and seeks to rectify the inequalities. In doing so, the DPM hearkens to Gilligan and Tronto in its use of the language of interdependency and personal assistance, help, or support in the place of care (Hughes et al., 2005). In fact, Watson et al. (2004) documented that care and dependency are terminologies that colonize and control

disabled people. They stipulated that the binary language of caring (e.g. care-giver and care-receiver) polarizes the reciprocal process of caring and the interdependency of all people. Criticisms of the operationalizing care as feminine or dependent have observed that this language excludes disabled people from dignity and autonomy. Fox (2000) suggests the vocabulary of care as a gift in order to firmly establish the post-modern perspective of care which is grounded in “ethics and politics of love and difference” (p. 347). Given its feminist and post-modern origins, the language and power structures of the ethics of care must be considered and considerate. In either case, power is an inherent element in the ethics of care and must be considered in the use of language. Terms such as caregiving burden or strain express notions of dependence in care that may be oppressive. Language that reflects interdependence would impact a movement to a more caring and ethical treatment of both care-givers and care-receivers.

Oppression of women

Caregiving is a role primarily held by women across the world. Along with that role come economic and labour burdens that significantly disadvantage women.

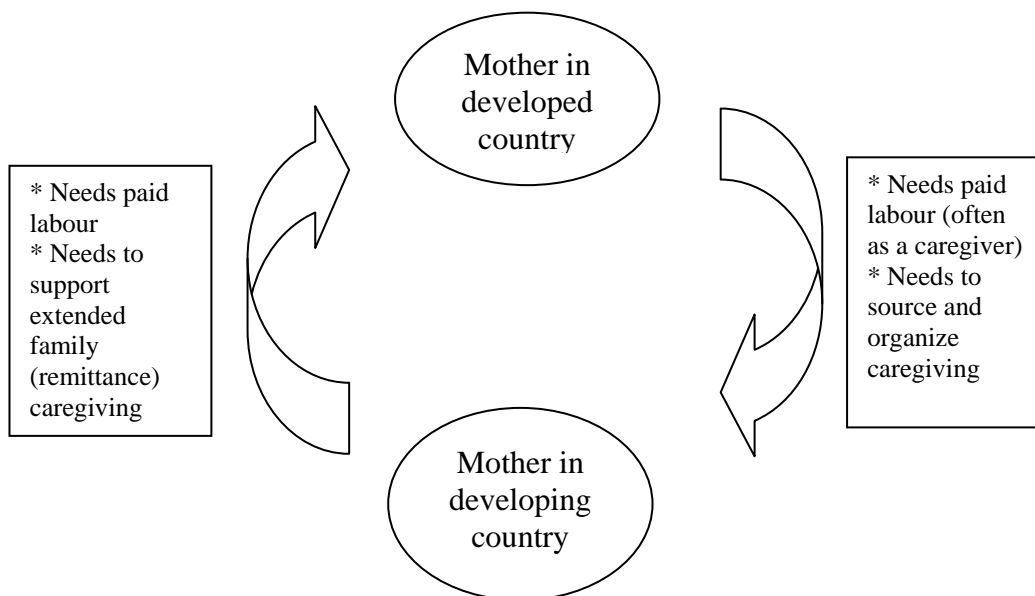
Women are the world’s primary, and usually only, caregivers for people in a condition of extreme dependency: young children, the elderly, and those whose physical or mental handicaps make them incapable of the relative (and often temporary) independence that characterizes so-called ‘normal’ human lives.

Women perform this crucial work, often, without pay and without recognition that it is work. At the same time, the fact that they need to spend long hours caring for the physical needs of others makes it more difficult for them to do what they want

to do in other areas of life, including employment, citizenship, play and self-expression (Nussbaum, 2000, p. 222).

Across the world, the involvement of women in the formal labour market is growing. However, many women encounter the “double workday” in that they have paid labour outside of the home and maintain primary responsibility in the home (unpaid labour; United Nations Development Program, 1999). In Canada, female caregivers outnumber males over the age of 45 (Statistics Canada, 2008). They also accounted for 14 hours of caregiving on average, as compared to men’s eight hours. In that same study, women were almost twice as likely to be informal (unpaid) caregivers as men. Even when hiring caregivers, women often remain responsible for the sourcing and organizing of care and lose a significant portion of their paid employment, on average 20%, to pay other women to caregive (McKie, Gregory, & Bowlby, 2002). Williams (2001) included aspects of migration into the genderization of labour. She argued that increased participation in the formal labour market by women has led to migratory practices that fill the caring gap. Hochschild (2000) called this phenomenon the global care chain. Women in developed countries maintain responsibility for the sourcing and organizing of caregiving, in spite of their increased involvement in the formal labour market. This has led to the need for replacement caregivers, which are often women from developing countries. These women fill the global care gap in order to provide for their families back in the developing country. A pictorial representation of the global care chain created by this writer can be seen in Figure 2.

Figure 2. Global care chain (Hochschild, 2000)



Equality of employment for women is compounded by the fact that their increased responsibilities as a result of caregiving limit their access to competitive employment. In Canada, 24.3% of caregivers miss full days of work, 15.5% have reduced hours of work, and 3.5% have had to turn down a job offer or promotion (Statistics Canada, 2008).

Given this information, caregivers, especially female caregivers continue to experience discrimination in their access to equal employment. This is a social justice issue that could be improved by access to appropriate formal supports and financial assistance from the government. Respite services and specialized alternative caregiving services for caregivers working outside the home would address this need directly.

Stigma

Stigma has been described by Goffman (1963) as an “attribute that is deeply discrediting” (p. 3). Individuals with FASD and their caregivers are discredited by

misrecognition and marginalization. Nussbaum (2000) wrote that all people should have a basic human capability for affiliation. Stigma interferes with this capability on many levels. Affiliation is:

Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails protections against discrimination on the basis of race, sex, sexual orientation, religion, caste, ethnicity, or national origin (p. 232).

Caregivers in general lack this foundational capability through the lack of recognition (personally and politically) and through the stigma of FASD. Everyone has an essential human need for recognition. Without recognition individuals and groups experience discrimination, a loss of self-respect, dignity, and are marginalized. Taylor (1994) aptly described the negative psychic consequences of misrecognition: “a person or a group of people can suffer real damage, real distortion, if the people or society around them mirrors back to them a confining or demeaning or contemptible picture of themselves” (p. 75). This subpopulation is seen as a drain on society, a demeaning image primarily due to their lack of involvement in the formal labour market. Taylor (1994) described identity formation as a dialogical process with significant others: “we need relationships to fulfill, but not to define, ourselves” (p. 79). Epstein (as cited in Young, 1990) affirmed this perspective and described identity as:

A socialized sense of individuality, an internal organization of self-perception concerning one’s relationship to social categories, that also incorporates views of the self perceived to be held by others. Identity is constituted relationally,

through involvement with – and incorporation of – significant others and integration into communities (p. 45).

A caregiver, especially a parent, is nothing if not a significant other. Every person will be a care-giver and a care-receiver at some point in his or her life, whether that is as an infant, a disabled person, or late in life. In the case of youth with FASD, the caregiver may also be their cook, janitor, chauffeur, advocate, teacher, mentor, counsellor, confidante, lawyer, etc... (This list is by no means exhaustive). Caregivers play multiple roles, sometimes at the same time, with far-reaching consequences. Identity formation will occur first and foremost with a caregiver. Recognition of the foundational and pivotal role caregivers play in society would lead to self-respect and dignity on an individual and group level.

Political recognition is also necessary. Taylor (1994) noted the importance that we “recognize the equal value of different cultures; that we not only let them survive, but acknowledge their worth” (p. 96). Young (1990) added social justice “requires not the melting away of differences, but institutions that promote reproduction of and respect for group differences without oppression” (p. 47). The nature of the disability of FASD is distinct and requires unique group recognition. Distinct interventions would decrease parental stress, which has been linked to better outcomes for both the child and caregiver (Crnic & Low, 2002). Political recognition can take a variety of forms. It may be public acknowledgment of distinctness or the allocation of public resources to address a social need. Either form of recognition would be welcome but the latter would go further to

addressing stigma and improving respect and ameliorating difficulties encountered by caregivers.

Caregivers of youth with FASD

In addition to the lack of recognition, which results in stigma and disrespect, youth with FASD and their caregivers experience significant discrimination as a direct result of the disability. Although Nussbaum (2000) addressed the issue of protection against discrimination, she failed to mention ability as a medium of discrimination. The DPM has highlighted this pertinent area of discrimination and the loss of dignity and respect for people with disabilities. Hughes et al. (2005) described care as “associated with institutional confinement, limited social engagement, partial citizenship, disempowerment and exclusion” (p. 261). Disabled people are seen as a “tragedy” deserving a charitable response, a burden on tax-payers, and a wasted existence (ibid, p. 267). Young (1990) described this form of oppression as marginalization, which she stated “is perhaps the most dangerous form of oppression. A whole category of people is expelled from useful participation in social life and thus potentially subjected to severe material deprivation and even extermination” (p. 53). Marginalization affects both the youth and their caregivers due to interdependence of identity formation.

This form of stigma is in part recognized in the literature under the terminology subjective externalized strain (Brannan & Heflinger, 2006). This type of caregiver strain encapsulates feelings of anger, resentment, and embarrassment about their child’s problems. This theoretical construct was found to be valid and was related most strongly to the child’s problematic symptomology and low material resources (Brannan &

Heflinger, 2001). As noted above, individuals with FASD have higher rates of problematic behaviour consequent to prenatal alcohol exposure (Streissguth et al., 1997b). It follows, then that caregivers of individuals with FASD may experience more feelings of anger, resentment, and embarrassment about their child's disability.

Biological mothers of youth with FASD

In addition to the discrimination and shame the caregiver will experience as a result of their interdependence with the disabled person, biological mothers of individuals with FASD experience a double dose of shame and social alienation for having caused the disability. As noted above, FASD has been reported to be the “single most preventable cause of congenital neurobehavioral dysfunction in the Western world” (Nash et al., 2006, p. 181). The development of FASD as a recognized disability has been described by Armstrong & Abel (2000) as a “moral panic”. It became a social focus on “individual, personal responsibility for ‘lifestyle choices’ and a belief in the power of broad-based public education campaigns to change behavior” (p. 277). The American mass media fuelled this crusade against alcoholic mothers with headlines such as “kids pay for prenatal drinking”, “an innocent inherits the anguish of alcohol”, and “the tragic inheritance” (p. 278). What was reported in the literature was that the risk for FASD was universal. However, upon closer examination of the risk factors there is a social bias in the acquisition of FASD. This has been oft overlooked in the literature and the media. Abel (1995) noted that FASD has never been an “equal opportunity birth defect” (p. 437); its “inseparable handmaidens are poverty and smoking” (Armstrong & Abel, 2000, p. 279). FAS is disproportionately represented in minority, impoverished, and otherwise

disadvantaged groups in spite of the fact that alcohol consumption is more common in middle- to upper-class segments of the population (ibid). Dignity and self-respect as well as freedom from discrimination are essential human capabilities that are often not available to caregivers of individuals with FASD due to shame and stigma associated with the disability and, for biological mothers, having caused the disability.

Not only is it relevant to identify areas of social injustice, as in the case of caregivers of youth with FASD, this area of inquiry will guide the discussion and recommendations from this project. The social justice issues presented in this study provide not only a philosophic foundation and a motivation for this project, they also will provide context for future directions as a result of this work.

In the next chapter the current study methods will be described.

CHAPTER FOUR: METHODS

Procedures

Ethics approval was granted from Capital Health, Health Ethics Research Board (Panel B; Appendix E), and University of Calgary Conjoint Faculties Research Ethics Board (Appendix F). Data collection occurred from September 2008 to November 2009 at the Centerpoint Program. The sample was taken from caregivers of youth with Fetal Alcohol Spectrum Disorder who were referred to the Centerpoint Program for either a court-ordered assessment or mental health treatment. The Centerpoint Program is an outpatient forensic mental health program for adolescents located in downtown Edmonton, AB, Canada.

First, caregivers of youth referred to the Centerpoint Program for mental health assessment or treatment in the past five years who were diagnosed with FASD (either in the current assessment or previously) were contacted by mail and asked to participate in the study ($n = 14$). Inclusion in the study was determined using the University of Washington FASD four-digit diagnostic code, where the youth met the criteria for FASD with at least a Code two (Neurobehaviour Disorder) on the CNS Damage digit.

Second, caregivers of youth diagnosed with FASD referred for current mental health assessment or treatment were asked to participate in the study ($n = 12$). Standard procedure of assessments at the clinic is to invite and include the caregiver. A letter is sent by the clinic or the therapist inviting the youth and caregiver asking them to attend the appointments as scheduled. The youth are required by the court order to attend but the caregiver's participation is voluntary. At times, the caregiver will not attend the

appointments and their involvement is not included in the assessment. If the caregiver attended the appointments they were asked to voluntarily participate in this study by completing four self-report questionnaires. The researcher assured the caregivers that their participation was voluntary and that they had the option of withdrawing at any time. They were also assured of confidentiality and that all of the information collected for research purposes will not be included in the youth's clinical file. The inherent risks and rewards of participating in the study were carefully explained.

Third, caregivers of clients who were referred to the Centerpoint Program for mental health treatment following a conviction for a criminal offence who were diagnosed with FASD (with the same criteria as above) were asked to voluntarily participate in the study ($n = 2$).

Measures

Four self-report questionnaires were completed by the caregivers who agreed to participate in the study. Each of the questionnaires measured the variables identified in the literature review as related to caregiver burden. The first questionnaire addressed the demographic characteristics of the caregiver (Appendix A). It included demographic information about the caregiver such as age, gender, relationship status, ethnicity, income, number of children in the home, education, caregiver type, and employment status.

The second instrument measured caregiver burden (Appendix B). The Caregiver Strain Questionnaire (Brannan & Heflinger, 1997) has been used clinically and for research purposes to assess the objective strain, subjective internalized strain, and

subjective externalized strain of caregivers of children and youth with behavioural and emotional problems (Schoeder & Remer, 2007). The instrument is a 21-item self-report with three sub-scales intended to measure the areas identified above. Each item is scored on a Likert scale from one (not at all) to five (very much). The mean score of all the items composed the global score (range from three to 15). Each subscale consists of four items, from which the mean is determined. This instrument has been used and validated in over 25 studies since 1997 (Kenny & McGilloway, 2007). These studies have assessed caregiver strain and other child and family variables in children's mental health research (seven published studies); the CGSQ or caregiver strain in general (seven published studies); impact of caregiver strain and other variables on service experience (such as service use and satisfaction, 13 published studies); and publications that describe studies in which the CGSQ is being used (three publications). The CGSQ has demonstrated excellent internal validity with alpha coefficients ranging from 0.73 to 0.91 (Brannan & Heflinger, 2006) as well as good external validity (Brannan & Heflinger, 1997).

The third instrument, the Multidimensional Scale of Perceived Social Support (MSPSS; Zimet et al., 1988), was used to measure the perceived social supports of the caregiver (Appendix C). This self-report questionnaire consists of twelve items that provide a global score of perceived social support of the caregiver by finding the mean of all the items. There are also three subscales: friend support, family support, and significant other support. Each subscale consists of four items, from which the subscale mean is determined. The MSPSS was used by Schoeder & Remer (2007) who found caregiver burden to be significantly correlated with perceived social supports for

caregivers of children with Tourette's Disorder. This instrument has also been empirically validated for construct validity and reliability with four groups of participants: university undergraduates, prepartum women, adolescent students separated from their families, and pediatric medicine residents (Zimet et al., 1990). That study indicated the measure had a high internal reliability (Cronbach's $\alpha = 0.84$ to 0.92).

The fourth instrument, The Fetal Alcohol Behavior Scale (FABS), also called the Personal Behavior Checklist (PBCL; Streissguth et al., 1998), is a 36-item self-report questionnaire that is completed by the caregiver of the individual with FASD (Appendix D). This instrument assessed the symptom severity of the individual with FASD from the caregiver's perspective. In addition to a global score (range 0 – 36), there are seven subscales imbedded in the instrument. The subscales are communication and speech (eight items), personal manner (five items), emotions (two items), motor skills and activities (two items), academic/work performance (three items), social skills and interactions (11 items), and bodily or physiologic functions (five items). Each item is scored by the caregiver as either being present, not present, or "don't know". Streissguth et al. (1998) developed and assessed the psychometric properties of the PBCL. The measure demonstrated high item-to-scale reliability (Cronbach's $\alpha = 0.91$) and good test-retest reliability ($r = 0.69$) over an average interval of five years. The PBCL also predicted dependent adult living amongst the participants.

Participants

Caregivers

Of the 28 youth identified for inclusion in the study, only nine had caregivers who agreed to participate in the study and had full-time caregiving role. Given the focus of the research questions and hypotheses, this researcher determined that it would not be appropriate to have rotating staff (such as in group care facilities) or Child & Youth Services workers complete the questionnaires. This unanticipated barrier to potential research participants provided opportunity to explore the impact of burden on caregivers of youth with FASD from a different perspective than the study and its design was originally intended. Further exploration of this issue will be found in chapter six.

Participants ($n = 9$) ranged in age from 33 to 67 years old ($M = 52.67$, $SD = 11.56$). Most were female (8/9). About half (4/9) were Aboriginal and the others were Caucasian (5/9). The average monthly income was approximately \$2800, with a wide range from \$1200 to \$5000 ($SD = \$3800$). Half of the participants had one child in the home and the other half had two. The education level for most of the participants reached high school ($Mdn = 12$ years of schooling, $SD = 2.92$), but one participant had only three years of formal education. The relationship status of the participants was quite evenly distributed: two were divorced, two were married, one was common-law, one was separated, and three were single. The hours employed outside of the home ranged dramatically from zero to 70. Four of the participants did not work outside of the home and the other five ranged in hours employed from 30 – 70 ($Mdn = 40$).

Biological parents of the youth were the most common (4/9), with only one of those being a biological father. The other caregivers were grandmothers ($n = 2$), a great aunt ($n = 1$), and a foster parent ($n = 1$).

Youth

The youth who were being cared for by the participants ranged in age from 13 to 19 ($M = 15.78$, $SD = 1.86$). All of the youth had interruptions in their schooling, which was defined as suspended, expelled, or dropped out of school. Interestingly, six out of the nine youth being cared for were not on medications, but the ones that were had three or four medications prescribed each.

Data analysis

Analysis of the data was conducted using SPSS 17.0.

1. Descriptive statistics were completed for all the identified variables. The central tendency and standard deviation were analyzed.
2. Bivariate analysis using Spearman's rho was conducted with all of the variables. This analysis provided rank order correlation analysis; given the sample size was too small to reach statistical significance with Pearson's Correlation Coefficient. Similarly, given the size of the sample multivariate statistical analysis or regression analysis was not possible, as was originally proposed.

The results of the data analysis are explored in the following chapter.

CHAPTER FIVE: RESULTS

Descriptive statistics

The descriptive statistics for the independent variables on the demographic questionnaire were reported in the participants section of chapter four. The following descriptive statistics are for the remaining independent variables and the dependent variable.

Caregiver Strain Questionnaire (CGSQ)

The CGSQ (Appendix B) produced a global score and three subscale scores. The results are outlined in Table 2 below. The subscale scores were objective strain (OS), subjective externalized strain (SES), and subjective internalized strain (SIS). Mean scores were calculated on each subscale for each participant. Table 2 shows the mean scores for each subscale across all participants. OS was calculated finding the mean of items 1 to 11 on the CGSQ. The SES score was calculated by finding the mean of items 13, 15, 19, and the reverse coded item 14. The SIS score was calculated by finding the mean of items 12, 16, 17, 18, 20, and 21.

Table 2

Descriptive data Caregiver Strain Questionnaire

	<i>M</i>	<i>SD</i>	Range	Scale range
Global score	9.56	1.54	7.41 – 12.09	3 - 15
Objective strain	3.28	0.66	2.27 – 4.09	1 - 5
Subjective externalized strain	2.50	0.84	1.00 – 3.50	1 - 5
Subjective internalized strain	3.78	0.56	3.0 – 4.67	1 - 5

Caregivers in this sample reported higher levels of strain than found in any other study, even with clinical samples (Brannan & Heflinger, 2006; Heflinger & Taylor-Richardson, 2004; Kenny & McGilloway, 2007; Taylor-Richardson, Heflinger, & Brown 2006). Objective strain in other samples was reported with a low of 2.03 in a sample of children with serious emotional disturbance in kinship care (Heflinger & Taylor-Richardson, 2004). The highest objective strain in reported in other samples was reported by Sales et al. (2004) at 2.31, with a sample of mothers receiving mental health treatment in an outpatient setting. Those findings contrasted with the much higher score of 3.28 in this sample.

The mean subjective externalized strain in this sample was noted to be 2.50. This compared with a minimum of 1.86 reported in Heflinger and Taylor-Richardson (2004) and a high of 3.01 by Sales et al. (2004). The latter results measure a slightly different variable, however, as Sales et al. (2004) used the older version of the CGSQ, which

combined subjective internalized strain and subjective externalized strain. If these results were calculated similarly, the combined subjective strain for this sample would be 3.14, which would be higher than those reported by Sales et al. (2004).

Subjective internalized strain (SIS) was found to be significantly higher at 3.78 in this sample than in other samples. Taylor-Richardson et al. (2006) found SIS to be 1.98 compared to 2.7 (Bussing et al., 2003); 2.93 (kinship caregivers) and 3.21 (parental caregivers; Heflinger & Taylor-Richardson, 2004).

In sum, caregivers in this sample reported higher levels of strain globally as well as on each of the three subscales when compared to other clinical samples.

Multidimensional Scale of Perceived Social Support (MSPSS)

The MSPSS (Appendix C) included a global score of caregiver perception of social support and three subscale scores that described family support (FAM), significant other support (SO), and friend support (FRI). The global score is the mean of the twelve items on the scale. The FAM subscale is the mean of items 3, 4, 8, and 11; the SO subscale is the mean of items 1, 2, 5, and 10; and the FRI subscale is the mean of items 6, 7, 9, and 12. See Table 3 below for full descriptions.

Table 3

Descriptive data Multidimensional Scale of Perceived Social Support

	<i>M</i>	<i>SD</i>	Range	Scale range
Global score	4.00	1.42	1.58 – 6.17	1 - 7
Family support	3.83	1.81	1.50 – 6.25	1 - 7
Significant other support	4.58	1.69	2.00 – 7.00	1 - 7
Friend support	3.58	1.85	1.00 – 6.25	1 - 7

Three other studies that used this scale and reported the raw data described higher levels of perceived social support globally and on all three subscales (Canty-Mitchell & Zimet, 2000; Cecil, Stanley, Carrion, & Swann, 1995; and Zimet et al., 1988). In fact, the present sample reported lower levels of perceived social support than outpatient psychiatric patients diagnosed with schizophrenia or a major mood disorder (global score = 5.0; Cecil et al., 1995).

Personal Behavior Checklist (PBCL)

The PBCL (Appendix D) produced a global score and seven subscale scores. Caregivers rated the youth in their care with a mean of 17.1 with a standard deviation of 8.4 (scale range of 0 – 36). The data from the subscales and global score are outlined below in Table 4.

Table 4

Descriptive data Personal Behavior Checklist

	<i>M</i>	<i>SD</i>	Range	Scale range
Global score	17.10	8.40	7 – 30	0 - 36
Communication and speech	4.30	2.90	0 - 8	0 - 8
Personal manner	1.90	1.83	0 - 4	0 - 5
Emotions	1.70	0.71	0 - 2	0 - 2
Motor skills and activities	1.30	0.46	1 - 2	0 - 2
Academic/work performance	2.20	0.97	1 - 3	0 - 3
Social skills and interactions	5.20	3.15	0 - 10	0 - 11
Bodily or physiologic functions	1.60	1.01	0 - 3	0 - 5

Streissguth et al. (1998) published the only results on the PBCL. Their findings identified the mean score for individuals with FASD was 20.3. That study identified a normative sample as having an 80% likelihood of having a score below 11 or 12, with the FASD sample having an 80% likelihood of having a score above 11 or 12 (ibid). In the present sample, caregivers rated problem behaviours of the youth in their care as higher than the previously identified normative sample (global score, $M = 17.10$, $SD = 8.40$).

Correlational analysis

The Spearman's rho correlational analysis rank-ordered the data and provided a description of the present sample. This test was chosen for its similarity to the Pearson correlation (Wilkinson, Engelman, & Marcantoni, 2007). The analysis yielded multiple

significant results. Some of the results were expected on the basis of literature review (Table 5). Others were not expected and provided novel data that may indicate opportunities for further research or may be spurious (Table 6). Due to the large number of variables, only the statistically significant correlations are reported in this document.

Table 5

Significant correlations

CGSQ	Significant correlate	Correlation Coefficient	<i>n</i>
1. Global score	Number of children in the home	-.66*	8
	Education level of the caregiver	-.61*	9
	Age of the youth	-.74*	9
	PBCL social skills (youth)	.64*	9
2. Objective strain	Income of the caregiver	-.69*	7
	Age of the youth	-.82*	9
	Number of medications (youth)	.80*	7
3. Subjective internalized strain	Number of children in the home	-.67*	8
	Age of the youth	-.59*	9
	Education level of the youth	-.70*	9
	PBCL emotional skills (youth)	.72*	9
4. Subjective externalized strain	PBCL social skills (youth)	.65*	9

* $p < .05$, one-tailed. ** $p < .01$

In the present sample global strain or strain measured on one of the three subscales was found to be significantly correlated with a number of demographic and behaviour scales (PBCL subscales). Strain was not found to be significantly correlated with the global score on the MSPSS or any of the subscales.

Table 6

Additional significant correlations

Variable 1	Variable 2	Correlation Coefficient	<i>n</i>
1. Number of medications (youth)	MSPSS family subscale	.76*	7
	MSPSS friends subscale	.74*	7
2. MSPSS significant other subscale	PBCL global score	-.64*	8
	PBCL personal manner	-.65*	9
3. Education level of the caregiver	PBCL communication	-.85**	9
	PBCL personal manner	-.87**	9
	PBCL motor skills	-.87**	8
	PBCL academic/work performance	-.74*	9
	PBCL social skills	-.69*	9
4. Income of the caregiver	Age of the youth	.77*	7
5. Age of the caregiver	PBCL body or physiological symptoms	.63*	9
6. Length of the caregiver/youth relationship	PBCL communication	.63*	9
7. Quality of the caregiver/youth relationship	MSPSS Friends	-.59*	9
	PBCL communication	.60*	9
	PBCL academic/work performance	.69*	9

* $p < .05$, one-tailed. ** $p < .01$

The significant correlations are explored further in the following chapter including possible explanations and opportunities for further research.

CHAPTER 6: DISCUSSION

This final chapter will explore the findings and limitations of the present study and directions for future research. Given the limitation of a small sample size, any conclusions drawn from the results of this study are sample-specific and should not be interpreted as applicable to other samples or populations. The explanations proposed here are based on previous literature, clinical experience of the writer, and in some cases speculation (where none of the above applies).

Findings of the study

Descriptive statistics

There are three major findings from the descriptive analysis of the study: this sample reported higher levels of strain than in previous published studies; the caregivers in this sample perceived they have less social support from friends, family, and significant others; and the youth with FASD being cared for by these participants have similar levels of behaviour problems to those previously reported.

Level of caregiver strain

Strain experienced by caregivers was found to be at higher levels than those reported in other studies with clinical samples (Brannan & Heflinger, 2006; Heflinger & Taylor-Richardson, 2004; Kenny & McGilloway, 2007; Taylor-Richardson, Heflinger, & Brown 2006). These results suggest that caregivers of youth with FASD in this sample are under extraordinary burden to provide for the needs of the individual in their care. Strain was the highest in the domains of objective strain (OS; $M = 3.28$, $SD = 0.66$) and subjective internalized strain (SIS; $M = 3.78$, $SD = 0.56$). Subjective externalized strain

(SES; $M = 2.50$, $SD = 0.84$) was by far the lowest reported on the three subscales. The items on that subscale include embarrassment, resentment, anger, and ability to relate to their child. This could reflect the caregiver's ability to not blame their child for the strain they are experiencing. It may imply a level of insight and perhaps resilience in the face of genuine difficulty.

Objective strain (OS) involved items that measure interruptions, disturbances in routines, physical and mental health consequences in this sample may be higher than other samples given the youth's involvement with the criminal justice system. Two of the four items with a mean above 4.0 contributed to the high levels of OS. They were: "interruption of personal time resulting from your child's emotional or behavioural problem" ($M = 4.00$, $SD = 0.87$) and "your child getting into trouble with the neighbours, the school, the community, or law enforcement" ($M = 4.00$, $SD = 0.87$). These findings are congruent with the reality that all of the youth being cared for in this sample had experienced conflict with the law. Also, as a direct result of the referral to the program, whether it was for a court-ordered assessment or for court-mandated treatment, the caregivers had interruption in their personal time.

Caregivers also reported a high level of subjective internalized strain (SIS). The other two of the four items with the highest endorsement by caregivers contributed to the SIS subscale. They were: "how worried did you feel about your child's future?" ($M = 4.89$, $SD = 0.33$) and "how tired or strained did you feel as a result of your child's emotional or behavioural problem?" ($M = 4.00$, $SD = 0.71$) The highest mean ranked item on the questionnaire indicates that caregivers in this sample have internalized their

fears about their child, and their child's future is their greatest contributor to strain. This item also had the lowest standard deviation, meaning the least variability from one participant to the next.

Levels of caregiver's perceived social support

Caregivers reported lower levels of perceived social support from friends, family, and significant other compared to findings reported previously (Cecil et al., 1995). They perceive the least support from friends ($M = 3.58$; $SD = 1.85$) and the most from a significant other ($M = 4.58$, $SD = 1.69$). Unfortunately, formal supports such as professional involvement (e.g. counsellors, family support workers, respite caregivers) were not measured on this scale. This may have influenced some of the results and will be discussed in greater detail below.

Levels of youth symptom severity

Youth with FASD being cared for by the participants in the present study had problematic behaviour similar to a previous sample of individuals with FASD. Those levels were much higher than that of normal controls: $M = 17.10$ ($SD = 8.40$; present sample) compared to $M = 6.1$ (normal controls; Streissguth et al., 1998). The lowest reported behavioural problems were with bodily or physiologic functions ($M = 1.60$, out of a possible 5, $SD = 1.01$) and personal manner ($M = 1.90$, out of a possible 5, $SD = 1.83$). The most concerning behaviour problems were with emotions ($M = 1.70$, out of a possible 2, $SD = 0.71$) and academic/work performance ($M = 2.20$, out of a possible 3, $SD = 0.97$). These last two subscales are conceptually congruent with caregiver's reported strain in relation to their child's future. Emotional problems may impact the

youth's relationships and occupational performance, both of which may have an effect on their child's future.

Correlational analysis

Several of the correlational findings were as predicted by the existing literature and others were unexpected. Caregiver strain in this sample was found to be significantly correlated to several variables. These findings will be summarized under three headings: correlates of strain and the demographics of the caregiver; correlates of strain and demographics of the youth; and correlates of strain and symptom severity of the youth. Additional significant correlations were identified through data analysis. They will be summarized below under the headings correlates of perceived social support and correlates of symptom severity.

Correlates of strain and demographics of the caregiver

Several demographic variables of the caregivers predicted strain including lower education level ($r_s = -.61$), lower income ($r_s = -.69$), and fewer children in the home ($r_s = -.66$). As indicated in the literature review, lower socio-economic status has been linked to increased caregiver burden in numerous studies (Baldwin et al., 1995; Barnett, 2008; Boyce & Behl, 1991; Brannan & Heflinger, 2001; Paley, O'Connor, Kogan, & Findlay, 2005; Paley et al., 2006; Webster-Stratton, 1990). The findings of this study were consistent with Heflinger and Brannan (2006) and Kang et al. (2005) who also found income of the caregiver to be negatively correlated with objective strain. In the present study, income of the caregiver was only significantly correlated with objective strain and not the other subscales or the global strain score. This finding makes sense, in that

caregivers with less financial resources may find attending appointments and paying for treatment (including medications) financially burdensome. Conceptually, income and education level of the caregiver are likely to be related to each other. However, in this sample that was not found to be the case. It does fit clinically that caregivers with less education and fewer economic resources would experience more strain. Possible explanations for this may have to do with the coping skills necessary to achieve higher education may translate into a protective factor for strain. Higher education also requires discipline and perseverance, which may be general qualities that reduce caregiver strain.

The third demographic characteristic of the caregivers that negatively correlated with strain was number of children in the home. This was in contrast with the literature review, which indicated more children in the home would result in more strain on the caregiver (Ostberg & Hagekull, 2000). In this sample, it is possible that more children in the home may reduce strain on the caregiver if they contribute to the care of the other children. For example, some older children will help with household responsibilities, accompany their younger siblings to appointments, or assist with other caregiving responsibilities. Indeed, they may also provide emotional support for the caregiver.

Correlates of strain and demographics of the youth

Certain demographic characteristics of the youth also predicted more strain such age of the youth ($r_s = -.74$), education level ($r_s = -.70$), and higher number of prescribed medications ($r_s = .80$). These findings indicate that as the youth ages, these caregivers experience less objective and subjective internalized strain. In conjunction with a higher education level, caregivers experience less fear about their child's future as they age and

receive more education. Objective strain increased for caregivers who cared for youth with multiple prescribed medications. These youth are likely to have more objective caregiving responsibilities such as appointments with physicians and perhaps other formal interventions (e.g. counselling or youth justice appointments). These expectations produce more observable strain on caregivers, which is measured as objective strain on the CGSQ.

Correlates of strain and symptom severity of the youth

Poor social skills ($r_s = .64$) and emotional problems ($r_s = .72$) also predicted strain on the caregiver. First, youth with problematic social skills correlated with subjective externalized strain (SES) of the caregiver. The items that compose the SES subscale measure the relationship, embarrassment, resentment, and anger towards the child. It fits, then, that caregivers for youth with social skill deficits would experience more strain on this scale. Second, subjective internalized strain (SIS) was elevated based on problematic emotional skills of the youth. The items on the Personal Behavior Checklist (PBCL) that measured emotional skills explained these two items as mood swings and overreactions to situations. These skills impact the ability of the youth to form healthy relationships with peers, employers, teachers, and intimate partners. Caregivers may experience fear about their child's future based on these deficits.

Correlates of perceived social support

The findings described in this section and the following one, correlates of symptom severity of the youth, were not predicted from the literature review. It is not known if these findings are specious or are indicative of a broader trend. Further research

is warranted in this area in order to determine the applicability of these findings.

Therefore, limited attention will be paid to the interpretation of these results.

Additional correlations with the global score and subscales of the Multidimensional Scale of Perceived Social Support (MSPSS) were number of medications the youth was taking (MSPSS family, $r_s = .76$, and friends subscale, $r_s = .74$) and length of the caregiver/youth relationship (MSPSS friends subscale; $r_s = -.59$). It is possible that caregivers perceive less social support from family and friends when the youth have more problematic behaviours that may lead to psychopharmacological intervention. The issues facing these youth are likely chronic, which Quittner et al. (1990) found affects access to social supports. Caregivers may likewise perceive less friend support based on the length of the caregiver/youth relationship also due to the chronic nature of the disability of FASD. As compared to foster parents and kinship caregivers, caregivers with the longest relationships were biological parents. Prior studies such as Heflinger and Brannan (2006) found biological parents experience more strain. Especially in the case of caregivers of youth with FASD, biological parents experience the added oppression and stigma for having caused the disability.

Correlates of symptom severity

The following correlates were found with the Personal Behavior Checklist (PBCL): MSPSS significant other (PBCL global score, $r_s = -.64$, and personal manner, $r_s = -.65$); education level of the caregiver (PBCL communication, $r_s = -.85$; personal manner, $r_s = -.87$; motor skills, $r_s = -.87$; academic/work performance, $r_s = -.74$; social skills, $r_s = -.69$); age of the caregiver (PBCL body or physiological symptoms; $r_s = .63$);

length of the caregiver/youth relationship (PBCL communication; $r_s = .63$); and quality of the caregiver/youth relationship (PBCL communication, $r_s = .60$; and academic/work performance, $r_s = .69$). These variables were not related to caregiver strain and may highlight opportunities for future research directions. At this time, they do not appear to represent any clear findings that fit with the existing literature or this writer's clinical experience.

Ethics of care

It was proposed in the ethics of care analysis (chapter three) that certain demographic factors may impact strain due to the added burden on caregivers. This writer proposed that female caregivers and, in particular, biological mothers would experience more strain than their male, non-biological caregiver counterparts. This sample included only one male caregiver, which precludes any statements about correlation of gender and strain. Another factor proposed in that chapter was that caregivers of youth with FASD would experience more strain than caregivers of other groups of individuals. The correlational analysis demonstrated that caregivers in this sample do indeed experience high levels of strain, even when compared to other studies with clinical samples. Social factors such as power, oppression, and stigma were not measured in the current study but should be considered in future research.

Limitations

The most obvious and perhaps the most limiting factor in this study was the small sample size. This exploratory study provides introductory knowledge about the issues

facing caregivers of youth with FASD. More research is necessary to understand the depth and breadth of the caregiver experience.

In addition, there were unforeseen complications in conducting this study that provide an interesting insight about this sample and points to future research opportunities. Although there were only nine caregivers who participated in the study, there were 19 other youth who were identified for inclusion in the study. As described in chapter four, youth were selected for inclusion in this study based on a diagnosis of FASD (at least a score of two on the CNS damage digit from the Four Digit Diagnostic Code criteria) and a referral to the Centerpoint Program for either court-assessment or treatment. Of the 28 youth that were deemed appropriate for inclusion in the sample, only nine had primary caregivers available to participate in the study. The other youth were incarcerated with no supportive caregivers to return to ($n = 4$); resided in group care facilities ($n = 6$); or were homeless or transient ($n = 3$). Several other caregivers were unable to be contacted due to change of address and/or phone numbers ($n = 5$) and one ($n = 1$) did not return the questionnaires despite agreeing to participate.

Prior to commencing data collection, there were no plans to exclude caregivers based on the nature of their relationship with the youth. However, upon further reflection the instruments and research questions specifically pertained to caregivers that resided full-time with the youth. Given the nature of either rotational shift work (group care staff) or occasional contact (Children and Youth Services worker) these caregivers would not be able to report items of caregiver strain. Considering that the dependent variable was caregiver strain, it was determined that caregivers who did not reside with the youth

full-time would not be included in the study. The result of this exclusion was a very small sample size ($n = 9$), compared to a possible 28.

An unfortunate conclusion from this outcome is that many of the youth with FASD that become involved in the criminal justice system have barriers to a long-term, stable, caregiver to provide important mentoring, support, and direction. It is this writer's clinical experience that these youth often exhaust their caregivers to the point of abandonment by the time they have reached adolescence. Unfortunately, the important protective factor of having a stable residence (Streissguth et al., 1994) may not be commonly experienced by this population.

Regardless of the limitations of this research, this exploratory work aimed at better understanding burden experienced by caregivers of youth with FASD is an important introduction to this unique and important population. The findings, although not generalizable, begin to describe how these caregivers experience strain and what factors may be related to strain.

Directions for future research

Given that this study is exploratory in nature and scope, it would be beneficial to continue collecting data to accumulate more robust results and conclusions. A broader sample that included caregivers from other settings would increase the applicability of this work to a wider group. This writer also recommends that in addition to the MSPSS, a standardized measure with good internal and external validity be utilized to measure formal social supports. As this critical area was not included in this study, it is difficult to determine how formal supports may buffer caregiver strain.

In addition, a mixed-method approach to the study design would provide a more rich understanding of the caregiver experience. A purely quantitative research method restricts the breadth of information that is possible to glean from caregivers. A qualitative research component could incorporate some of the feminist theoretical concepts of power, oppression, and stigma experienced by caregivers introduced in chapter three. The current study design was limited in its ability to address and respond to the identified social justice issues.

Conclusions

The current study is useful in providing an introductory knowledge of the experience of caregivers of youth with FASD. It highlights critical issues that may provide opportunities for future research, clinical direction, and political decision-making. In this sample, strain experienced by caregivers is a significant problem that requires more attention and a broader understanding. Several demographic characteristics of caregivers and youth correlated with strain, as did symptom severity of the youth. While much is left unknown, it is this writer's hope that these findings will underscore the need for future research to better understand the caregiver experience in order to improve outcomes for both youth with FASD and their caregivers.

Beyond the scope of this study remain several other potential factors that may contribute to strain and remain aloof and poorly comprehended. These contributions to strain are subtle and difficult to disentangle from the more obvious and easier to measure factors noted above. Oppression on multiple levels experienced by caregivers of youth with FASD, especially biological mothers, remains one of these critical issues that may

impact this population. One of the biological mothers who participated in the study opined that her son's difficulties were "all my fault". She reported she "deserved" to endure frequent abusive behaviour from her son, which seemed to this writer to be a form of penance. Just as this writer proposed that oppression occurs on multiple levels, the responsibility for prevention and intervention must also be multi-dimensional and systemic. The health care system bears some responsibility to change the perception that mothers who drink alcohol when they are pregnant carry the sole responsibility for outcomes of individuals with FASD. In fact, the literature indicates other contributing factors that place responsibility at a much broader level including family, corporate, community, and government (see Armstrong & Abel, 2000). It is often the default position to place blame on an individual for addictions and poverty, instead of the much more difficult position that requires social and political intervention. Families and communities can support women and individuals with addictions to live healthier and care for their children conscientiously. Governments contribute to solutions by ensuring a living wage and encouraging corporate responsibility to provide quality and financially viable childcare for women who are employed outside the home. Political recognition of the value of caregiving can be improved by providing financial incentives to men and women who are primary caregivers of the young, elderly, and/or disabled. Cultural values in Canada and across the world seem to mirror the value that capital, not people or relationships, are of utmost importance. If these values were to shift even slightly towards human capital and less with revenue capital, our social investments may see

long-term gain. Each level of our society needs to take responsibility for the good of the other. Archbishop Desmond Tutu (as cited in Alberta Government, 2009) said:

Our humanity is caught up in that of all others. We are human because we belong. We are made for community, for togetherness, for family, to exist in a delicate network of interdependence... We are sisters and brothers of one another whether we like it or not, and each one of us is a precious individual.

Martin Luther King, Jr. described a vision that all people be granted the “riches of freedom and the security of justice” in his monumental speech at the Lincoln Memorial in Washington, D.C. on August 28, 1963. Though he was crusading for basic human rights and freedom from discrimination for African Americans, this concept could be extended to all oppressed peoples. It has been argued in chapter three that caregivers of youth with FASD, and in particular caregivers who are biological mothers, experience oppression that threatens to undermine their freedom and social justice. It is this writer’s hope that this study compels each of us to advocate for change on individual, family, community, corporate, and government levels.

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APPENDIX A: DEMOGRAPHIC QUESTIONNAIRE

Please circle the appropriate selection below:

1. What is your age? _____
2. What is your gender? Male Female
3. What is your current relationship status? Single (never married)
 Married
 Divorced
 Common-law
 Widowed/Widower
4. What is your ethnic background (e.g. Caucasian, Aboriginal)?

5. What is your usual total monthly household income (net)? _____
6. How many children live in your home? _____
7. What is the highest grade of regular school have you completed? (Circle One)
 7 8 9 10 11 12 GED 13 14 15 16 17 18 19 20 +
 Jr. High Sr. High University Graduate School
8. What is your employment status?
 Not working outside the home
 Working part-time (ave. hours per week: _____)
 Working full-time (ave. hours per week: _____)
 Volunteering (ave. hours per week: _____)

APPENDIX B: CAREGIVER STRAIN QUESTIONNAIRE

Please think back over the past 6 months and try to remember how things have been for your family. We are trying to get a picture of how life has been in your household over that time.

For each question, please tell me which response (which number) fits best.

In the past 6 months, how much of a problem was the following:

	Not at all	A little	Somewhat	Quite a bit	Very much
1. Interruption of personal time resulting from your child's emotional or behavioral problem?	1	2	3	4	5
2. You missing work or neglecting other duties because of your child's emotional or behavioral problem?	1	2	3	4	5
3. Disruption of family routines due to your child's emotional or behavioral problem?	1	2	3	4	5
4. Any family member having to do without things because of your child's emotional or behavioral problem?	1	2	3	4	5
5. Any family member suffering negative mental or physical health effects as a result of your child's emotional or behavioral problem?	1	2	3	4	5
6. Your child getting into trouble with the neighbors, the school, the community, or law enforcement?	1	2	3	4	5
7. Financial strain for your family as a result of your child's emotional or behavioral problem?	1	2	3	4	5
8. Less attention paid to other family members because of your child's emotional or behavioral problem?	1	2	3	4	5
9. Disruption or upset of relationships within the family due to your child's emotional or behavioral problem?	1	2	3	4	5
10. Disruption of your family's social activities resulting from your child's emotional or behavioral problem?	1	2	3	4	5

In this section, please continue to look back and try to remember how you have felt during the past 6 months.

For each question, please tell me which response (which number) fits best.

In the past 6 months:

		Not at all 1	A little 2	Somewhat 3	Quite a bit 4	Very much 5
11.	How isolated did you feel as a result of your child's emotional or behavioral problem?					
12.	How sad or unhappy did you feel as a result of your child's emotional or behavioral problem?	1	2	3	4	5
13.	How embarrassed did you feel about your child's emotional or behavioral problem?	1	2	3	4	5
14.	How well did you relate to your child?	1	2	3	4	5
15.	How angry did you feel toward your child?	1	2	3	4	5
16.	How worried did you feel about your child's future?	1	2	3	4	5
17.	How worried did you feel about your family's future?	1	2	3	4	5
18.	How guilty did you feel about your child's emotional or behavioral problem?	1	2	3	4	5
19.	How resentful did you feel toward your child?	1	2	3	4	5
20.	How tired or strained did you feel as a result of your child's emotional or behavioral problem?	1	2	3	4	5
21.	In general, how much of a toll has your child's emotional or behavioral problem taken on your family?	1	2	3	4	5

Roxanne Pereira

From: Brannan, Ana Maria [ana.m.brannan@Vanderbilt.Edu]
Sent: Monday, April 14, 2008 10:03 AM
To: Roxanne Dohms
Subject: RE: Caregiver Strain Questionnaire

Roxanne,

Perfect. This email grants formal permission for you to use the CGSQ in the project you have described.

Good luck with your thesis and let me know if I can be of further assistance.

Sincerely,

Ana Maria

Ana Maria Brannan, Ph.D.
Senior Research Associate
Vanderbilt University

APPENDIX C: MULTIDIMENSIONAL SCALE OF PERCEIVED SOCIAL SUPPORT

Instructions: We are interested in how you feel about the following statements. Read each statement carefully. Indicate how you feel about each statement.

Circle the "1" if you **Very Strongly Disagree**
 Circle the "2" if you **Strongly Disagree**
 Circle the "3" if you **Mildly Disagree**
 Circle the "4" if you are **Neutral**
 Circle the "5" if you **Mildly Agree**
 Circle the "6" if you **Strongly Agree**
 Circle the "7" if you **Very Strongly Agree**

1.	There is a special person who is around when I am in need.	1	2	3	4	5	6	7	SO
2.	There is a special person with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	SO
3.	My family really tries to help me.	1	2	3	4	5	6	7	Fam
4.	I get the emotional help and support I need from my family.	1	2	3	4	5	6	7	Fam
5.	I have a special person who is a real source of comfort to me.	1	2	3	4	5	6	7	SO
6.	My friends really try to help me.	1	2	3	4	5	6	7	Fri
7.	I can count on my friends when things go wrong.	1	2	3	4	5	6	7	Fri
8.	I can talk about my problems with my family.	1	2	3	4	5	6	7	Fam
9.	I have friends with whom I can share my joys and sorrows.	1	2	3	4	5	6	7	Fri
10.	There is a special person in my life who cares about my feelings.	1	2	3	4	5	6	7	SO
11.	My family is willing to help me make decisions.	1	2	3	4	5	6	7	Fam
12.	I can talk about my problems with my friends.	1	2	3	4	5	6	7	Fri

The items tended to divide into factor groups relating to the source of the social support, namely family (Fam), friends (Fri) or significant other (SO).

APPENDIX D: PERSONAL BEHAVIOR CHECKLIST

DEPARTMENT OF PSYCHIATRY & BEHAVIORAL SCIENCES, BOX 359112,
UNIVERSITY OF WASHINGTON SCHOOL OF MEDICINE,
SEATTLE, WA 98195 PHONE: 543-7155
Ann P. Streissguth, Ph.D.; Helen Barr, M.A., M.S.

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PBCL - 36 **Personal Behaviors Checklist**

TEAR OFF SHEET

(For confidentiality, tear off before filing data)

Name of Study Site: _____

Person Being Described:

LAST _____

FIRST _____

ID #: _____

Person Filling Out Form:

LAST _____

FIRST _____

Date: _____

1. The Scale was designed to be filled out by parents, caretakers or others who know the person well (*i.e.*, teacher, parole officer, etc.), not by the individual about themselves. It is most useful when filled out by a respondent who knows the person in a social or familial context, rather than in an office setting.
2. The scale was meant to be applicable for ages 2 years through adulthood (perhaps 35 years), although it is not necessary that the respondent knows the person across their whole lifespan.
3. Please do not give any further instructions other than those printed. It usually takes about 5 minutes to fill out.

ID#: _____ STUDY SITE: _____ DATE: _____ PBCL-36, PAGE 2 of 4

PBCL - 36

Personal Behaviors Checklist

DEPARTMENT OF PSYCHIATRY & BEHAVIORAL SCIENCES, BOX 359112,
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SEATTLE, WA 98195 PHONE: 543-7155
Ann P. Streissguth, Ph.D.; Helen Barr, M.A., M.S.

FACE SHEET

1. PERSON BEING DESCRIBED IN PBCL:

BIRTHDATE: ____ / ____ / ____, OR AGE IN YEARS: ____, MONTHS: ____
YEAR/MONTH/DAY

What is the highest grade of regular school has the person completed? (**Circle One**)

7 8 9 10 11 12 GED 13 14 15 16 17 18 19 20 +
JR. HIGH HIGH SCHOOL UNIVERSITY GRADUATE SCHOOL

Has the person described ever failed a grade? Yes: ____, No: ____

Has the person described ever been suspended, expelled, or dropped out of school?
Yes: ____, No: ____

Is the person described taking any psychotropic medications at this time? Yes: ____, No: ____

If yes, number of different kinds of psychotropic medications per day (**Circle One**)

1 2 3 4 5 6 7 8 9 10 +

Name of Drugs (IF KNOWN): _____

2. PERSON FILLING OUT PBCL: (Check one)

- | | |
|---|--|
| <input type="checkbox"/> 01 = Bio Mother | <input type="checkbox"/> 11 = Spouse |
| <input type="checkbox"/> 02 = Bio Father | <input type="checkbox"/> 12 = Legal Guardian |
| <input type="checkbox"/> 03 = Adoptive Mother | <input type="checkbox"/> 13 = Case Worker |
| <input type="checkbox"/> 04 = Adoptive Father | <input type="checkbox"/> 14 = Residential Caretaker |
| <input type="checkbox"/> 05 = Stepmother | <input type="checkbox"/> 15 = Patient Self-Report |
| <input type="checkbox"/> 06 = Stepfather | <input type="checkbox"/> 16 = Other Relative, Specify: _____ |
| <input type="checkbox"/> 07 = Foster Mother | <input type="checkbox"/> 17 = Other Non-relative, Specify: _____ |
| <input type="checkbox"/> 08 = Foster Father | <input type="checkbox"/> 18 = Other |
| <input type="checkbox"/> 09 = Grandmother | |
| <input type="checkbox"/> 10 = Grandfather | |

3. WHAT IS THE CONTEXT IN WHICH YOU KNOW THE PERSON BEING DESCRIBED:

4. HOW LONG HAVE YOU KNOWN THE PERSON DESCRIBED: YEARS: ____ MONTHS: ____

5. HOW WELL DO YOU KNOW THE PERSON BEING DESCRIBED: (**Circle one**)

HARDLY AT ALL 1 2 3 4 5 EXTREMELY WELL

ID#: _____ STUDY SITE: _____ DATE: _____ PBCL—36, PAGE 3 of 4

PBCL - 36

Personal Behaviors Checklist

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Ann P. Streissguth, Ph.D.; Helen Barr, M.A., M.S.

INSTRUCTIONS

Below are some statements about people's behaviors. For each statement, please circle "yes", "no" or "don't know" regarding the person identified on page 1.

COMMUNICATION AND SPEECH:

- | | | | | |
|----|-----|----|------------|--|
| 1. | yes | no | don't know | Loud, deep, or unusual sounding voice. |
| 2. | yes | no | don't know | Talks too much and too fast. |
| 3. | yes | no | don't know | Interrupts; talks with poor timing in terms of the listener. |
| 4. | yes | no | don't know | Unusual conversational topics; dwells on one or two particular subjects or speaks about unrealistic or unusual topics. |
| 5. | yes | no | don't know | Likes to talk; the talking seems more important than the context. |
| 6. | yes | no | don't know | Repeats certain words or phrases often. |
| 7. | yes | no | don't know | Makes "off the wall" comments; sometimes says things that seem completely out of context. |
| 8. | yes | no | don't know | Talks a lot but says little; is chatty but with shallow content. |

PERSONAL MANNER:

- | | | | | |
|----|-----|----|------------|--|
| 1. | yes | no | don't know | Klutzy: tasks often unintentionally end up in a mess; tends to upset or spill things more than normal. |
| 2. | yes | no | don't know | Messy: paper work is smudgy and crumpled; makes more of a mess eating than others the same age; unconcerned about personal cleanliness (for example, hands, face and clothes are often dirty). |
| 3. | yes | no | don't know | Touches things and people frequently; seems to need to touch or be touched more than others. |
| 4. | yes | no | don't know | Loves to be the center of attention; draws attention to self. |
| 5. | yes | no | don't know | Tends to lose or misplace things a lot. |

EMOTIONS:

- | | | | | |
|----|-----|----|------------|---|
| 1. | yes | no | don't know | Has rapid mood swings; can be happy one moment and mad or upset the next, with mood swings triggered by seemingly small things. |
| 2. | yes | no | don't know | Overreacts to situations; emotional reactions are often stronger than you would expect. |

MOTOR SKILLS AND ACTIVITIES:

- | | | | | |
|----|-----|----|------------|--|
| 1. | yes | no | don't know | Has difficulty performing precise tasks or difficulty learning precise tasks. |
| 2. | yes | no | don't know | Finds team sports like soccer or football difficult, or has had trouble playing on a team. |

ACADEMIC/WORK PERFORMANCE:

ID#: _____ STUDY SITE: _____ DATE: _____ PBCL—36, PAGE 4 of 4

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Personal Behaviors Checklist

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- | | | | | |
|----|-----|----|------------|--|
| 1. | yes | no | don't know | Has poor attention span. |
| 2. | yes | no | don't know | Tries hard and wants to please, but the end result is often disappointing. |
| 3. | yes | no | don't know | Has trouble completing tasks. |

SOCIAL SKILLS AND INTERACTIONS:

- | | | | | |
|-------|-----|----|------------|---|
| 1. | yes | no | don't know | Overly friendly with strangers. |
| 2. | yes | no | don't know | Often demands attention or monopolizes a conversation. |
| 3. | yes | no | don't know | Establishes superficial friendships easily but has no close friends. |
| 4. | yes | no | don't know | Seems unaware of the consequences of his/her behavior, particularly the social consequences. |
| 5. | yes | no | don't know | Seems unaware of or ignores "good manners," for example may pass gas or burp. |
| 6. | yes | no | don't know | Can't take a hint; needs strong, clear commands because the fine points escape him/her. |
| 7. | yes | no | don't know | Is physically loving and demonstrative; enjoys bodily contact more than most people his/her age; sometimes touches peers more than they prefer. |
| 8. | yes | no | don't know | Gets over stimulated in social situations, especially in a crowded room or when strangers are present. |
| 9. | yes | no | don't know | Shows poor judgment in whom he/she trusts. |
| 10. | yes | no | don't know | Inappropriate interactions at home, for example with brothers or sisters, parent, family pets. Please describe: _____ |
| <hr/> | | | | |
| 11. | yes | no | don't know | Inappropriate interactions outside the home, such as at school with teachers or other students, in the neighborhood. |

BODILY OR PHYSIOLOGIC FUNCTIONS:

- | | | | | |
|----|-----|----|------------|--|
| 1. | yes | no | don't know | Seems very sensitive to loud noises (for example, startles easily; does not tune out repetitive noises; seems bothered by certain sounds.) |
| 2. | yes | no | don't know | Fidgety; can't sit still. |
| 3. | yes | no | don't know | Has had sleeping problems (such as unpredictable sleep/wake patterns; difficulty going to sleep at night; waking very early in the morning; irregular naps.) |
| 4. | yes | no | don't know | Has problems with personal hygiene; for example, forgets to bathe, wash hands, brush teeth. |
| 5. | yes | no | don't know | Has had problems with sexual functioning, such as inappropriate masturbation; inappropriate touching of others; other unusual sexual activity. |
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