

**THE PSYCHOLOGICAL AND PHYSICAL HEALTH, STRESS AND NEEDS OF
CAREGIVERS OF CHILDREN WITH DISABILITIES ENROLLED IN FAMILY-
CENTERED SUPPORT PROGRAMS**

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Dedication

This dissertation is dedicated to those who have supported me to pursue my aspirations, including my family and my husband. My interests in counselling psychology have been shaped by my parents who have made positive contributions to their community through their acts of compassion, empathy and altruism. They have inspired me to measure my success by the extent to which I can improve the lives of others through kindness, advocacy and education. This dedication is also shared with my husband, Kevin, who has enabled me to thrive by continuously providing me with comfort and encouragement.

Abstract

Caregivers of children with disabilities, in comparison to caregivers of typical children, experience an exorbitant amount of stress, which can have detrimental effects on their physical and psychological health. The purpose of the present study was to investigate the psychological and physical health, stress, and needs of caregivers of children with disabilities between the ages of 3 and 12, who were enrolled in family-centered support programs in Alberta, Canada. A cross-sectional survey design was used to compare the psychological and physical health, and stress levels of caregivers of children with disabilities with caregivers of typical children. The present study illustrated that caregivers of children with disabilities experienced an array of unmet needs, and high levels of depression, anxiety and stress, which were all associated with their frequency of socialization. Thus, families of children with disabilities may benefit from support services that reduce barriers to well-being and promote caregiver psychological and physical health.

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Chapter 1: Introduction

Overview

Caring for a child can be a challenge for any parent, although it can be exceptionally challenging for parents of children with disabilities (Brehaut et al., 2004; Lee, Park, Matthews, & Hsieh, 2017). Furthermore, caregivers of children with disabilities, in comparison to caregivers of typical children, experience considerably greater stress, which can negatively impact their physical and psychological health. The purpose of the present study was to expand on previous findings and to investigate the psychological and physical health, stress, and needs of caregivers of children with disabilities, who were enrolled in family-centered support programs in Alberta, Canada. This chapter comprises an introduction to the literature concerning the psychological and physical health, stress and needs of caregivers of children with disabilities. Furthermore, I will demonstrate the rationale of the present study and introduce the study design.

Defining Disability

The World Health Organization (WHO) and World Bank (2011) have provided a definition of disability that was developed for the International Classification of Functioning, Disability and Health (ICF) and describes disability as “an umbrella term for impairments, activity limitations, and participation restrictions. Disability refers to the negative aspects of the interaction between individuals with a health condition (such as cerebral palsy, Down syndrome, depression) and personal and environmental factors (such as negative attitudes, inaccessible transportation and public buildings, and limited social supports)” (p. 7). The World Health Organization and World Bank (2011) suggest that disability should be viewed through the lens of both a medical and social model.

Alberta's Family Support for Children with Disabilities (FSCD) program has defined a disability as "a chronic, developmental, physical, sensory, mental or neurological condition or impairment that does not include a condition for which the primary need is for medical care or health services to treat or manage the condition, unless it is a chronic condition that significantly limits a child's ability to function in normal daily living" (Alberta Human Services, 2011). This definition addresses the service requirements of that organization and was used as the working definition of disabilities for the present study as participants of children with disabilities were enrolled in the FSCD Specialized Services program. However, there are a wide variety of definitions of disabilities from various sources, which will be described in this section.

The World Health Organization and World Bank (2011) suggest that disabilities can be viewed from a medical model perspective as physical and mental conditions that deviate from what would be expected in a specific population. Conversely, a social definition of disability may posit that an individual may be labelled as disabled because society has created social restrictions and environmental limitations that have decreased that individual's ability to fully participate in their community. Social restrictions may include social behaviour expectations, such as sitting still in a classroom during school hours or making eye-contact in conversations, whereas environmental limitations may include accessibility and transportation options that have not been modified for individuals who use wheelchairs or crutches. These social rules and expectations can become significant stressors for individuals with disabilities and, at times, may discourage or prevent them from participating in certain activities, such as using a public recreational facility, seeking employment, or socializing with others, because the

challenges they are presented with are too overwhelming or daunting.

The World Health Organization and World Bank (2011) further argue that disabilities can be perceived as both an internal and external construct, as individuals with disabilities face challenges on both a personal and environmental level. By using a bio-psycho-social model, disability support workers can understand disabilities in the context of a continuously evolving interactive relationship between mental and physical health conditions and contextual factors. These contextual factors may include environmental barriers, such as the abundance of stairs versus wheelchair ramps in North American society. Moreover, contextual factors may include the negative attitudes or assumptions of others which can limit access to a safe, supportive and healthy environment for individuals with disabilities to live and engage in meaningful participation in society.

The World Health Organization and World Bank (2011) have also identified personal factors which may impact the extent to which an individual feels limited by their ability to engage in meaningful participation in society. For example, an individual with a disability who feels helpless, experiences minimal self-esteem, feels stigmatized by society and lacks motivation to create changes in their life will likely feel more limited by their disability than an individual who actively challenges the dominant culture's definition of disability as being limiting in itself. For this purpose, the World Health Organization and World Bank (2011) recommend that disabilities be viewed on a spectrum, in which there exists a vast array of individual differences encompassing a variety of strengths, skills, interests, abilities and levels of participation in societal activities.

When disabilities are perceived as a continuum, an argument can be made that each individual with a disability and their family would benefit most from individualized support which targets and reduces barriers related to the health conditions, personal factors and environmental factors that contribute to the disability (World Health Organization & the World Bank, 2011). Furthermore, the World Health Organization and World Bank (2011) argue that there is a need for proactive strategies to ensure that individuals with disabilities can live healthy lives and learn about strategies and support services that are available to assist them if and when they encounter challenges that research has demonstrated may arise in their future.

Lastly, there is a need for society to work collaboratively with the community of individuals affected by disabilities to acquire information and implement societal changes that can reduce barriers to well-being and increase meaningful participation in society, such as socialization, volunteering and employment (World Health Organization & the World Bank, 2011). Beyond reducing barriers, individuals with disabilities require communities that will provide advocacy and protect their human rights to dignity, respect, and equal opportunities for autonomy, accessibility and well-being (World Health Organization & the World Bank, 2011). Thus, it can be argued that it is a societal responsibility, not simply a familial duty, to support and care for individuals with disabilities. When communities, professionals, families and individuals with disabilities collaborate and share their knowledge and concerns, greater improvements can be made to ensure that society is creating an environment that supports individuals with disabilities to thrive and develop the self-confidence and motivation needed to overcome barriers in their lives.

The United Nations Educational, Scientific and Cultural Organization (UNESCO, 2017) also describes the complexities and difficulties involved with shaping a definition of disabilities. For the purpose of conducting research, UNESCO (2017) has suggested that a person can be considered to have a disability if they report having “a lot of difficulty” or “cannot do at all” in response to at least one of the following six areas of functioning: walking, self-care, cognition, communication, seeing, or hearing (p. 2). This definition of disability was shaped by the Washington Group and has been used in census documents (UNESCO, 2017). If the three definitions above are compared, it can be suggested that the UNESCO and FSCD definitions are more reflective of a medical model which reflects mental, physical and/or functional impairments (UNESCO, 2017; Alberta Human Services, 2011), whereas the WHO definition perhaps speaks more clearly about the complexities of disabilities and how they consist of a combination of personal, contextual and environmental factors, which reflects a bio-psycho-social model (World Health Organization & the World Bank, 2011).

There are various other models that have been used to define disabilities besides the bio-psycho-social, medical and social models which have previously been described. Berghs, Atkin, Graham, Hatton, and Thomas (2016) provided an important critique of the medical model by stating that a significant limitation of the medical model is that it suggests that the problem or pathology lies within the individual, thus the natural solution would be to treat the individual. They further assert that the medical model, when used to define disabilities on its own, can appear to be a simplified explanation of a very complex issue. A potential strength of the medical model is that it has helped to classify, treat and conduct research on disabilities. A limitation of the medical model is that it solely places

the responsibility on the individual with the disability to change or treat their condition, rather than exploring how familial, societal and environmental factors have contributed to the condition. Thus, this model can lack context and appear to be a less holistic way of understanding and supporting individuals with disabilities. The medical model, sometimes referred to as the biomedical model, can also lead to the labelling and categorization of individuals with disabilities. This may be helpful to researchers and professionals who wish to organize information and similar symptoms for the purposes of diagnostic assessments and research, but consequently, many individuals with disabilities may feel that they are dismissed, stereotyped or stigmatized.

Berghs et al. (2016) have argued that the social model can be understood in terms of social oppression as society disables individuals or places limitations on their abilities by utilizing specific social rules and expectations for members of society. The benefit of using a social model is that it can externalize the challenges faced by individuals with disabilities and provide a platform for individuals with disabilities to engage in activism campaigns to fight for their rights to equal accessibility, respect and opportunities. Society, as a whole, is viewed as a contributing factor to the disability, so the natural approach to resolving these concerns would be to create modifications in society to ensure that individuals with disabilities have equal opportunities to participate in their communities. This theory has been criticized for neglecting discussions about pathology or physical or mental differences among individuals with disabilities. It can be argued that social barriers can be changed or removed, but an individual's physical condition will remain the same. Thus, the social model may improve an individual's ability to cope or function in society, but it does not necessarily mean that the individual with disabilities

will be able to live a life without challenges, as disabilities can affect an individual's emotions, motivation, self-esteem, self-confidence, self-perception and interpersonal relationships.

Durham and Ramcharan (2018) presented another model that can be used to define disabilities, the moral model, which has been developed from religious influences. The moral model suggests that disabilities result from an immoral act or sin which may cause shame or social persecution. The moral model suggests that the affected individual (or his/her parents) is responsible for the development of their disability, which may be the result of a punishment from God or another supernatural force, or the result of spiritual possession. Although this model has historical roots, it is still relevant to some cultures and religions in the present day.

The human rights model has gained political significance because it argues that individuals with disabilities do not simply need equality, accessibility and equal opportunities, but rather, they have a human right to live in a society that reduces barriers for the well-being of all members of society (Berghs et al., 2016). Moreover, this model stipulates that discriminatory practices in society should be taken more seriously as individuals with disabilities have a right to be protected from social rules that render them feeling vulnerable, patronized or excluded (Berghs et al., 2016). A strength of this approach is the emphasis on protecting individuals with disabilities on a societal level by creating new laws to protect their human rights (Berghs et al., 2016). Unfortunately, professionals in the legal field have experienced difficulty using this model to fight for the rights of their clients as the human rights models lacks applicability (Berghs et al., 2016). For example, it remains unclear what should be considered reasonable

accommodations for individuals with disabilities (Berghs et al., 2016). Despite the intention of this theory to produce radical changes in society, society appears to remain unclear about which modifications should be implemented first (Berghs et al., 2016). The lack of clarity surrounding the human rights of individuals with disabilities has consequently led to insufficient structural, legal and social changes, and the tendency of social justice advocates to rely on other disability models to defend their cases (Berghs et al., 2016).

The definition of the term ‘disability’ can also vary among different service providers in the province of Alberta, where the present study was conducted. For example, the Alberta Human Rights Commission defines a physical disability as “any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness. This includes, but is not limited to, epilepsy; paralysis; amputation; lack of physical coordination; visual, hearing and speech impediments; and physical reliance on a guide dog, service dog, or wheelchair or other remedial appliance or device” (Alberta Human Rights Commission, 2018). They also provide a definition for a mental disability which includes “any mental disorder, developmental disorder or learning disorder, regardless of the cause or duration of the disorder” (Alberta Human Rights Commission, 2018). This definition appears to strongly reflect the medical model. There are also nationwide differences in the definition of disability. The Ontario Human Rights Commission’s (2018) definition is very similar to the definition provided by the Alberta Human Rights Commission, although it recognizes the interaction between attitudinal and environmental barriers, inaccessibility difficulties and physical or mental impairments that may affect the way an individual is able to

participate in society. This definition appears to align itself more closely with the bio-psycho-social model currently used by WHO.

Furthermore, some Canadian education systems have also provided definitions of the term ‘disability’ to determine who should be provided with special education programs (Ontario Ministry of Education, 2018). The Ontario Ministry of Education (2018) argues that individuals with certain “behavioural, communicational, intellectual, physical or multiple exceptionalities” may benefit from unconventional teaching methods and individual learning plans. These students with special or exceptional needs may or may have a current diagnosis, although their teachers may have identified them because their academic performance deviated from the school board standard scores (Ontario Ministry of Education, 2018). Students with special and exceptional needs may perform above or below the class average and will be provided with an Individual Identification Plan (IEP), which may include goals that will be targeted by classroom staff, such as the development of behavioural, cognitive, social and communication skills (Ontario Ministry of Education, 2018). Prior to the development of the IEP, students will be assessed by a professional, such as a registered psychologist, to determine the potential diagnosis and needs of the child (Ontario Ministry of Education, 2018). Students may also be assigned a code to track their diagnoses and individual needs (Ontario Ministry of Education, 2018).

Alberta Education (2018) provides a similar framework to support students with special needs and has developed a coding system based on the Diagnostic and Statistical Manual for Mental Disorders – Fifth Edition. The following statistics are the different coding categories used by Alberta Education (2018) and the percentage of special and

exceptional needs students in grades 1 to 12 who had a code during the 2016/2017 school year: severe cognitive disability (0.24%), severe emotional/behavioural disability (10.71%), severe multiple disability (1.58%), severe physical or medical disability (13.1%), deafness (43.41%), blindness (0.21%), mild cognitive disability (6.1%), moderate cognitive disability (0.6%), emotional/behavioural disability (7.16%), learning disability (25.61%), hearing disability (0.62%), visual disability (0.17%), communication disability (9.16%), physical/medical disability (10.01%), multiple disability (4.56%), gifted or talented (7.89%) and more than one special education code (1.12%). As many families are affected by disabilities, it is essential that professionals in the community and within the education system have the knowledge and skills to support individuals with disabilities.

The models and definitions of disability presented in this paper can be seen as competing perspectives, although they are likely to be more useful if used simultaneously to understand perceptions of disabilities. As the term 'disability' has been created and defined by various professionals to understand a specific population, it is the opinion of the author that one must also consider the family's and individual's definition of disability when providing treatment and support services. Although, theorists have made great strides in their conceptualization of disabilities, it is of utmost importance that service providers treat the individual who has the disability, rather than summarizing an individual's experiences by the use of a theoretical model or disability label.

There are various definitions of the term disability and it is important to maintain an open mind when interpreting the research that has been conducted in this field. Although, a bio-psycho-social definition of disabilities may present a more holistic

approach to understanding disabilities, the present study will be using the FSCD definition of disabilities, which relies on the medical model. The FSCD definition will be used for the purpose of the present study because participants who cared for children with disabilities were required to be enrolled in the FSCD Specialized Services program. The research in this paper will demonstrate that families of individuals with disabilities want to be heard, not simply dismissed, diagnosed and stereotyped (Ryan & Quilan, 2017). Thus, the author would recommend asking families and individuals how they would personally define disabilities and acknowledging the individual differences and perspectives throughout the time that support services are provided to them. By providing families with a platform to define and share their personal experiences, support service providers have an opportunity to increase the compassion, empathy and understanding that they can weave into the treatments they provide.

In summary, the purpose of this paper is to provide valuable perspectives and research to shed some light on the experiences of caregivers of children with disabilities. As many Canadian families are affected by childhood disabilities, it is essential that social service providers understand the complex experiences and challenges that these families face in order to develop effective support services for this population.

Caregiver Stress

The literature in this field, although limited, has strongly demonstrated that caregivers of children with disabilities, in comparison to caregivers of typical children, experience an exorbitant amount of stress, which can have detrimental effects on their physical and psychological health (Brehaut et al., 2004; Grant et al., 2013; Jackson, Wegner, & Turnbull, 2010; Lee, Park, Matthews, & Hsieh, 2017; Seltzer, Floyd, Song,

Greenberg, & Hong, 2011). Some of the most common stressors reported by these parents include financial strain (Bobbitt et al., 2016; Heller, Miller & Hsieh, 1999), social isolation (Kimura & Yamazaki, 2013), increased child behavioural problems (Neece, Green, & Baker, 2012), rejection from society (You & McGraw, 2011), and disrupted family cohesion (Mitchell, Szczerepa, & Hauser-Cram, 2016). In addition, high parental stress has also been shown to negatively impact the well-being of the child by increasing child behavioural problems (Neece et al., 2012) and reducing the effectiveness of therapeutic interventions for the child (Osborne, McHugh, Saunders, & Reed, 2008). Thus, it is important to mitigate parental stress for the well-being of the entire family (Mitchell, Szczerepa, & Hauser-Cram, 2016; Neece et al., 2012; Osborne et al., 2008).

Various disability support services have been found to effectively alleviate stress and improve the personal well-being of caregivers, such as providing access to a multidisciplinary team to provide professional support (McConkey, Gent, & Scowcroft, 2013), financial assistance (Heller et al., 1999), cognitive-behavioural therapy (Wong, Ng, Ip, Chung, & Choi, 2018), the parent-to-parent support program (Banach, Iudice, Conway, & Couse, 2010; Mathiesen, Frost, Dent, & Feldkamp, 2012), mindfulness-based stress reduction techniques (Bazzano et al., 2015; Lo, Chan, Szeto, Chan, & Choi, 2017; Rayan & Ahmad, 2017) and various parent training programs which improve the parent-child relationship and provide parenting strategies, such as the Happy Parenting program (Leung, Chan, Lam, Yau, & Tsang, 2016), Stepping Stones Triple P program (Roux, Sofronoff, & Sanders, 2013) and Parents Plus Children's Programme (Hand, Raghallaigh, Cuppage, Coyle, & Sharry, 2013). Thus, disability support organizations may benefit from integrating these programs into their existing services.

Statement of the Problem

Previous research suggests that a family-centered approach, which provides support for the personal needs of the caregivers as well as the child, is the most effective and humanistic approach to helping parents of children with disabilities (Dunst, 2002). Dunst's (2002) seminal and profoundly influential work shaped disability services and family-centred care in Alberta, so while his work is dated, it remains the foundation for existing services in Alberta, where this study was based. Other research supports the assertion that a family-centered approach is the most effective way to support families of children with disabilities by reducing their unmet needs, increasing their quality of life and well-being and improving parental competence to care for a child with specialized needs (Dempsey, Keen, Pennell, O'Reilly, & Neilands, 2009; Litt & McCormick, 2015; King & Chiarello, 2014; Zajicek-farber, Long, Lotrecchiano, Farber, & Rodkey, 2017).

Overall, however, the literature lacks a thorough investigation of the stress, psychological and physical health problems and needs of caregivers of children with disabilities. Furthermore, the existing research focuses on caregivers of children with specific diagnoses, which raises concerns of generalizability. For example, a study on parents of children with learning disabilities will differ in its applicability to parents of children with a rare chromosomal disorder that causes severe functional impairment. Previous research has demonstrated that parents of children with autism experience higher levels of stress in comparison to parents of children with Down syndrome (Cuzzocrea, Murdaca, Costa, Filippello, & Larcan, 2016). These findings may be related to higher levels of stress associated with caring for a child with more challenging behaviours and greater dependence on the parents (Cuzzocrea, Murdaca, Costa,

Filippello, & Larcan, 2016; Neece et al., 2012). Lastly, there is limited research exploring the male caregiving experiences as the literature seems to emphasize a gender-biased definition of caregiving which excludes hegemonic masculine caregiving roles and responsibilities, such as providing financial support for the family (Kramer & Thomson, 2002).

The Present Study

The purpose of the present study was to expand on previous findings and to investigate the psychological and physical health, stress, and needs of caregivers of children with disabilities, who were enrolled in family-centered support programs in Alberta, Canada. The intent of the author was to explore the experiences of both male and female caregivers, who care for children with a wide variety of disabilities. A cross-sectional survey design was used to compare the psychological and physical health and stress levels of caregivers of children with disabilities (CD) with caregivers of typical children (CT) by analyzing the results of four subscales of the survey instrument that was used. The CD group completed an additional subscale to assess what services they were using at the time of the study and what types of support they were interested in acquiring in the future. Participants were recruited through community organizations and Facebook groups that support families with children with or without disabilities in Alberta.

Definitions

The present study operationally defined ‘caregiver’ as a person who is primarily responsible for fulfilling a child’s intrinsic and extrinsic needs, which include providing emotional, psychological, physical and financial support. The term caregiver encompassed a variety of different roles such as biological, adoptive and foster parents,

relatives, legal guardians, and any other person who was predominantly involved in the decision-making and care of the child and was not compensated for their duties. This definition of caregiver was created to be inclusive of both male and female caregiving experiences as many families continue to adhere to the traditional gender roles perpetuated by society (Kramer & Thomson, 2002). For example, Western cultural norms dictate that fathers are expected to assume the role of providing financial support, while mothers are expected to undertake responsibilities associated with addressing the physical, psychological and emotional needs of the child, such as domestic duties and soothing the child in times of distress (Kramer & Thomson, 2002). These stereotypes can lead to men feeling reluctant to engage in conventional feminine caregiving tasks (Kramer & Thomson, 2002). Furthermore, men may also feel neglected when they are excluded from conversations about caregiving, such as in the context of casual socialization, professional consultation or research (Kramer & Thomson, 2002; Laxman et al., 2015). Thus, the current study presented a gender-inclusive definition of caregiving to encourage both men and women to share their experiences and seek support in times of need.

There are a few other salient terms which relate to the hypotheses of the present study which will be discussed to provide clarity and context. The Diagnostic and Statistical Manual – Fifth Edition (DSM-V) provides definitions for depression and anxiety, which have been shaped by the medical model and used for the purpose of this paper. Depression is described as feelings of sadness, irritability, or emptiness, along with physical and mental changes that significantly impair an individual's ability to function in every day life (American Psychiatric Association, 2013). Moreover, the DSM-V defines

anxiety as feelings of excessive fear or intense worry about future outcomes or perceived threats, which may be accompanied by somatic sensations and changes in behaviour or cognitive processing (American Psychiatric Association, 2013).

The term 'stress' has been defined by the American Institute of Stress (2018) as a physical, emotional, and psychological experience in which the perceived demands of a given situation extend beyond the capacities and resources of the individual. The definition of 'physical health' that was used in the present study was shaped by the World Health Organization (2018) which describes physical health as the absence of disease and physical weakness, and the maintenance of functional abilities based on normative data provided by research conducted with individuals of the same population.

Lastly, the author has defined support needs, for the purpose of this paper, as areas of support that a caregiver feels their family needs to fulfill in order to maintain their mental and physical health and overall sense of well-being. Therefore, unmet support needs would be defined as support needs that caregivers perceive that they have, but currently do not access. For example, a caregiver may suggest that they feel overwhelmed, stressed and sleep deprived, which has impacted their health and overall sense of functioning. Thus, they feel that they need respite care in order to have access to mental breaks and opportunities to catch up on sleep throughout the week. If the caregiver is not currently accessing these services, respite care would be an unmet need of the caregivers.

Hypotheses

The following five hypotheses were tested in the present study:

- 1) Caregivers of children with disabilities will have significantly different levels of depression in comparison to caregivers of typical children.
- 2) Caregivers of children with disabilities will have significantly different levels of anxiety in comparison to caregivers of typical children.
- 3) Caregivers of children with disabilities will report a significantly different quantity of physical health concerns in comparison to caregivers of typical children.
- 4) Caregivers of children with disabilities will have significantly different levels of stress in comparison to caregivers of typical children.
- 5) Caregivers of children with disabilities will report that they have at least one unmet support need.

Summary

Overall, chapter one has captured some of the challenges that are faced by caregivers of disabilities as explicated in the extant literature. Furthermore, the purpose of the present study and the research questions have been introduced. This thesis has been organized into chapters to highlight how the present study has been shaped by the extant literature which formed the foundation of caregiver health and disability research. As previously mentioned, chapter one introduces the study. Chapter two comprises the literature review, spanning topics such as the psychological and physical health, stress, unmet needs and support services for caregivers of children with disabilities. Chapter three will describe the method, research design, analysis, instruments, participant characteristics, recruitment strategies, procedure, and ethical considerations of the present

study. Chapter four will provide an overview of the statistical analyses that were used and the findings that they produced. Lastly, chapter five will contain a discussion about the findings of the present study and the implications for future research in the field of disability support services.

Chapter 2: Literature Review

In chapter two, I will introduce previous studies that have contributed to an understanding of the experiences of caregivers of children with disabilities. Some of the challenges associated with the literature include a lack of diversity as many of the studies have been conducted by the same researchers over long periods of time and a limited amount of research produced in the last decade. The literature in this field is both qualitative and quantitative in nature, thus both forms of research will be presented in this paper.

In this chapter, I will describe the previous studies that have been conducted on the psychological and physical health, stress and needs of caregivers of children with disabilities. First, I will describe the mental and physical health of caregivers of children with disabilities (including the effects of gender), followed by the effects of parental stress on the child, cultural similarities and differences, family needs, support programs, FSCD programs in Alberta for children with disabilities, limitations in the literature, and finally, the rationale for the present study. I will delineate and describe a variety of studies that discuss the challenges that caregivers of children with disabilities face, such as decreased physical health and increased health risk behaviours (Lee, Park, Matthews, & Hsieh, 2017), as well as some of the contemporary strategies that have been successfully used to reduce stress and increased mental health among caregivers, such as mindfulness-based programs (Bazzano et al., 2015; Lo, Chan, Szeto, Chan, & Choi, 2017; Rayan & Ahmad, 2017).

Psychological and Physical Health of Caregivers

The literature demonstrates that caregivers of children with disabilities are more likely to suffer from impaired psychological and physical health, in comparison to caregivers in the general population (Brehaut et al., 2004). In one study, Brehaut et al. (2004) sought to compare the psychological and physical health of 468 caregivers of children with cerebral palsy with the general population of caregivers. Participants were recruited through the CanChild Centre for Childhood Disability Research, and data were collected through in-home interviews and questionnaires. Data obtained from caregivers of children with cerebral palsy were then compared with data from two national surveys: the National Population Health Survey (NPHS) and the National Longitudinal Study of Children and Youth (NLSCY). Results obtained using chi-square (χ^2) tests of association for discrete variables and *t*-tests of independent means revealed that the caregivers of children with cerebral palsy, in comparison to caregivers of the general population, experienced decreased income and number of hours spent at work, and increased number of hours caring for their family, more contact with their social support group, and increased levels of distress and chronicity of distress. Furthermore, a higher proportion of individuals in the CanChild group, in comparison to the national survey groups, reported emotional problems (i.e., unhappy or little interest in life), cognitive problems (i.e., difficulty with memory or problem solving), and physical health problems (i.e., non-food allergies, asthma, arthritis/rheumatism, back problems, high blood pressure, migraine headaches, sinusitis, diabetes mellitus, heart disease, cancer, stomach/intestinal ulcers, other chronic conditions, vision problems, hearing problems and physical pain). These researchers postulated that stress may be a mediating factor for caregiver health because

caregivers of children with cerebral palsy were more likely to report certain health conditions that are frequently related to stress, such as ulcers and migraines. As stress reduction techniques have already been demonstrated to increase psychological well-being (Bazzano et al., 2015), future researchers may want to empirically test the effects of stress reduction strategies on the physical health of caregivers of children with disabilities.

Grant et al. (2013) sought to compare the mental health of 46 parents of children diagnosed Mucopolysaccharidosis type III (MPS III; Sanfilippo syndrome) or intellectual disabilities (ID). MPS III was described as a rare disorder which causes progressive psychological and physical degeneration when the child is 1-2 years old (Valstar et al., 2008). By using the Pediatric Inventory for Parents (PIP) and the General Health Questionnaire (GHQ-12), the researchers were able to assess the levels of stress, depression and anxiety experienced by the parents in their study (Grant et al., 2013). Their findings suggest that parents from both groups suffered from high levels of stress, and clinical levels of depression and anxiety (Grant et al., 2013).

Smith and Grzywacz (2014) conducted a longitudinal study to understand the psychological and physical health of parents of children with chronic diseases and disabilities over a 10-year period. The Midlife Development in the United States (MIDUS) survey was administered to 646 parents at two time points. Their findings suggest that parents of children with chronic diseases and disabilities experience reduced psychological health, increased depressive symptomology, and more difficulties in instrumental activities of daily living, in comparison to parents of typical children. Furthermore, depressive symptomology and limitations in instrumental activities of daily

living were significantly more likely to become exacerbated over time among parents of children with chronic diseases and disabilities, in comparison to the control group.

Parents who perceived having control over their situation experienced improved mental and physical health. Thus, the researchers concluded that the key to building resilience among parents of children with chronic diseases and disabilities may lie within therapeutic interventions which target parental perceived control, which has previously been demonstrated in the literature (Bobbitt et al., 2016; Hill & Rose, 2009; Lucyshyn, Miller, Cheremshynski, Lohrmann, & Zumbo, 2018; Song, Mailick, Greenberg, Ryff, & Lachman, 2016).

Seltzer, Floyd, Song, Greenberg, and Hong (2011) explored the effects of aging on the psychological and physical health of 220 parents of individuals with disabilities. Participants of the study were divided into three groups: a control group of parents of individuals without disabilities, parents of individuals with disabilities who lived with their child and parents of individuals with disabilities who did not live with their child. The findings of the longitudinal study demonstrated that the psychological and physical health of parents of individuals with disabilities deteriorated over time, such that elderly participants experienced more health problems and functional impairments than they did at middle age. The psychological and physical health of elderly parents of individuals with disabilities was significantly reduced in comparison the control group. Although, these differences were not significant for midlife participants. These findings suggest that raising a child with disabilities can have long-term effects on the psychological and physical health of parents of children with disabilities regardless of whether their children continue to live with them throughout adulthood. Song, Mailick, Greenberg, Ryff, and

Lachman (2016) have also demonstrated that caregivers of children with disabilities can experience a faster decline in health as they age.

In a study conducted by Song, Mailick, Greenberg, Ryff, and Lachman (2016), 128 parents of children with a variety of disabilities and 512 parents of typically children were analyzed to determine if the experience of raising a child with disabilities could contribute to accelerated cognitive aging. Data were extracted from the National Survey of Midlife in the United States, which included a telephone interview and a self-administered questionnaire. Cognitive functioning was measured by evaluating executive functioning skills and episodic memory abilities. The researchers found that mothers of children with disabilities experienced reduced episodic memory over time, in comparison to mothers of typical children. They postulated that these differences may be attributed to higher levels of stress among caregivers of children with disabilities. Negative parenting experiences were also found to be negatively correlated with episodic memory functioning. Mothers and fathers of children with disabilities were significantly more likely to report negative parenting experiences in comparison to the control group. Mothers of children with disabilities also reported higher rates of depression and reduced health in comparison to mothers of typical children. Social support was significantly positively correlated with executive functioning skills and episodic memory abilities of mothers and fathers. Mothers experienced elevated memory capabilities when they simultaneously experienced a perceived sense of control over their life. Lastly, mothers and fathers who engaged in vigorous physical activity experienced elevated executive functioning skills, in comparison to parents who were less physically active. This study presented important insights about gender differences, as executive functioning skills and

episodic memory abilities were not related to age, group (caring for a typical child or a child with disabilities) or the presence of negative parenting experiences among fathers of children with disabilities. Lastly, this study also highlights the importance of exercise and physical health as involvement in vigorous physical activity was associated with improved executive functioning.

In a study conducted by Lee, Park, Matthews, and Hsieh (2017), caregivers of children with disabilities were compared to a control group of caregivers of typical children on the basis of self-reported chronic health conditions and health risk behaviours. The term 'health risk behaviours' was used to describe behaviours that impaired the individual's health, such as physical inactivity, smoking, excessive drinking, and irregular sleeping habits (i.e., minimal or excessive sleep). The presence of chronic health conditions was measured with a subscale of the National Population Health Survey (NPHS), which was also used in the study conducted by Brehaut et al., 2004. The data from this study was extracted from the 2015 National Health Interview Survey (NHIS), which provided a large sample size of 1,436 caregivers of children with disabilities and 8,599 caregivers in the control group. Their findings indicated that caregivers of children with disabilities were more likely to experience chronic health issues (such as asthma, back pain, chronic bronchitis, heart conditions, migraines, and obesity) and were more likely to engage in health risk behaviours, specifically smoking and irregular sleep, in comparison to the control group. The study conducted by Brehaut et al. (2004) demonstrated similar findings with respect to the higher frequency of self-reported chronic health conditions experienced by caregivers of children with disabilities in comparison to the control group. It would be of interest to know if health risk behaviours

are a precursor to or a consequence of raising a child with disabilities. Thus, future researchers may want to further explore the relationship between raising a child with disabilities and engaging health risk behaviours to develop a better understanding of the challenges that caregivers of children with disabilities face. Moreover, it is imperative that service providers develop an accurate understanding of the experiences of caregivers of children with disabilities to ensure that they can effectively support them to overcome the obstacles that may hinder their well-being and health.

Kapasi and Brown (2017) led a study which described strengths of caregivers of children with fetal alcohol spectrum disorder (FASD) which have contributed to increases in their sense of well-being and ability to function as a parent. Participants comprised of 32 parents of children with FASD, who engaged in telephone interviews. The themes that were extracted from their narratives were analyzed using concept mapping. The findings of this study revealed that parents of children with FASD suggested that it was important to adapt their parenting style and expectations to meet the needs and abilities of the child. The participants of the study also emphasized the importance of maintaining patience and understanding within their family unit, as raising a child with disabilities can be a stressful and overwhelming experience. Parents reported that increasing their knowledge about their child's diagnosis improved their ability to remain patient and understanding in times when their child presented with problematic behaviours. Moreover, these parents described the benefits of securing external social support on both a personal and professional level. Personal support included family members, friends and neighbours, while professional support included support group groups, respite care workers, pediatricians and other specialized professionals who may target parenting support or

caregiver well-being. Overall, this study demonstrated the complexities of raising a child with disabilities and the strength and resilience that many families utilize when raising a child with unique abilities and challenges.

In a study by Mitchell, Szczerepa, and Hauser-Cram (2016), 190 parents and their adolescents with disabilities participated in in-home interviews and assessments, as well as the completion of self-reported questionnaires. The purpose of their study was to analyze family cohesion and its relationship to stress, marital satisfaction, and child behaviours. Their findings suggest that child behavioural problems were negatively correlated with family cohesion, while marital satisfaction was positively correlated with family cohesion. Furthermore, increases in partner stress predicted reduced family cohesion among fathers and mothers. This study emphasizes the importance of understanding the complexities of family relationships and dynamics when supporting caregivers of children with disabilities. It further highlights the necessity of professionals who support caregivers of children with disabilities to understand that an individual's experiences of emotions and stress can affect the emotions and levels of stress of other family members, and vice versa.

Masulani-Mwale, Kauye, Gladstone, and Mathanga (2018) utilized a cross-sectional survey design to study the prevalence of psychological distress among parents of children with intellectual disabilities. In support of previous research (Grant et al., 2013; Pisula & Porebowicz-Dorsmann, 2017), the findings of the study revealed that 41.2% of caregivers of children with disabilities experienced psychological distress. In addition, several factors were found to be significant predictors ($p < .05$) of psychological distress among caregivers of children with intellectual disabilities, including lack of

confidence in raising a child with disabilities, living in an urban versus rural setting, awareness of their child's disability, increased perceived burden of care and an absence of mental health support. These findings are both alarming and pertinent as they describe the high rate of psychological distress among caregivers of children with disabilities, as well as highlight the many factors that contribute to their reduced mental health.

In another study which focused on parental stress, Nadeem, Choudhary, Parveen, and Javaid (2016) investigated parental stress among parents of children with and without disabilities. They recruited 100 parents of children with disabilities and 100 parents of typical children, who served as a control group. A differential research design and convenience sample was used as all parents and children were recruited through local schools. Participants completed the Parental Stress Scale, a self-reported questionnaire, and the results demonstrated significant differences between the two groups. Parents of children with disabilities reported that they experienced significantly more stress ($M = 55, SD = 13.62$) than parents of typical children ($M = 39.09, SD = 8.92, p < .01$). This research supports previous studies conducted by Grant et al. (2013), Pisula and Porebowicz-Dorsmann (2017) and Masulani-Mwale, Kauye, Gladstone, and Mathanga (2018) who also demonstrated that caregivers of children with disabilities experience exorbitant amounts of stress which can have detrimental effects on their health and well-being.

In a study conducted by Hill and Rose (2009), interviews were conducted with 44 mothers of adults with intellectual disabilities to understand the relationship between parental self-esteem, locus of control (perceived control over one's life) and stress. Participants also completed the Parenting Stress Index, the Vineland Adaptive and

Maladaptive Behaviour Scale, the short version of the Parental Locus of Control Scale, the Family Support Scale, and the Parenting Sense of Competence Scale. Regression analyses indicated that 61% of the variance in parenting stress was attributed to parental locus of control and self-esteem. Their findings further revealed that adaptive behaviours among adults with disabilities was negatively associated with parental stress, while challenging behaviours among the adults with disabilities were positively associated with parental stress. Increases in social support were correlated with decreases in parental stress. This finding has been supported by various studies which have demonstrated the benefits of socialization (Kapasi & Brown, 2017; Kimura & Yamazaki, 2013; McConkey, Gent, & Scowcroft, 2013; Song, Mailick, Greenberg, Ryff, & Lachman, 2016; Yamaoka et al., 2015). Furthermore, increased parenting satisfaction was also related to decreased parental stress. These results provide evidence for the salient needs of caregivers of individuals with disabilities to be supported on a personal level, such as improving their self-esteem and locus of control, while simultaneously providing behaviour strategies for parenting the child to enhance adaptive behaviours and reduce parental stress. Research by Minnes, Perry, and Weiss (2015) further supports the findings of this study by demonstrating that parental perceptions can be used to predict distress among parents of children with developmental delays and disabilities.

In a study led by Minnes, Perry, and Weiss (2015), 155 mothers of 113 male and 42 female children with developmental disabilities participated in an online survey to discover potential predictors of caregiver distress. Participants were recruited from three Canadian provinces (Ontario, Quebec and Nova Scotia) through organizations serving individuals with disabilities and various advertisement modalities, such as e-mails,

posters and websites, were used to recruit participants. Their findings revealed that parental perceptions had a significant impact on self-reported levels of distress. Parents reported more benefits of raising a child with disabilities when they felt empowered and were able to reframe their experience in a more positive and optimistic way. Conversely, financial strain and reduced feelings of empowerment were direct predictors of parental distress. These findings draw attention to the importance of increasing feelings of empowerment and positive thinking and reducing stressors, such as financial strain, to enable parents of children with disabilities to cope with the inevitable stress that will arise when raising a child with disabilities. It would be of particular interest to know if fathers perceive their parental role in the same way that mothers do. It would be beneficial for future researchers to investigate the male caregiving experience to determine if strategies that increase feelings of empowerment and teach parents how to reframe experiences would be equally as helpful in reducing stress among males.

In a study designed by Cuzzocrea, Murdaca, Costa, Filippello, and Larcan (2016), 30 parents of children with disabilities and 20 parents of typically developing children completed three questionnaires (the Parent Stress Index, Coping Orientation to Problems Experienced and the Social Support Questionnaire) to determine if stress, coping strategies and perceptions of social support differed between the two groups of participants. The researchers found that parents of children with autism experienced significantly more stress and reported greater child behavioural difficulties than parents of children with Down syndrome and parents of typically developing children. Parents of children with Down syndrome and parents of typically developing children reported that they resolved challenging parenting situations by maintaining a positive attitude, while

parents of children with autism relied on problem solving skills to cope with their child's difficult behaviours. Many families in all groups also revealed that religion remained an important coping strategy for them when they encountered problematic situations. Parents of children with low functioning autism reported significantly lower satisfaction with the social support that they received in comparison to parents of children with high functioning autism, Down syndrome and typically developing children. Furthermore, social support appeared to decrease distress among parents of children with high functioning autism, Down syndrome and typically developing children, but it did not have an affect on the distress levels of parents of children with low functioning autism. These findings suggest that parents of children with disabilities experience parenting differently and may therefore benefit from individualized support services that are tailored to their family's specific needs. For example, certain families, such as parents of children with disabilities who are lower functioning or who have greater behavioural difficulties, may benefit from additional services as some protective factors, such as social support, may be less effective and therefore rendering these parents more vulnerable to distress and diminished health.

A qualitative study by Mofokeng and van der Wath (2017) raised awareness about the challenges that parents experience when raising a child with attention-deficit/hyperactivity disorder (ADHD). Participants were parents of children with ADHD between the ages of 6 and 12 who received psychiatric services at an outpatient clinic. Data consisted of interviews response and researcher observations. Upon analysis, five common themes were used to describe the experiences of parents who cared for children with ADHD. The first theme explored burden of care as parents described their parenting

experience as stressful and demanding in response to their child's behavioural problems. Secondly, participants expressed feelings of frustration, helplessness, sadness, anger, and physical symptoms, such as pain, in response to stress related to parenting and decisions about ADHD medication use. Thirdly, parents reported concerns that their child was stigmatized and socially rejected, which had a negative impact on their ability to benefit from socialization with friends and family. A prominent theme was also concern and frustration related to the education system in which parents were exposed to frustrated teachers and schools who lacked the resources to understand and support students with ADHD. Finally, participants revealed that they struggled to manage their child's behaviour and expressed frustration that punishments did not seem to change their child's behaviours over time.

The narratives arising from the work of Mofokeng and van der Wath (2017) display the sorrow, exhaustion, frustration and hopelessness that parents of children with disabilities may experience when caring for a child with challenging behaviours. They also highlight the burden that many caregivers of children with disabilities must carry when deciding whether their child should be medicated or not. As caring for a child with disabilities, such as ADHD, can have such an incredible emotional toll on the parents, it would be beneficial for professionals to ensure that they are able to provide empathy and possibly counselling when parents feel the need to process the difficulties they are experiencing and the parenting decisions they must make, such as medication and academic decisions for their child.

The effects of gender. Azeem et al. (2013) contributed to the literature by exploring gender differences in Pakistan and found that mothers of children with

intellectual disabilities were more likely than fathers to meet DSM-IV criteria for depression, anxiety or both (89% versus 77%). Among female caregivers, 40% were diagnosed with depression, 35% with anxiety and 13% with both depression and anxiety. Among male caregivers, 31% were diagnosed with depression, 42% with anxiety and 3% with both depression and anxiety. Thus, there was an association between the gender of the participants and their psychiatric diagnosis. Moreover, a diagnosis of depression, anxiety or both among mothers was related to the severity of their child's intellectual disability. These findings demonstrate the high importance of developing support programs for families of children with disabilities, which include strategies and services to identify and address distress, depression and anxiety among parents. In the future, researchers may want to explore the effect that gender can have on the caregiving experience, as there are very few studies that have analyzed this relationship.

Almansour, Alateeq, Alzahrani, Algeffari and Alhomidan (2013) found that 84% of caregivers reported that their quality of life has been greatly impacted by their child's diagnosis of autism spectrum disorder (ASD). In their study, 50 caregivers of children with ASD were compared with a control group of 50 caregivers of typical children in Saudi Arabia. The children in the ASD group were diagnosed using DSM-IV criteria and psychopathology was measured among caregivers with the use of the Arabic version of the Hospital Anxiety and Depression scale (HADS). In the ASD group, 96% of caregivers had one child with autism and 4% of caregivers in the ASD group had 3 children with autism. Their findings demonstrated that significantly more caregivers in the ASD group versus the control group reported a history of visiting a mental health professional (16% versus 4%) and experiencing psychiatric health concerns (22% versus

2%). Moreover, the ASD group experienced significantly higher levels of depression and anxiety in comparison to the control group. Their findings revealed that differences did not exist between male and female caregivers, nor between parents and other types of caregivers, when anxiety and depression scores were assessed. Finally, participants who cared for 3 children with ASD experienced significantly higher levels of depression and anxiety than participants who cared for a single child with ASD. These findings presented by Almansour (2013) have been supported by previous research (Brehaut et al., 2004; Grant et al., 2013; Kimura & Yamazaki, 2013), with the exception of the finding that gender did not have an effect on psychopathology, which contrasts findings presented by Azeem et al. (2013).

Pisula and Porebowicz-Dorsmann (2017) investigated the stress, functioning and quality of life of mothers and fathers who had children with autism spectrum disorder (ASD). The participants consisted of 49 couples who had children with disabilities and 52 couples who had typically developing children, which served as a control group. A self-reported questionnaire was used to collect the data and statistical analyses revealed significant differences between the two groups. Parents of children with disabilities experienced significantly reduced family functioning, in comparison to the control group. Mothers reported similar levels of family functioning in comparison to fathers. The researchers postulated that the differences between the ASD and control groups may have been attributed to the possibility of the ASD group experiencing reduced family cohesion and difficulties expressing feelings to other family members. Couples who had children with ASD also reported higher levels of stress than the control group, with mothers of children with disabilities reporting significantly more stress than fathers (Pisula &

Porebowicz-Dorsmann, 2017). Gender differences did not exist in the control group on the basis of self-reported levels of stress. Lastly, parents of children with ASD reported reduced quality of life in comparison to the control group, in that they experienced reduced psychological and physical health and fewer opportunities to develop social relationships. Mothers and fathers reported that they experienced a similar quality of life. These findings suggest that both mothers and fathers can be negatively affected by the experience of raising a child with disabilities and there is a necessity for support services to extend beyond the basic need of providing for the child and to increase the quality of life and well-being of the family unit.

Laxman et al. (2015) studied the effects of father involvement in child rearing practices on maternal depressive symptoms in families with children with disabilities. The researchers recruited 3,550 children (1,700 females and 1,859 males) and their parents through the National Center for Education Statistics (NCES) in Illinois, United States. The children in the study were diagnosed with a variety of disabilities and were between 9 months and 4 years of age when their parents completed the short-form version of the Center for Epidemiological Studies-Depression Scale during the longitudinal study. Their findings suggest that increases in father literacy (i.e., engaging in reading and language activities) and responsive caregiving involvement (assisting the child in secondary care activities which extend beyond addressing the basic needs of the child, such as soothing the child or attending medical appointments) are related to decreases in depressive symptoms among mothers. Thus, it could be argued that families as a whole benefit when services are tailored to support fathers and increase their involvement in caregiving tasks that are traditionally performed by mothers. This

research has been further supported by Song, Chun, and Choi (2015) who also studied the effects of father involvement on the stress levels of mothers of children with disabilities.

Song, Chun, and Choi (2015) recruited 82 mothers from local therapy centres and evaluated their levels of stress with self-reported questionnaires. On average, mothers reported that father involvement in parenting duties was above average in comparison to previous studies. Father involvement was measured by engagement in the following activities: participation in play, providing guidance, sharing housekeeping duties and interacting with the family. Mothers suggested that they experienced a moderate level of stress, reporting an average score of 52 out of 100 on the Parenting Stress Index/Short Form. Mothers who reported that they cared for a difficult child were more likely to report reduced father involvement. In support of research conducted by Laxman et al. (2015), increases in father involvement in parenting duties was associated with improved mental health among mothers, specifically reduced parenting stress.

Overall, these findings support previous research which suggests that caregivers of children with disabilities are more likely to suffer from mental and physical health problems, in comparison to caregivers of typical children (Jackson et al., 2010). Brehaut et al. (2004) have suggested that researchers and service providers should explore the value of family-centered services, which recognizes the symbiotic relationship between caregivers and their children with disabilities. Presently, the literature lacks an in-depth exploration of the relationship between stress and the physical health of caregivers. Going forward, researchers may want to explore the effects of stress reduction techniques on the physical health of caregivers of children with disabilities. Lastly, the literature lacks a thorough investigation of the male caregiving experience, such that previous research has

utilized a traditional definition of caregiving which may capture a more conventional feminine experience of caregiving, while inadvertently neglecting to acknowledge stereotypical masculine caregiving roles and responsibilities. Research presented by Almansour et al. (2013), Azeem et al. (2013), and Pisula and Porebowicz-Dorsmann (2017) stipulates that both female and male caregivers of children with disabilities are vulnerable to psychopathology and struggle to maintain a life filled with balance, well-being and health. Thus, it is important for service providers to develop an understanding of the unique challenges that mothers and fathers face in order to develop effective support programs to alleviate their discomfort and/or suffering.

The Effects of Parental Stress on the Child

Neece, Green and Baker (2012) contributed to the literature by empirically analyzing the relationship between parental stress and behaviours of children with developmental delays. The term ‘developmental delay’ was used in place of the term ‘intellectual disability’ to acknowledge the possibility that the diagnoses of the participants may evolve over time, such that the children were very young (ages 3 to 9 years). In their study, 237 families completed the Family Impact Questionnaire to measure parental stress levels and the Child Behaviour Checklist to assess child behaviours. Their results demonstrated that child misconduct was both a precursor to and a consequence of parental stress. Moreover, the researchers discovered that a positive correlation existed between parental stress and child behaviours, such that as parental stress increased, child behaviour problems increased as well. This is an important finding because it provides an opportunity for disability support organizations to empower distressed parents by teaching them that they can reduce their child’s behavioural issues

by engaging in self-care practices to reduce their own stress levels and increase their personal well-being.

Osborne, McHugh, Saunders, and Reed (2008) sought to understand the impact of parental stress on child outcome gains by comparing pre- and post-test assessment scores of 65 children with autism spectrum disorder (ASD) who were exposed to therapeutic interventions. Questionnaires were completed by teachers and parents to evaluate the child's progress as both parties were involved in intervention implementation. Their findings suggest that parental stress has a significant negative impact on the child's development of intellectual, educational, behavioural and social skills. Children with ASD whose parents experienced high levels of stress were less likely to make progress, in comparison to children of parents who experienced minimal levels of stress. Furthermore, children of parents in the low stress group made the most progress when they were exposed to interventions for longer periods of time, whereas children of parents with high stress levels made the least progress when they were exposed to long-term interventions. This finding is crucial in highlighting the importance of reducing parental stress because it demonstrates that simply providing parents with therapeutic strategies for the child is insufficient and ineffective if parents are experiencing high levels of stress. If therapists and disability support organizations wish to optimize child development and family well-being, the literature supports the notion that it is necessary to address parental and child needs simultaneously (Neece, Green & Baker, 2012).

Although there exists a limited amount of literature to support the claim that parental stress can have detrimental effects on the well-being of the child, the findings of such studies are consistent (Neece, Green & Baker, 2012; Osborne et al., 2008). Based on

the findings reviewed in this paper, parental stress is associated with reduced parental psychological and physical health (Brehaut et al., 2004), reduced effectiveness of therapeutic interventions for the child (Osborne et al., 2008) and increased child behavioural problems (Neece et al., 2012). Thus, it appears that disability support programs can improve the effectiveness of their therapeutic interventions for the child and increase the well-being of the whole family by targeting and addressing parental distress.

Cultural Similarities and Differences

Previous findings have demonstrated that caregivers in different parts of the world report some similarities and differences in their caregiving experiences (Kimura & Yamazaki, 2013; You & McGraw, 2011). In one study, Kimura and Yamazaki (2013) used an interpretative phenomenological analysis to explore the lived experiences of 10 Japanese mothers of multiple children with intellectual disabilities. When investigating the meaning within their narratives, the researchers found that a common theme was loss of hope for an ordinary life. Six of ten participants expressed that their desire to have a second child stemmed from an intense longing to raise a typical child and to normalize their experience as a parent. For some mothers, this sense of hopelessness evolved into a deep state of depression, distress, shame, fear and social isolation after their second child was also diagnosed with a disability. Furthermore, the participants described motherhood as a mentally and physically exhausting experience due to insufficient social support and psychoeducation, marginalization within society and lack of time to rest. These mothers found strength in maintaining a positive attitude, being grateful for their child's uniqueness, finding purpose in raising a child with disabilities, advocating within the

disability community, securing social support and reconstructing their view of an ordinary life. These findings appear to demonstrate that there are cross-cultural similarities that are shared by caregivers of children with disabilities. Although caregivers express a deep sense of gratitude for their children with disabilities, the findings presented by Kimura and Yamazaki (2013) demonstrate the enormous need for support programs to alleviate the stress associated with their challenging life circumstances.

In a similar study, You and McGraw (2011) explored sociocultural beliefs held by fourteen Korean mothers of children with disabilities. A common theme among the mothers in their study was shame for being blamed by others for causing their child's disability and for questioning their own ability to be a 'good' mother (You & McGraw, 2011). In support of previous findings, these mothers suggested that protective factors contributing to their well-being included retaining a support group of mothers in the disability community and redefining normality within their lives (Kimura & Yamazaki, 2013; You & McGraw, 2011). Conversely, these mothers also experienced feelings that were unique because they were strongly influenced by their Korean culture (You & McGraw, 2011). For example, these women graciously accepted their culturally ascribed role of motherhood, but they struggled to live up to standards of what it is to be a 'good' mother in Korea (You & McGraw, 2011). They believed that their status and reputation were deeply intertwined with the success of their children (You & McGraw, 2011). Thus, they felt discouraged when, despite their best efforts to help their children with disabilities achieve celebrated milestones, their family and community shamed them for their child's inability to achieve a prominent academic and social status (You & McGraw, 2011). Similar to findings described by Kimura and Yamazaki (2013), these parents

described how they resisted the adverse reactions their child was subjected to in society and began embracing their child for the unique qualities that they possessed (You & McGraw, 2011). Despite severe depression and suicidal ideation among some mothers, these women found the strength and motivation to support their children to achieve realistic goals with little to no support from other family members (You & McGraw, 2011). Similar findings were also presented by Kimura and Yamazaki (2013) which demonstrates the incredible strength and perseverance that many of these mothers experienced in the face of adversity (You & McGraw, 2011). The findings by You and McGraw (2011) further highlight the importance of individualized and culturally sensitive services, as caregivers may experience unique challenges that are deeply intertwined with their cultural beliefs, roles and values.

Yamaoka et al. (2015) contributed to the international literature by extracting data from 549 families who completed the 2010 Comprehensive Survey of the Living Conditions in Japan. With use of the Japanese version of the Kessler Psychological Distress Scale (K6) scale, the researchers found that 44.4% of caregivers of children (6 to 17 years old) with disabilities experienced psychological distress and 8.9% of caregivers described a deficient mental state akin to having a serious mental illness. Furthermore, psychological distress was associated with the presence of a mental health symptom, reduced social support and engagement in activities and belonging to the 25th percentile of monthly household expenditures. Thus, it appears that lower socioeconomic status was a risk factor for poor mental health, while living with a three-generation family was a protective factor, perhaps because this familial living situation provided caregiving and emotional support for the parent. Another possibility is that having a lower

socioeconomic status is a consequence of experiencing poor mental health and raising a child with disabilities, such that caregivers may work fewer hours and incur greater expenses, such as private therapy for their child.

John and Roblyer (2017) interviewed 47 urban Indian mothers of children with intellectual disabilities to develop a better understanding of the stress and resilience experienced by caregivers of children with disabilities. The researchers used directed content analysis to code the responses of participants. The interviews revealed that some participants felt devastated, were disappointed and experienced grief in response to their child's diagnosis. In addition, many parents expressed that they lacked confidence and courage during the early years of raising their child with disabilities. Several mothers reported that their strength and resilience developed over time as they became more accustomed to raising a child with disabilities.

Common stressors reported by John and Roblyer's (2017) participants included lacking meaning in their lives, financial strain, marital and family conflicts, exhaustion, limited time to focus on other areas of their life, their child's challenging behaviours and the possibility of their child's lifetime dependence on their parents. Several mothers described various ways in which they coped with their parenting experiences, such as: obtaining education about their child's diagnosis; finding meaning within their religion; becoming an advocate and provider for their child; accessing social, academic and professional support; and, appreciating moments when their child appeared to be happy. This study reveals that, although many similarities exist among caregivers of children with disabilities who live in different countries, there are a few differences that are noteworthy to build strength and resilience among vulnerable parents. For example, this

study has demonstrated the possibility that culture, religion and socioeconomic status may have a profound effect on the way that mothers interpret, react and cope with their experience of raising a child with disabilities. Thus, it can be argued that professionals who support parents of children with disabilities may benefit from understanding the cultural and environmental influences that shape their experiences of raising their child(ren).

The literature demonstrates that there are many similarities and differences in the lived experiences described by caregivers of children with disabilities in various countries across the world (Brehaut et al., 2004; John & Roblyer, 2017; Kimura & Yamazaki, 2013; You & McGraw, 2011). Thus, one could posit that cultural diversity is an important aspect that should be addressed in family-centered support programs for families with children with disabilities.

Family Needs and Support Programs

Although solution-focused research is limited, there are several studies which have reported on the implementation and effectiveness of services for caregivers of children with disabilities (Heller et al., 1999; Lo, Chan, Szeto, Chan, & Choi, 2017; Rayan & Ahmad, 2017; Wong, Ng, Ip, Chung, & Choi, 2018).

Heller, Miller and Hsieh (1999) sought to understand the extent to which financial strain prevented caregivers from utilizing services that were available to them. They found that caregivers of adults with a developmental disability who were offered financial assistance to cover additional services for the family (i.e., transportation, respite care, counselling services, recreational activities, medication, support groups), reported using more services to fulfill their unmet needs, they significantly improved their self-

efficacy (although caregiver burden did not ameliorate), and they were less likely to want to place their relative in a residential care facility, in comparison to a control group.

These findings suggest that socioeconomic status is an important factor to consider when assessing caregiver health, as previous research has demonstrated that caregivers of children with disabilities report that financial strain is a significant stressor in their lives they consider financial assistance to be a salient need (Bobbitt et al., 2016), and they are more likely to satisfy their unmet needs when financial assistance is provided to them (Heller et al., 1999).

Lucyshyn, Miller, Cheremshynski, Lohrmann, and Zumbo (2018) utilized a repeated measure, quasi-experimental group design to evaluate the functioning of families of children with developmental disabilities enrolled in the Positive Behaviour Support (PBS) program. The PBS program was employed to support caregivers to change coercive behaviours into constructive behaviours to improve family functioning and quality of life among participants. Thus, parents and professionals identified two to four family routines that would be targeted, and behaviour plans were developed to support parents in identifying stressors and triggers to problematic behaviours. Moreover, professionals supported parents in implementing proactive strategies to increase the likelihood that their child would successfully participate in the targeted family routines. On average, parents received 78 PBS sessions, which lasted approximately 65 minutes each, and occurred over the course of 113 weeks. The PBS sessions were individualized, and the frequency, content and duration of the sessions were based on participant needs. Ten families participated in the study and completed questionnaires at three time points during the baseline, intervention and post-intervention phases.

Lucyshyn et al. (2018) found that mothers experienced significant increases in quality of life and reductions in levels of stress during the intervention and post-intervention phases. Furthermore, mothers reported increased feelings of being in control of their life during the post-intervention phase. Fathers also experienced improvements with their level of stress during the intervention phase of the study, although they did not experience significant changes in their self-reported quality of life or sense of control. This study draws attention to the intensity of services to which some families of children with disabilities are exposed, which can provoke caregivers to feel gratitude for the support, while simultaneously feeling overwhelmed and stressed by the expectations of parent participation in services. It further highlights the strong level of commitment that caregivers must experience when seeking support for their child with disabilities. Lastly, it suggests that fathers may benefit from individualized services which target potential gender differences to ensure that they can experience as many benefits as mothers when enrolled in support programs such as the PBS program.

Wong, Ng, Ip, Chung and Choi (2018) used a quasi-experimental design to study the effects of CBT on the psychological health and quality of life of Chinese parents of children with attention-deficit/hyperactivity disorder (ADHD). The researchers found that CBT significantly improved the mental health and quality of life of parents of children with disabilities. Furthermore, the findings demonstrated that the effects of the therapeutic interventions on the psychological health and quality of life were mediated by two factors, parenting stress and dysfunctional attitudes. As there is a long-term trend in the literature demonstrating that CBT is a useful intervention to improve problem-solving skills, interpersonal skills, communication skills, stress levels, psychological health and

quality of life of caregivers of children with disabilities (Wong, Ng, Ip, Chung, & Choi, 2018), it is surprising that contemporary research in this area is highly limited and difficult to procure. This study highlights the potential benefits of CBT for caregivers of children with disabilities and further stresses the importance of developing service programs and studies that can evaluate the strengths and limitations of this approach in a modern context (Wong, Ng, Ip, Chung, & Choi, 2018).

Nazer, Riyahi and Moktaree (2016) studied the effects of a stress management course on the psychological health and stress levels of parents of children with intellectual disabilities. Stress levels were assessed using the Harry Stress Inventory (HSI) and mental health was assessed using the General Health Questionnaire (GHQ). Pre-test and post-test scores were obtained from 60 couples who participated in six stress management sessions. These sessions included psychoeducation about mental health, therapeutic strategies and opportunities to learn and practice coping strategies and problem-solving skills. The findings of the study revealed that the stress management program significantly reduced depression symptoms and stress levels among parents of children with disabilities. Although, a couple of limitations of the stress management program were noted by the researchers, such that the positive effects of the intervention did not last long-term as depression and stress scores at a one month follow-up after the intervention were not significantly different from pre-test scores. Moreover, the stress management program did not appear to reduce anxiety among parents of children with disabilities as pre-test and post-test scores for anxiety were not significantly different. Thus, it can be argued parents of children with disabilities may benefit most from support programs that address other needs, such as anxiety, while simultaneously providing stress

management training.

Mathiesen, Frost, Dent, and Feldkamp (2012) studied the effects of a parent-to-parent support program which included 31 parents of children with birth defects. Parent-to-parent support can be defined as a bidirectional supportive relationship between two or more parents experiencing similar life circumstances (Mathiesen, Frost, Dent, & Feldkamp, 2012). Parents who care for children with birth defect often experience high levels of stress related to the possibilities of chronic illness, long term disabilities and premature death of their child. Participants were recruited from the Utah Birth Defect Network (UBDN) and were divided into four focus groups. Each focus group lasted 2 to 2.5 hours and was led by two facilitators who provided discussion questions related to the experiences of raising a child with a birth defect.

Mathiesen, Frost, Dent, and Feldkamp (2012) found that parents felt comforted when they spoke with family members, friends, neighbours or an online community who shared similar experiences of raising a child(ren) with birth defects. Parents further reported that a benefit of an organization-facilitated parent-to-parent support program was that the intention of the group was to meet other parents who were also interested in seeking peer support. Participants expressed that, at times, they had met a family in the community who had a child with a birth defect, but they were unsure how appropriate or interested the other family was to engage in a bidirectional, ongoing supportive relationship with them. Thus, in many cases, their connection with the other family was short lived and remained supportive for a minimal period of time. Parents also expressed that it was difficult to find a parent-to-parent support group in their community that was reliable enough to provide them on-going social and emotional support.

The responses extracted from the qualitative study conducted by Mathiesen, Frost, Dent, and Feldkamp (2012) indicate that communities can fill a gap in their services by implementing a parent-to-parent support program that can provide families with the social and emotional support needed to increase their health and well-being. Parent-to-parent support programs can also reduce caregiver dependence on the health care system, such as is the case when caregivers seek out psychologists for basic emotional and social support when their needs may be better suited for a community support group with other parents. These findings have been replicated several times in the field which supports the notion that parent-to-parent support programs have strong direct benefits for caregivers by offering social and emotional support (Banach, Iudice, Conway, & Couse, 2010; Mathiesen, Frost, Dent, & Feldkamp, 2012) and strong indirect benefits for children who gain from having a parent with reduced stress levels and improved psychological and physical health (Brehaut et al., 2004; Kimura & Yamazaki, 2013).

Bazzano et al. (2015) studied the effects of a mindfulness-based stress reduction (MBSR) program on the self-reported stress of caregivers of children with developmental disabilities. Sixty-six parents and caregivers took part in eight weekly two-hour classes which consisted of mindfulness meditation practices, gentle yoga and facilitated group discussions surrounding stress-related issues experienced by the participants. Two assessments, the Perceived Stress Scale and the Parental Stress Scale, were used to compare the stress levels of the participants before and after they received the MBSR intervention. The MBSR intervention had a significant effect on the stress experienced by participants, such that parents reported a 22% decrease in parental stress and all parents and caregivers experienced a decrease in perceived stress (33%). In addition, post-test

findings revealed that participants experienced significantly more self-compassion, mindfulness and psychological well-being. Furthermore, the MBSR program had residual effects such that participants experienced even higher levels of mindfulness two months after the completion of the program than they did immediately following the MBSR intervention. Participants experienced slightly more stress at the two-month follow-up than they did immediately following the intervention, although they continued to report a significant reduction in perceived stress and parental stress in comparison to their baseline pre-test scores. Mindfulness meditation significantly increased self-reported physical health scores from “good” to “very good” immediately following the MBSR program, although these effects had dissipated two months later. As Bazzano et al. (2015) have suggested, one benefit of mindfulness meditation is that it can be practiced at home with an audio recording once the initial skills are learned, which may address potential transportation issues experienced by caregivers. However, a barrier that caregivers of children with disabilities may face is the ability to secure child care which would enable them to be fully engaged in their mindfulness practices, and thus reap the full benefits that they have to offer. Nonetheless, these findings suggest that mindfulness practices can greatly improve psychological health and moderately improve physical health by significantly reducing stress among caregivers of children with disabilities. Thus, disability support organizations may benefit from integrating these techniques into their existing services.

Lo, Chan, Szeto, Chan, and Choi (2017) also conducted a study which demonstrated the benefits of mindfulness practices for parents of children with disabilities. Their study included 180 parents of children with developmental disabilities

who participated in a mindfulness-based program over six weeks. Participants who completed nine hours of the mindfulness program and ten minutes of daily mindfulness practices at home reported significantly reduced feelings of stress and depression. Parents reported that they experienced improved emotional regulation and had a greater capacity to cope with stress following the mindfulness intervention. These findings have been supported by Bazzano et al. (2015) and Rayan and Ahmad (2017) which suggests that mindfulness-based programs may be useful to improve the well-being and mental health of parents of children with disabilities.

McConkey, Gent, and Scowcroft (2013) further contributed to this literature through a qualitative study which explored the lived experiences of 17 parents of children with disabilities who experienced severe behavioural concerns. Severe behavioural concerns were assessed by the duration, intensity and frequency of challenging behaviours which demonstrated a strong risk of harm to others. The researchers conducted interviews with parents who lived in the United Kingdom to discuss their experiences related to three services that were offered to them: overnight respite care in a residential facility for periods up to seven days at a time; access to a support worker to accompany the child or adolescent with disabilities during community outings; and, in-home consultations with a professional to provide strategies for managing difficult behaviours. Interviews were also conducted with the key workers and professionals, primarily social workers, who were assigned to support the families who participated in the study.

In the study conducted by McConkey, Gent, and Scowcroft (2013), several common themes emerged from the interviews. Parents and professionals stated that the

needs that these families experienced were very complex in nature, thus they required support in many different areas, including financial difficulties, strained relationships, inadequate housing, and various challenges related to the child's delays in functioning. Families also report that services were often complex in nature, such that multiple agencies were often involved which sometimes led to confusion, extensive time commitments to work with a variety of professionals at multiple locations within the community, and stigma or shame related to feeling dependant on a multi-disciplinary team to support them in caring for their child(ren). Moreover, parents reported that services were often limited and inconvenient, such that the children were sometimes provided services in groups and as such, some groups consisted of children with a wide variety of ages, abilities and challenges, which some parents argued may have been a disservice to their child (McConkey, Gent, & Scowcroft, 2013).

Caregivers further argued that some services were not readily available until their family experienced a crisis, thus many parents felt that they would benefit from more proactive services. The interviews revealed that families may benefit from services that target the development of important relationships in their lives, such as their marital relationship, sibling relationships among the children, and the caregivers' relationships to their child(ren), other family members and the professionals who support them. Social support for both the caregivers and children was noted as a salient need for families of children with disabilities (McConkey, Gent, & Scowcroft, 2013).

Lastly, participants in McConkey, Gent, and Scowcroft's (2013) study expressed concerns about the future and suggested that caregivers of children with disabilities would benefit most from services that prepared them for possible future outcomes related

to their child's progress, support services for adults with disabilities, potential challenges related to future developmental stages of the child and support related to feelings of helplessness or fear that their child will experience a lifetime of dependence on their parents. These findings stress the importance of developing support services that address the past (including strained relationships and emotional difficulties that have been shaped by past experiences), the present (such as, current concerns and challenges) and the future (for example, preparing families for possible challenges and potential services that can be accessed throughout puberty and adulthood).

Ryan and Quilan (2017) contributed to the qualitative disability research by exploring parental perspectives of support services and their experiences with professionals who provide academic and therapeutic support to their children. Thematic analysis was used to extract common themes from focus group responses of 24 parents of children with disabilities. Their findings revealed that parents sometimes felt dismissed by professionals and often felt as though they were fighting for their child's right to access services in the community. Parents described experiences of conflict and struggle, in which they fought with professionals who lacked patience and understanding when they expressed their concerns. Some parents reported that advocacy took the form of continuous arguments with service providers, which exacerbated their level of stress.

Furthermore, in Ryan and Quilan's (2017) study, caregivers of children with disabilities expressed concerns that there was a disconnect between their academic and therapeutic supports for their child. They argued that they would have benefitted most from a more collaborative approach with stronger communication between different service providers. Parents further expressed frustration towards the lack of individualized

care and suggested that they sometimes felt that their child was labelled and categorized, rather than treated as an individual with unique strengths, skills, challenges and interests. Moreover, participants stated that they experienced a multitude of unmet needs, they struggled to navigate the support services system and they felt worried about the future of their child. They suggested that access to a key worker, who would be able to educate, support and advocate for their family, would be a viable option to improve the experiences of caregivers of children with disabilities who access support services. This study demonstrated the potential benefits of hosting focus groups to determine potential approaches that can be used to improve the current state of disability support services, to increase ease of navigation in the system and to reduce parental stress.

A study by Roux, Sofronoff and Sanders (2013) found that the group Stepping Stones Triple P program in Australia effectively supported children with disabilities and their families in a multitude of ways. The researchers of the study recommended this program as an effective way to support families of children with disabilities as the positive effects of the program lasted six months after the intervention. The group Stepping Stones Triple P program was described as a parent training program that aims to improve the relationships of caregivers and their children, increase the use of adaptive behaviours among children with disabilities and to teach parents strategies to implement a positive parenting style that can increase parenting satisfaction.

Roux, Sofronoff and Sanders (2013) employed a randomized controlled trial which used a mixed design between groups (participation in the Stepping Stones program ($n = 28$) versus the waitlist control group ($n = 24$) and across three time points (preintervention, postintervention and six month follow-up). Participants consisted of

parents of children with a variety of disabilities between the ages of two and nine years old. Participants who were exposed to the intervention took part in nine training sessions, which included six group sessions of four to six parents that lasted for up to 2.5 hours, as well as three individual phone sessions which lasted up to 30 minutes. Participants completed a questionnaire at each of the three time points to evaluate their child's behaviour, parenting style, interparental conflict related to parenting, depression, anxiety, stress, quality of their relationships, goal attainment, and their satisfaction level in response to the training program they participated in.

The findings of the study provided a favourable evaluation of the Stepping Stones Triple P program as results found that the participants demonstrated significant improvements, in comparison to the control group, in relation to their child's behaviours, in their use of a positive parenting style, and in parenting satisfaction (Roux, Sofronoff & Sander, 2013). Changes in parenting styles employed by participants included calmer, more purposeful reactions to their child's challenging behaviours in comparison to exaggerated reactions that did not improve their child's ability or motivation to modify their behaviour in the future. Participants also reported significant reductions in parental conflict related to parenting, which demonstrated an interpersonal effect of the parent training program. Families also reported very high satisfaction rates with their experience in the training program with an average score of 83.98 out of 91 ($SD = 5.1$). Overall, these results indicate that the Stepping Stones Triple P program successfully targets and supports areas that parents of children with disabilities deem to be important areas of concern.

Leung, Chan, Lam, Yau, and Tsang (2016) studied the effectiveness of a parent

training program entitled the 'Happy Parenting' program which was designed to target similar areas as the Triple P program, such as increasing positive parenting opportunities, enhancing the child-parent relationship and decreasing difficult child behaviours, and to increase feelings of empowerment among parents of pre-school children with developmental disabilities. Parents participated in eight two-hour group sessions which consisted of discussions and lectures. Parents also received homework after each session to encourage participants to engage in role-plays and practice strategies that were suggested by the group facilitator. The researchers employed a randomized controlled trial design and participants were assigned to one of two groups: an intervention group that participated in the Happy Parenting program ($n = 62$) and a control group that did not receive any additional support ($n = 57$). Self-reported questionnaires were used to assess parental stress, parenting styles and child behaviours of participants in both groups during three time periods: preintervention, postintervention and at a three-month follow-up.

Results of the Leung et al. (2016) study were similar to the findings of Roux, Sofronoff and Sanders (2013) who used the Triple P program as the intervention in their study. Significant differences were found between the two groups as participants in the intervention group reported significant improvements postintervention in relation to their child's behaviours, and their stress. Moreover, the invention group experienced significant increases in their use of positive behaviours postintervention when responding to their child's challenges, such as limiting their verbal output and expressing expectations in a simplified manner to enhance their child's understanding. Their findings also indicated that parents who participated in the Happy Parenting program retained the benefits of the parent training program at a three-month follow-up, which demonstrates

the potential long-term benefits of parent training programs, such as the Happy Parenting program (Leung, Chan, Lam, Yau, & Tsang, 2016) and the Triple P program (Roux, Sofronoff, & Sanders, 2013).

Hand, Raghallaigh, Cuppage, Coyle, and Sharry (2013) conducted an evaluation of the Parents Plus Children's Programme (PPCP), which is a program that aims to reduce child behavioural difficulties and increase opportunities for child learning and attachment. The program was designed for parents of children between the ages of 6 and 12 and emphasizes the use of strategies to increase pro-social behaviour and decrease the use of coercive parenting strategies. The PPCP utilizes videos of families modelling the parenting strategies to provide participants with a template that they can learn from. The study consisted of 29 parents of children with mild intellectual disabilities, 16 of which were exposed to the PPCP and 13 of whom served as a control group.

In this study by Hand et al. (2013), self-reported questionnaires revealed that the intervention group, during the postintervention phase of the study, experienced significant reductions in parent stress, difficult child behaviours and improvements in their self-confidence and parenting satisfaction, in comparison to the control group. These findings have been supported by studies who implemented similar programs, such as the Happy Parenting program (Leung, Chan, Lam, Yau, & Tsang, 2016) and the Triple P program (Roux, Sofronoff, & Sanders, 2013). A limitation of this study was that follow-up measures were not conducted to determine potential long-term effects of the treatment.

Bobbitt et al. (2016) explored the experiences of 125 caregivers of children with FASD by analyzing their responses to the Family Caregiver Survey and the Perceived Stress Scale. ANOVA and correlational analyses revealed that most caregivers felt

positive about their caregiving experience in that they felt satisfied with the education they had received pertaining to their child's diagnosis and pleased with their level of control over their child's treatment; however, 89% of caregivers also felt that they lacked sufficient support to care for their child. For example, caregivers expressed a desire for disability support organizations to develop policies which accurately reflect caregiver needs (86%), facilitate network development between familial and professional caregivers (94%), promote education about the effects of mental illness (95%), and provide emotional (92%) and financial support (80%), personalized psychoeducation (92%), and respite care (90%).

Bobbitt et al. (2016) also found that caregivers of individuals with FASD reported experiencing high levels of stress, and commonly expressed concerns surrounding feeling upset (55%), having a lack of control over important aspects of their life (47%), and feeling nervous or stressed. In addition, less than a third of participants felt satisfied and in control of their current situation (26%). The level of concern among caregivers was mediated by the age of the child and the period of time that the child was cared for by the caregiver, such that caregivers who reported the most concerns cared for adolescents (versus children under 12 years of age) for a minimum of 6 years (versus 5 years or less). In addition, biological and adoptive parents expressed a greater number of concerns, in comparison to other caregivers. This research provides important insights into the needs and personal struggles of caregivers of individuals with FASD. Disability support organizations have an opportunity to improve their current services by empowering parents of children with disabilities, developing an understanding of their individualized concerns, and setting them up for success by collapsing their barriers and providing them

with the supports and skills they need to be healthy and effective parents.

The research presented by Bobbitt et al. (2016) suggests that caregivers of children with disabilities have a wide range of internal (i.e., emotional support) and external needs (i.e., respite care, psychoeducation) which may or may not be addressed by their current service providers. The literature suggests that caregivers can experience high levels of stress when these needs are not met, which can negatively impact their psychological and physical health (Kimura & Yamazaki, 2013). Future researchers may want to explore parental views surrounding counselling to develop a better understanding of why counselling services may not be utilized when psychopathology rates are so high among caregivers of children with disabilities (Azeem et al., 2013). The literature has also demonstrated that current support programs for families with children with disabilities appear to be most effective when they target therapeutic goals for the child, while simultaneously addressing the needs of the caregivers for emotional and social support, and stress reduction (Kapasi & Brown, 2017; Kimura & Yamazaki, 2013; Lo, Chan, Szeto, Chan, & Choi, 2017; McConkey, Gent, & Scowcroft, 2013; Rayan & Ahmad, 2017; Ryan & Quilan, 2017; Song, Mailick, Greenberg, Ryff, & Lachman, 2016; Yamaoka et al., 2015).

FSCD Programs in Alberta

Alberta has built a reputation for having some of the most thorough and well-rounded assistance programs for families of children with disabilities within Canada. The Family Support for Children with Disabilities Act (FSCD) was enacted in 2004 with the purpose of improving the services available to children with disabilities, and their families, by employing a family-centered model (Alberta Children's Services, 2004). The

family-centered approach is based on four main principles, such that: 1) caregivers will provide continuous support in the child's life but professional help may not always be available; 2) family members are the centre of knowledge for the child's needs and sense of well-being; 3) the best way to help the child is to help the family as a whole; and, 4) family empowerment is key and should be implemented by respecting the family's decisions, building on their strengths and enhancing their control over the therapeutic services that their child is exposed to (Dunst, 2002).

The aim of FSCD supports is to empower the family (not just the child), enhance the strengths and skills of the family, promote autonomy versus dependency on formal government and community supports, place the family at the centre of therapeutic goal development and implementation, and encourage the family to use their informal social support network to seek assistance and address family needs (Alberta Children's Services, 2004). The program retains similar goals and services as previously mentioned parent training programs, such as the Happy Parenting program (Leung, Chan, Lam, Yau, & Tsang, 2016), Stepping Stones Triple P program (Roux, Sofronoff, & Sanders, 2013) and Parents Plus Children's Programme (Hand, Raghallaigh, Cuppage, Coyle, & Sharry, 2013).

FSCD services have greatly enhanced to the quality of life of many Alberta residents by aiding approximately 10,000 children with disabilities and their families (Alberta Human Services, 2015). Within FSCD, there is an in-home program entitled 'Specialized Services for Children with Severe Disabilities' which intends to provide additional support to families with a child diagnosed with a severe disability (Alberta Children's Services, 2004). A severe disability is defined as "the child's limited ability to

function in activities of normal daily living combined with the need for continual and ongoing supervision and support to ensure their safety and participation in these activities” (Alberta Children’s Services, 2004, p. 272). Specialized Services aims to promote child development by teaching parents specific strategies to improve a variety of skills within the realms of communication, social interaction, behaviour regulation, emotional development, daily living activities, gross and fine motor development and sensory regulation (Alberta Human Services, 2015). A multi-disciplinary team (MDT) is assembled to reflect the needs of the family and may include professionals such as speech-language pathologists, occupational therapists, physical therapists, and/or psychologists (Alberta Human Services, 2015). Other services, such as respite care, may be used in conjunction with Specialized Services if a family meets the eligibility criteria and is able and willing to utilize such services (Alberta Human Services, 2015).

In the present study, the author intended to develop a better understanding of the experiences of caregivers of children with severe disabilities enrolled in family-centered wrap-around services in Alberta, Canada. As Dunst (2002) suggested, the best way to help the child is to help the family. Thus, the purpose of the present study was to expand on previous findings and to investigate the psychological and physical health, stress and needs of caregivers of children with disabilities. Furthermore, disability service providers may benefit from such research as it could illuminate deeper insights about feelings of triumph and despondency that are experienced by caregivers of children with disabilities, which can create an opportunity to improve services for these families.

Limitations in the Literature

The current state of the literature presents several limitations which are important

to consider. There exists a gender bias as many studies utilized an entirely female sample of caregivers, while other studies presented a sample which was predominantly female (Brehaut et al., 2004; Kimura, & Yamazaki, 2013). Thus, the findings presented in this paper may not reflect the caregiving experiences of males; however, Azeem et al. (2013) have demonstrated that both mothers and fathers share some commonalities as they both experience high levels of stress and high rates of psychopathology. In addition, within the disability research field, the focus tends to be on the individual with the disability, rather than the caregivers of that person. This focus is particularly interesting because previous findings have demonstrated that the caregiving experience can prove to be incredibly stressful, which can negatively impact caregiver health (Brehaut et al., 2004; Grant et al., 2013; Jackson et al., 2010), and in turn negatively affect family cohesion (Mitchell, Szczerepa, & Hauser-Cram, 2016) and child well-being (Neece et al., 2012; Osborne et al., 2008;). Furthermore, there is a lack of research exploring the relationship between high levels of stress and increases in physical health problems among caregivers. There are even fewer studies that have empirically tested different methods of improving the physical health of this population. Moreover, many studies focused on specific populations of disabilities, such as individuals with autism or Down syndrome, which further compounds generalizability concerns (Cuzzocrea, Murdaca, Costa, Filippello, & Larcan, 2016).

Many studies in this field are qualitative in nature (Kimura & Yamazaki, 2013; You & McGraw, 2011) which complements the quantitative research by providing context to the results, although it also creates a limitation as these studies utilize small sample sizes and are unable to be generalized to the population of caregivers of children

with disabilities. As previously discussed, research in this field is limited and even fewer studies have analyzed cultural diversity and sensitivity issues, which are important to understand when creating support programs which will serve a variety of cultures, such as Alberta's FSCD program which serves a population with a high immigration rate (Statistics Canada, 2011). Although there exist a few Canadian studies, it appears that no study, at the availability of the author, has studied the experiences of caregivers of children with disabilities in Alberta. This is particularly interesting because Alberta has developed a reputation for having some of the most thorough and well-rounded programs for families with children with disabilities in Canada.

There is a necessity of future research in this field to offer a contemporary lens, replicate and expand on previous findings and provide novel ideas, reliable and valid assessment tools and proactive measures to support caregiver health. In order to address the weaknesses in the literature, future researchers may want to investigate the male experience of caring for a child with disabilities, the relationship between stress and the physical health of caregivers, strategies to support caregiver physical health, parental psychopathology, experiences of parents of children with different types of disabilities, empirical studies which evaluate whether parental needs are being met within the services that are offered to them, and the effects that culture has on the needs and values expressed by families of children with disabilities.

Conclusion

Parents of children with disabilities face a unique set of challenges and stressors which have been shown to impact their psychological and physical health (Brehaut et al., 2004; Grant et al., 2013; Jackson et al., 2010). This paper has presented some of the most

salient concerns expressed by this population to provide insight about factors which may have contributed to their increased levels of stress and their declined psychological and physical health (Brehaut et al., 2004; Lee, Park, Matthews, & Hsieh, 2017; Smith & Grzywacz, 2014). Some of the contributing factors explored in this paper include financial strain (Bobbitt et al., 2016; Heller et al., 1999), social isolation (Kimura & Yamazaki, 2013), increased child behavioural issues (Neece et al., 2012), rejection from society (You & McGraw, 2011), unpredictability of their child's condition, fearing their child's death (Grant et al., 2013), lack of respite care (Bobbitt et al., 2016; Heller et al., 1999), disrupted family cohesion (Mitchell, Szczerepa, & Hauser-Cram, 2016), physical and psychological dependence of their child, and lack of free will for dedicating their life to caring for their child (McConkey, Gent, & Scowcroft, 2013).

Moreover, the literature demonstrates that high parental stress and reduced psychological well-being are associated with increased child behaviour problems (Neece et al., 2012) and reduced effectiveness of therapeutic interventions for the child (Osborne et al., 2008). Thus, the family benefits when caregivers experience psychological well-being and minimal levels of stress (Neece et al., 2012; Osborne et al., 2008). Lastly, this review of the literature examined various types of supports and services which have been found to address caregiver needs and increase personal well-being, such as access to a multi-disciplinary team to provide professional support (McConkey, Gent, & Scowcroft, 2013), financial assistance (Heller et al., 1999), cognitive-behavioural therapy (Wong, Ng, Ip, Chung, & Choi, 2018), parent-to-parent support (Banach, Iudice, Conway, & Couse, 2010; Mathiesen, Frost, Dent, & Feldkamp, 2012), mindfulness (Bazzano et al., 2015; Lo, Chan, Szeto, Chan, & Choi, 2017; Rayan & Ahmad, 2017) and various parent

training programs (Leung, Chan, Lam, Yau, & Tsang, 2016; McConkey, Gent, & Scowcroft, 2013; Roux, Sofronoff & Sanders, 2013). There is a lack of research exploring these barriers and there exists even less empirical research evaluating effective methods of supporting caregivers of children with disabilities.

The Present Study

The purpose of the present study was to expand on previous findings and to investigate the psychological and physical health, stress and needs of caregivers of children with disabilities. The literature recommends that disability support programs utilize a family-centered approach which aims to address the needs of the caregivers, as well as the child (Dunst, 2002). Currently, there is a lack of research that explores the lived experiences of caregivers of children with severe disabilities who are enrolled in wrap-around services in Alberta, Canada. As Alberta's FSCD Specialized Services program was designed using a family-centered model (Alberta Children's Services, 2004), it is of interest to know the psychological and physical health, stress and needs of caregivers of children with disabilities enrolled in the program.

To the knowledge of the author, the present study was the first of its kind to explore the mental and physical health, stress and needs of caregivers of children with disabilities enrolled in a family-centered wraparound services program in Alberta, Canada. To provide context, wraparound services can be described as a diverse support network that is created for a family or individual, consisting of natural supports, such as family members, and a variety of professional supports which may be used to provide therapeutic, legal, case management and/or vocational services (Wallace, Quetsch, Robinson, McCoy, & McNeil, 2018).

Chapter 3: Methods

In this chapter, the author will discuss the components of the present study such as participant characteristics, recruitment strategies, ethical considerations, survey instruments that were employed, and procedures that were used. This study employed a cross-sectional survey design as two pre-existing groups were compared: caregivers of children with disabilities (CD) and caregivers of typical children (CT). The independent variables in the current study were caregiving for a child(ren) with or without disabilities, and the dependant variables were stress and psychological and physical health. Five digitized psychometric instruments were used: the Center for Epidemiological Studies-Depression Scale (CES-D) to measure caregiver depression symptoms, the State-Trait Anxiety Inventory–Form Y (STAI; Spielberger, 1989) to measure caregiver state and trait anxiety, the Perceived Stress Scale-10 (PSS-10; Cohen, Kamarck, & Mermelstein, 1983) to measure caregiver stress levels, and an expanded version of the Family Support Index (Heller & Factor, 1993) to determine how many unmet needs caregivers of children with disabilities have and how many support services they are using (Heller et al., 1999).

Recruitment

The present study operationally defined caregiver as a person who is primarily responsible for fulfilling a child's intrinsic and extrinsic needs which include providing emotional, psychological, physical and financial support. The term *caregiver* was used to encompass a variety of different roles such as biological, adoptive and foster parents, relatives, legal guardians and any other person who is predominantly involved in the decision-making and care of the child and is not compensated for their duties. The literature has demonstrated that caregivers, in which in the extant literature to date has

included relatives, biological, adoptive, and foster parents, share similar experiences to one another when raising a child with disabilities. Thus, these stressors appear to impact the caregivers' physical and psychological health in similar ways (Brehaut et al., 2004). The intent of studying caregivers versus parents solely was to increase the probability of achieving a larger sample size by using a broader definition to describe the target population. Given the similar experiences of different types of caregivers (including non-parent caregivers), combining these would enhance the sample size while also giving voice to non-parent caregivers.

Using a sample size calculator, and based on population estimates (Raosoft, 2004), a sample size of 340 caregivers of children with disabilities was sought, representing approximately 11% of families enrolled in the Specialized Services program, and a control group of the same size ($\alpha = .05$, $\beta = .15$). The author contacted organizations throughout Alberta that serve families in cities and rural areas, with the intent of obtaining a sample of caregivers and children that was both culturally diverse and gender balanced, although this proved to be challenging. As Alberta has a high immigration rate (Statistics Canada, 2011), it may have been possible to achieve a multicultural sample, although language barriers may have discouraged some caregivers from participating in the study. Achieving a gender balanced sample of caregivers also proved to be very challenging, which has been reflected in the literature as previous research has primarily utilized a predominantly female sample. A possible explanation for this gender bias is that many families have identified the mother to be the primary caregiver of the child (Brehaut et al., 2004). Even though the present study used a more gender-neutral definition of caregiving, which included working for pay to provide

financial support, it appears that male caregivers may have been less interested in completing the survey or less likely to relate to the content of the survey, in comparison to female caregivers.

Consistent with previous research, the author recruited caregivers between the ages of 18 to 65 (Azeem et al., 2013; Grant et al., 2013). An age cut-off of 65 was used in an attempt to minimize the effect that age can have on the psychological and physical health of elderly participants (Dobrzyn-Matusiak, Marcisz, Bąk, Kulik, & Marcisz, 2014). The study was limited to caregivers of children between the ages of 3 and 12 to maintain consistency with the extant literature (Neece et al., 2016). Lastly, the present study achieved a sample of caregivers of both typical children (control group) and those with a variety of disabilities to contribute to the diversity of diagnoses in the literature and to increase the generalizability of the results. As the Family Support for Children with Disabilities (FSCD) program requires families to provide proof of their child's diagnosis of disability before enrolling in the program, the disability diagnoses of the children would likely have been ascertained by pediatricians, psychiatrists and registered psychologists prior to the commencement of the study (Alberta Children's Services, 2004).

Caregivers of children with disabilities (CD) were recruited through Pacekids, a non-profit organization in Calgary, Alberta which provides Specialized Services contracts through FSCD. The author abided by the consent and ethical guidelines set forth by the University of Lethbridge and Pacekids. Pacekids volunteered to contact clients who were eligible to participate in the study, and to support the recruitment process by way of e-mail, social media and advertisements that were distributed at the organization's two

locations (see Appendix K).

To increase participation rates of caregivers of children with and without disabilities, the author contacted 172 organizations and Facebook groups by phone, e-mail, in-person and on social media that serve Alberta families and of these, nine organizations and groups offered to advertise the study to their clients and group members. These organizations included: Family Centre (in Lethbridge), Key Connections Consulting (in Lethbridge), Children's Allied Health Services (in Lethbridge), Picture Butte Parent Link Centre, Coaldale Parent Link Centre, Taber Parent Link Centre, Parenting Power (in Calgary), Alberta Parents of Children with Special Needs, and Canadian Parents for French Alberta. Various strategies were used by these organizations to recruit participants such as handing out flyers (Appendix L), discussing the purpose of the study in-person (in the clients' homes or at the organizations), e-mailing eligible participants (Appendix M), and advertising the study on Facebook and Twitter (Appendix M).

Furthermore, a gratuitous Facebook advertisement valued at \$50.00 was used to advertise the study to eligible participants on social media by targeting social media users within the appropriate age range (18 to 65 years old) who have previously liked, shared or joined groups associated with families, parenting, and caring for children with and without disabilities in Alberta. The author attempted to advertise the study to as many eligible participants as possible to increase the likelihood of obtaining a sample which reflected cultural diversity, gender equality and the experiences of caregivers of children with a variety of disabilities.

An incentive was also added to the study to increase participation rates.

Participants were offered the opportunity to enter into a draw for one of four \$50.00 Amazon gift cards, where the odds of winning the draw were 1 chance in 25 (assuming a sample size of 100). Not all participants received the invitation to the incentive, as the entry form appeared at the end of the survey to motivate participants to complete the survey in its entirety. Personal information was collected in a separate secure website linked from the data collection tool if participants chose to participate in the lottery (Appendix N). As data collected from the online draw and survey were kept completely separate from one another, confidentiality was maintained by ensuring that personal information could not be connected to the survey data. To satisfy federal legal requirements with respect to lotteries, receipt of the prize had to be dependent, to some extent, on skill. Therefore, the online survey asked participants to answer a skill-testing question ($1 + (2 \times 10) = \underline{\quad} ?$). Thus, only participants who correctly answered the skill-testing question were eligible to participate in the draw. On the survey, at the launching point at the end, the last page of the survey stated: “Thank you for participating in this survey. This is the end of the survey. Please click the “Next” button below to submit your responses. You will then be automatically re-directed to another site at which, if you like, you can enter your name and contact information into the draw to win one of four \$50 Amazon gift cards. The draw entry form is entirely separate from the survey, and your name and contact information will be used only for the lottery, and will then be destroyed.”

Despite rigorous recruitment efforts, several barriers prevented the author from obtaining a target sample size of 340 participants. While positive feedback was received from several organizations and participants about the purpose of the study, many

organizations were reluctant to participate in the study for reasons that are unknown. Potential barriers that may have discouraged organizations or Facebook groups from advertising the study may include a lack of time or interest, or perhaps an unwillingness to advertise external material to clients or group members of an organization. Paper and online surveys were prepared, although only one participant chose to complete a paper survey. The data from the paper survey was entered manually into the online research tool, thus, all data was collected and stored online.

Ethics

Ethics approval was granted by the Office of Research Ethics at the University of Lethbridge (Protocol Number 2018-001). All steps in the recruitment process of participants, design of the study and implementation of the procedures were shaped to meet the standards of the ethical guidelines set forth by the University of Lethbridge (including the Faculty of Education) and the Canadian Tri-Council Research policy statement entitled 'Ethical Conduct for Research Involving Humans.' Ethical certification was maintained throughout the duration of the study. Furthermore, the confidentiality of all participants was maintained throughout the study, as questionnaires did not require the names of participants, rather, a numerical code was used to label the raw data from a single paper survey. A list was kept linking the participant's name to the numerical code. This list was kept separate and secure from the signed consent form and completed survey for enhanced protection of confidentiality. In addition, identifying information of the participants was not released to Specialized Services providers and participants were assured that participation in the study would not affect the services that their family received.

In order to obtain informed consent, all caregivers who completed a digital survey clicked a button in the online survey tool which stated that they understood the risks and benefits associated with their participation and they agreed to participate in the study. The participant who completed a paper survey wrote their name, signed and dated the consent document to provide consent for their participation in the study. These documents were locked in a cabinet in Dr. Em Pijl's locked office and will be stored for up to five years. All data from this study and copies of the consent forms will be destroyed within five years of concluding the study.

The consent document included the purpose of the study, basic background information on the researchers, and information pertaining to the use of the data, such that total frequencies may be released to the public if the research is published in the future, and raw data may be kept at the University of Lethbridge for up to 5 years. The consent document also stated that participants were acknowledging that they understood that the results of the study could reach policy makers and service providers. Thus, their participation had the potential to influence future program development and policy reform. The consent forms also assured participants that their participation in the study was completely voluntary and that they reserved the right to drop out of the study at any time without causing any negative repercussions to themselves or the researchers. The participant who completed a paper survey was notified that they could request that their data be destroyed before they returned the documents, if they chose to withdraw from the study. Conversely, participants who completed online surveys were notified that it would not be possible to remove the data submitted up to the point of withdrawal because the survey did not contain personal identifying information that could be used to identify

their specific responses. If participants did not complete the survey, their data was included in the study at the discretion of the author and the supervisor. In addition, the consent document provided the contact information of the researchers involved in the study in the event that participants had follow-up questions or concerns.

Counselling services, such as community-based programs and a distress hotline, were provided on the consent form to ensure that participants had access to emotional support if the experience of taking part in the study provoked any feelings of distress or discomfort. Informed consent was especially important because caregivers of children with disabilities can be considered a vulnerable population since previous research has demonstrated that they often experience high levels of distress and psychopathology (Azeem et al., 2013; Brehaut et al., 2004).

Lastly, there was a note within the consent form that this study solely reflected the interests of the researchers and was not representative the opinions of FSCD, Pacekids or the various organizations which provide Specialized Services to the community. All participants were e-mailed or handed a paper copy of their consent form, which included the pertinent information. All information received from participants was stored on a USB key that was locked in an office at the University of Lethbridge to safe guard all confidential information.

SPSS Statistics® v. 24 software was used to analyze the data on a password-protected computer. Raw data were organized in Excel® and SPSS and were kept on a password protected or encrypted USB key that was either stored in a locked cabinet in Dr. Pijl's locked office, or in the hands of the author and/or the supervisor.

Furthermore, it is the ethical duty of a researcher to reveal any preconceived

biases and potential conflicts of interest, and to address these concerns in an ethical manner. As such, it should be noted that the author has worked within multiple Specialized Services therapy teams for two years prior to developing the design for the current study. Thus, the author feels a strong desire to advocate for caregivers of children with disabilities. This potential area of bias was addressed by discussing these concerns with the supervisor of the study and collaborating with the research committee to ensure that the results were interpreted in the most objective way possible.

Survey Instruments

This study utilized several existing, validated quantitative health tools: the Center for Epidemiological Studies – Depression Scale (CES-D; Radloff, 1977), the State-Trait Anxiety Inventory – Form Y (STAI; Spielberger, 1989), the National Population Health Survey (NPHS; Statistics Canada, 2012), the Perceived Stress Scale-10 (PSS-10; Cohen, Kamarck, & Mermelstein, 1983), and an expanded version of the Family Support Index (Heller & Factor, 1993). These tools were predominantly chosen because they were affordable and have, for the most part, been used with the population of interest. The author received permission to use four scales free of charge and secured funding through Dr. Em Pijl to cover the costs of the remaining scale (Appendices A, B, C, D and E). These instruments will be described below.

A demographic section and the instruments were entered into Qualtrics Research Suite®, an online research survey tool. These data were stored in Canada and the platform was password protected and encrypted. The online survey was created, reviewed by the thesis committee, and then pilot-tested by a small test sample from the projected sample. Modifications were made to ensure complete understanding, as well as ease of

navigation and robustness of the platform, by projected respondents. The revised online survey was then re-tested. The majority of the questions on the survey provided categories or response options, rather than an open text box for participants to manually enter their responses. The purpose of structuring the survey in this manner was to increase response rates (through decreasing the amount of time required) and to improve the consistency of the data, since a distinct set of variables was being assessed and measured. It is of interest to note that Qualtrics Research Suite® automatically saved the data from partially completed surveys, even if the window on the computer screen had been closed. Thus, partial data was used at the discretion of the researchers involved in the study.

Eligibility. The first set of questions in the survey determined if participants met the eligibility requirements to participate in the study. Specifically, these questions asked participants to report whether they: were between the ages of 18 and 65; lived in Alberta, Canada; had at least one child between the ages of 3 and 12 years old living in the home; and, had at least one child between the ages of 3 and 12 years old with a disability who was enrolled in Specialized Services at time of the study. If survey responses indicated that the participant did not meet the eligibility requirements for the study, Qualtrics Research Suite® automatically terminated the survey and thanked the participant for their time and participation. Any data collected to the point of survey termination for participants, who were not eligible to participate in the study, were then destroyed and excluded from analysis.

Demographics. The second set of questions gathered demographic information. In this section, participants were asked to specify their: age; gender (male, female, trans*

or other); income (\$0-\$29,999, \$30,000-\$59,999, \$60,000-\$89,999, \$90,000-\$119,999, \$120,000 or more); highest level of education attained (some high-school but did not graduate, high school diploma, some college courses but did not graduate, completed college diploma or certificate, some university courses but did not graduate, completed university degree, some graduate studies but did not graduate, completed graduate studies); and ethnicity (Caucasian, African Canadian, Indigenous (First Nations, Metis, Inuit), Latino/Latina, Asian, or other). All questions had the optional response “prefer not to say.”

The next section asked participants about their daily activities. Participants were asked to report: the number of hours per week that they work for pay (1-10 hours, 11-20 hours, 21-30 hours, 31-40 hours, more than 40 hours, or not currently working for pay); the number of hours per day that they spend caring for their child(ren) (1-5 hours, 6-10 hours, 11-15 hours, 16-20 hours, or more than 20 hours); the number of hours per week that they are in school (1-10 hours, 11-20 hours, 31-40 hours, more than 40 hours, or not currently a student); and, the frequency of opportunities they have to socialize with relatives or friends (daily, weekly, several times per month, once per month, once per year, more than one year has passed since last socialization, or never).

The final demographic set of questions pertained to the children in their care. Specifically, these questions asked participants to specify: the total number of children living in the home; the number of children with a disability between the ages of 3 and 12 living in the home; the number of children with a disability who receive Specialized Services; the diagnosis of the child/children (text response); their caregiver status (single or living with another caregiver); their relationship as a caregiver to the child/children

(biological parent, adoptive parent, step-parent, other family member, foster parent or other); the total number of therapy hours per month for the child/children (if receiving therapy); and, total number of therapy hours per month for the caregiver(s) (if receiving therapy).

Psychological health. In the present study, psychological health among caregivers was evaluated using the Center for Epidemiological Studies-Depression Scale to measure depression (Radloff, 1977) and the State-Trait Anxiety Inventory © – Form Y (STAI) to measure anxiety (Spielberger, 1989).

The Center for Epidemiological Studies-Depression Scale (CES-D) is a 20-item self-reported measure to detect depression symptoms in the general population (Radloff, 1977). The CES-D was selected for the present study because it is a free, widely used scale that is comparable to the Beck Depression Inventory (Fountoulakis et al., 2007; Shafer, 2006) and incorporates items from various validated depression scales found in the literature (Beck, Ward, Mendelson, Mock, & Erbaugh, 1961; Radloff, 1977; Raskin, Schulterbrandt, Reatig, & McKeon, 1969; Zung, 1965). Furthermore, the CES-D has demonstrated good scale reliability ($\alpha = 0.90$; Milette, Hudson, Baron, & Thombs, 2010), internal consistency reliability ($\alpha = 0.88$) and convergent validity (Thombs, Hudson, Schieir, Taillefer, & Baron, 2008). The CES-D has previously been used to assess the mental health of caregivers of children with disabilities (Laxman et al., 2015). The scoring procedures for the CES-D include reverse coding responses to questions 4, 8, 12 and 16 and calculating a total sum of the responses (Radloff, 1977). Scores can range from 0 to 60, where a cut-off score of 16 is used to detect clinical depression (Radloff, 1977). Higher scores above the cut-off indicate increases in the severity of depression

symptoms (Radloff, 1977). A copy of the CES-D can be found in Appendix F.

The State-Trait Anxiety Inventory (STAI) is a 40-item self reported measure for general anxiety which takes approximately 10 minutes to complete (Julian, 2011). The STAI consists of 20 questions on form Y1 to measure state anxiety and 20 questions on form Y2 to measure trait anxiety (Spielberger, 1989). State anxiety is defined as an individual's reaction at a given moment in time, thus it is short-term and context-based (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 2015). Conversely, trait anxiety is defined as an individual's general way of reacting to a situation, such that this type of reaction is more consistent on a long-term basis (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 2015). State and trait anxiety scores are obtained by reverse coding items 1, 2, 5, 8, 10, 11, 15, 16, 19 and 20 in form Y1 and items 21, 23, 26, 27, 30, 33, 34, 36 and 39 in form Y2 and then summing all the scores on each form to obtain two scores for state and trait anxiety, respectively (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 2015). Scores can range from 20 to 80 and are then compared to reference scores based on age and gender (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 2015). The STAI has been used with many different cultures and has been translated into 48 languages (Julian, 2011). This questionnaire has good to very good test-retest reliability, ranging from 0.69 to 0.89 (Spielberger, 1989) and its internal consistency reliability ranges from 0.86 to 0.95 (Spielberger, Gorsuch, Lushene, Vagg, & Jacobs, 1983). The STAI demonstrates good construct and concurrent validity, which have been measured by evaluating the ability of the scale to discriminate between depression and anxiety, and comparing the sensitivity and specificity of the STAI to the General Health Questionnaire, the Symptom Checklist-90 anxiety scales and the Hospital Anxiety and Depression Scale (Julian, 2011);

Spielberger, 1989). In addition, the STAI has been used in previous studies to evaluate caregiver anxiety (Elliott, Shewchuk, & Richards, 2001; Shewchuk, Richards, & Elliott, 1998). A portion of the STAI can be found in Appendix G, with respect to copyright agreements.

Physical health. The physical health of caregivers was assessed by administering a portion of National Population Health Survey (NPHS) which was administered by Statistics Canada in 1996 and 1997 (Statistics Canada, 2012). The NPHS is a cross-sectional and longitudinal survey that was administered to a sample of Canadians every two years from 1994 to 2011 (Statistics Canada, 2012). The present study utilized a section of the NPHS that lists 17 chronic physical health conditions (Statistics Canada, 1996). Participants were asked to answer “yes” or “no” to each of the chronic health conditions to indicate whether they have an active diagnosis of that condition and if their symptoms have persisted for a minimum of 6 months (Statistics Canada, 1996). Statistics Canada (2012) suggests that the complete version of the NPHS is a valid and reliable measure of health status trends in Canada as rigorous sampling and testing procedures were executed during the development of the survey. It is important to note that the reliability and validity of the NPHS may have been affected as the present study limited its use to a subsection of the survey. The purpose of using the NPHS in the present study was to compare current findings with those presented by Brehaut et al. (2004) who found that caregivers of children with disabilities reported more chronic physical health conditions than caregivers of typical children when using the NPHS. A copy of the portion of the NPHS utilized in the present study can be found in Appendix H.

Four additional questions were added to the survey to seek information that was

related to, but not directly addressed by the existing instruments. The first two questions asked if participants had been diagnosed with a mood or anxiety disorder. These questions were included to determine if the presence of depression or anxiety symptomology was related to the presence of a mood or anxiety disorder respectively. The last two questions asked if participants had been diagnosed with fibromyalgia or chronic fatigue syndrome as both physical health conditions have previously been associated with stress (Beshai, Mishra, Mishra, & Carleton, 2017; de Oliveira et al., 2018; Drummond, & Willox, 2013; Fischer, Doerr, Strahler, Mewes, Thieme, & Nater, 2016; Kempke, Luyten, Mayes, Van Houdenhove, & Claes, 2016).

Stress. Caregiver stress was measured using the Perceived Stress Scale-10 (PSS-10) (Cohen, Kamarck, & Mermelstein, 1983). The PSS-10 consists of 10 questions and uses a 5-point Likert scale (Cohen, Kamarck, & Mermelstein, 1983). The PSS-10 is scored by reverse coding items 4, 5, 7, and 8, and summing the scores of all the items (Cohen, Kamarck, & Mermelstein, 1983). This final score is then compared to a reference group based on age, gender and/or ethnicity (Cohen, Kamarck, & Mermelstein, 1983). A review of the literature revealed that the PSS-10 demonstrated an internal consistency reliability of 0.7 and a test-retest reliability score of 0.7 (Lee, 2012). Previous findings have shown that the PSS-10 holds moderate construct and criterion validity, as the results of the PSS-10 were highly predictive of depression and anxiety diagnoses, which is expected because distress is often a symptom of these two disorders (Lee, 2012). This scale was also selected because it has previously been used to evaluate the perceived stress of caregivers of children with disabilities (Bazzano et al., 2015). A copy of the PSS-10 can be found in Appendix I.

Caregiver needs. The present study used an expanded version of the Family Support Index (Heller & Factor, 1993) to determine how many unmet needs caregivers of children with disabilities have and how many support services they are using (Heller et al., 1999). In the present study, this questionnaire was not completed by caregivers of typical children. The Family Support Index is a 29-item questionnaire which requires “yes” or “no” responses to determine which services have been used by the family, and which services are of interest to the caregivers but are not presently utilized by them (Heller et al., 1999). This questionnaire was selected because it has previously been used by Heller et al. (1999) to evaluate the needs of caregivers of children with disabilities. Therefore, the present study can contribute to the literature by evaluating whether the current research will support or contrast previous findings. Although the expanded version of the Family Support Index was created in 1999, it was selected because it is comprised of a list of services that are still relevant today and it most accurately measures caregiver needs of interest to the author in comparison to other pre-existing surveys. Moreover, the design of the Family Support Index was based on a review of other measures and disability support programs described in the literature. Lastly, the Family Support Index was chosen for the present study because it has previously been administered to caregivers of individuals with disabilities. One item from the Family Support Index was excluded from the present study as it was related to vocational training for the individual with disabilities, which was irrelevant as the present study focused on the experiences of children with disabilities, rather than adults. A copy of the Family Support Index can be found in Appendix J.

Procedure

Data collection. Once participants were recruited, the author e-mailed all participants a link to an online survey which included the CES-D, the STAI- Form Y, a portion of National Population Health Survey, the PSS-10, the expanded version of the Family Support Index (CD group only), and 23 additional questions related to demographics, eligibility criteria and variables that previous researchers have suggested may be related to caregiver stress and health.

The author invited participating organizations to support caregivers in completing the surveys in their home or at the organizations by caring for their children during the completion of the survey. The author perceived this to be an important concern to ensure that caregivers completing the survey were able to maintain focus and experience minimal levels of stress during the study. Participating organizations reported that some participants completed the survey with the support of an in-home aide, respite care worker, and/or clinician. At the end of the survey, caregivers were able to submit their responses electronically and a debriefing document was e-mailed to them. One participant completed a paper survey as they did not have access to an electronic device. The participant signed a consent form (Appendix O) and completed the lottery form, which was deposited into a blank envelope that the author then sealed and initialled. The completed survey was then deposited in another blank envelope that was also sealed and initialled to maintain the confidentiality of the data.

Once the online survey was closed, 139 surveys were recorded in Qualtrics Research Suite®. Data were downloaded into Statistical Package for the Social Sciences (SPSS)® v. 24 for analysis. The responses from the paper survey were transcribed into

SPSS. Upon cleaning the data, 90 surveys were identified as containing sufficient data to include in the analysis process. The data from 49 surveys was destroyed because these surveys did not contain any completed scales which were selected to measure stress, and psychological and physical health. Thus, the sample for the present study included 90 participants, consisting of 45 caregivers of children with disabilities and 45 caregivers of typical children. SPSS software was used to calculate descriptive statistics, *t*-tests, one-way ANOVAs, and one-way ANCOVAs to compare the means of independent samples, and chi-square tests of association for discrete variables, according to the distribution and type of data.

Summary

In summary, the author discussed the components of the present study in chapter three, such as participant characteristics, recruitment strategies, ethical considerations, survey instruments that were employed, and procedures that were used. This study employed a cross-sectional survey design as two pre-existing groups were compared: caregivers of children with disabilities (CD) and caregivers of typical children (CT). The following five survey instruments were administered to participants in the present study: the Center for Epidemiological Studies – Depression Scale (CES-D) to measure caregiver depression symptoms, the State-Trait Anxiety Inventory – Form Y (STAI; Spielberger, 1989) to measure caregiver state and trait anxiety, the Perceived Stress Scale-10 (PSS-10; Cohen, Kamarck, & Mermelstein, 1983) to measure caregiver stress levels, and an expanded version of the Family Support Index (Heller & Factor, 1993) to determine how many unmet needs caregivers of children with disabilities have and how many support services they are using (Heller et al., 1999). Participants were caregivers of children with

and without disabilities between the ages of 18 to 65 who cared for a child(ren) between the ages of 3 and 12. The present study consisted of two comparison groups: caregivers of children with disabilities enrolled in the Specialized Services program for children with severe disabilities and a control group consisting of caregivers typical children. Data was collected and stored in Qualtrics Research Suite® and downloaded into Statistical Package for the Social Sciences (SPSS)® v. 24 for analysis. Ethical approval was granted by the Office of Research Ethics at the University of Lethbridge and the procedures were shaped to meet the standards of the ethical guidelines set forth by the University of Lethbridge (including the Faculty of Education) and the Canadian Tri-Council Research policy statement entitled “Ethical Conduct for Research Involving Humans.”

Chapter 4: Results

The purpose of the present study was to expand on previous findings and to investigate the psychological and physical health, stress, and needs of caregivers of children with disabilities. In this chapter the author will describe the findings of the study, including an analysis of the demographic details of participants and the results of the four instruments, analyzed and compared by group (parents of typical children and parents of children with disabilities). The author will then proceed to address the research question and additional relationships that were identified within the data. Depending on the nature of the data and the purpose of analysis, the author utilized descriptive statistics, *t*-tests, one-way ANOVAs, and one-way ANCOVAs to compare the means of independent samples, and chi-square tests of association for discrete variables. The following five hypotheses were tested in the present study:

- 1) Caregivers of children with disabilities will have significantly different levels of depression in comparison to caregivers of typical children.
- 2) Caregivers of children with disabilities will have significantly different levels of anxiety in comparison to caregivers of typical children.
- 3) Caregivers of children with disabilities will report a significantly different quantity of physical health concerns in comparison to caregivers of typical children.
- 4) Caregivers of children with disabilities will have significantly different levels of stress in comparison to caregivers of typical children.
- 5) Caregivers of children with disabilities will report that they have at least one unmet support need.

Demographic Information

In the present study, 139 participants began the survey, and a total of 90 participants completed the survey. There were 45 participants in CD parent group and 45 in the CT group. The sample included caregivers of children with disabilities and caregivers of typical children who were predominately Caucasian females (84.4%) with an approximate average age of 36 (range 19 to 55), although male participants and different ethnicities were also represented in the sample. The average household income was approximately \$90,000 (range \$0-\$29,999 to > \$210,000) and on average, participants had taken some university courses but had not graduated (ranging from *did not graduate high school* to *completed graduate studies*). These descriptive statistics are presented in Table 1.

Two equivalent groups were created to compare the CD group ($n = 45$) with the CT group ($n = 45$). A t -test was conducted to determine whether the average age of caregivers of children with disabilities ($M = 37.89$; $SD = 6.15$) was significantly different from the average age caregivers of typical children ($M = 35.76$; $SD = 6.17$). The t statistic was not significant, $t(88) = -1.64$, $p = .104$ (2-tailed, equal variance assumed), indicating that the CD and CT groups were similar in age.

The distribution of ethnicity (Caucasian, African Canadian, Indigenous, Asian, other or prefer not to say) as a function of caring for a child with or without disabilities is displayed in Table 1. A chi-square test was conducted to evaluate whether the CD and CT groups differed by ethnicity. A significant chi-square statistic was obtained, $\chi^2(5, N = 90) = 12.85$, $p = 0.025$, suggesting that there were differences in the two groups on the basis of ethnicity. There was a similar percentage of Caucasian participants in the CD (80%)

and CT groups (84.4%). The CD group consisted of a greater percentage of participants who identified as African Canadian (6.7%), Indigenous (4.4%), or another ethnicity (6.7%). Conversely, the CT group consisted of more participants who identified as Asian (8.9%) than the CD group (2.2%). The CT group did not have any participants who identified as African Canadian, Indigenous or another ethnicity, although 6.7% of participants reported that they would prefer not to disclose their ethnicity, thus their ethnicity is unknown. Although, there was a significant chi-square suggesting significant differences based on ethnicity between the CD and CT groups, follow-up z -tests of column proportions with a Bonferroni correction indicated there were no statistically significant differences between the groups for any of the ethnicity categories individually. It should be noted that significant differences in the ethnicity distribution of the CD and CT groups may have been found if the sample size had been increased.

The distribution of gender as a function of caring for a child with or without disabilities is displayed in Table 1. A chi-square test was conducted to evaluate whether the CD and CT groups differed by gender. A significant chi-square statistic was obtained, $\chi^2(1, N = 90) = 4.94, p = 0.026$ as the CD group consisted of more male participants ($n = 7$) than the CT group ($n = 1$). Conversely, the CT group consisted of more female participants ($n = 44$) than the CD group ($n = 38$). None of the participants selected the *trans** or *prefer not to say* options within the survey.

A t -test was conducted to determine whether the average annual household income of the CD group ($M = 3.36; SD = 2$) was significantly different than the CT group ($M = 3.87; SD = 2.46$). As annual household income was grouped into 9 categories, a mean between 3 and 4 suggests that the average annual household income for both

groups was between \$60,000 and \$119,999. The t statistic was non-significant, $t(88) = 1.08$, $p = 0.283$ (2-tailed, equal variance assumed), indicating that the CD and CT groups were similar on the basis of average annual household income. It is of interest to note that significant differences in income between the CT and CD groups may have been found if a larger sample size was obtained and if the survey collected scale versus categorical data, such as specific annual household incomes. Categorical response options were provided on the survey to increase the probability of obtaining complete and meaningful responses as income can be perceived as a sensitive question for participants to answer. A summary of the distribution for each income category can be found in Table 1.

A t test was conducted to determine whether the education level of participants in the CD group ($M = 4.36$; $SD = 1.97$) was significantly different than the CT group ($M = 5.61$; $SD = 1.91$). As level of education was grouped into 9 categories, a mean between 4 and 5 suggests that the average rank education level of the CD group was between *completed college diploma or certificate and some university courses, but did not graduate*. Conversely, the average rank education level of the CT group was between *some university courses, but did not graduate and completed a university degree*, which represents an overall higher education level for the CT group in comparison to the CD group. There were 44 cases in the CT group and 45 cases in the CD group that were included for analysis. The t statistic was significant, $t(87) = 3.06$, $p = .003$ (2-tailed, equal variance assumed), indicating that the CT and CD groups were significantly different on the basis of their education level. A follow-up z -test of column proportions with a Bonferroni correction was conducted to determine if the proportions of participants in each specific education category were significantly different between the

two groups ($p < .05$). The z -test demonstrated that significantly more participants in the CT group reported having a completed graduate degree in comparison to the CD group. A summary of these findings can be found in Table 1 below.

Table 1. Demographic Information

Demographic Information	CT group ($n = 45$) (%)	CD group ($n = 45$) (%)
Ethnicity		
Caucasian	84.4	80.0
African Canadian	0.0	6.7
Indigenous	0.0	4.4
Asian	8.9	2.2
Other	0.0	6.7
Gender		
Female	$n = 44^*$	$n = 38$
Male	$n = 1$	$n = 7^*$
Average annual household income		
Prefer not to say	11.1	4.4
\$0-29,999	4.4	4.4
\$30,000 - \$59,999	13.3	26.7
\$60,000 - \$89,999	17.8	33.3
\$90,000 - \$119,999	24.4	13.3
\$120,000 - \$149,999	11.1	8.9
\$150,000 - \$179,999	8.9	2.2
\$180,000 - \$209,999	4.4	4.4
\$210,000 or more	4.4	2.2
Education level		
Some high school, but did not graduate	2.3	11.1
High school diploma	4.5	8.9
Some college courses, but did not graduate	6.8	6.7
Completed college diploma or certificate	18.2	33.3
Some university courses, but did not graduate	4.5	4.4
Completed university degree	36.4*	24.4
Some graduate studies, but did not graduate	2.3	4.4
Completed graduate studies	25.0*	6.7

Note. * $p < .05$

Daily Activities

A *t*-test was conducted to determine whether the number of hours the CD group spent caring for their child(ren) on a daily basis ($M = 2.93$; $SD = 1.32$) was significantly different from the number of caregiving hours reported by the CT group ($M = 2.78$; $SD = 1.54$). As caregiving hours were grouped into 5 categories (ranging from one hour to 21 or more hours), a mean between 2 and 3 indicates that the average caregiving hours for both groups was between 6 to 15 hours per day. The *t* statistic was non-significant, $t(88) = -0.52$, $p = 0.608$ (2-tailed, equal variance assumed), indicating that the CD and CT groups were similar in the average number of hours spent caring for their child per day. A summary of proportions for each category of caregiving hours can be found in Table 2.

Two *t*-tests were conducted to determine whether the CD group, in comparison to the CT group, had a significantly different proportion of participants who were working for pay and if differences existed between the groups based on the average number of hours worked per week. Both *t* statistics were found to be non-significant, indicating that the CD and CT groups did not differ significantly based on the proportions of employed participants, $t(88) = 0.86$, $p = 0.39$ (2-tailed, equal variance assumed), nor average number of hours worked per week, $t(54) = -0.2$, $p = 0.845$ (2-tailed, equal variance assumed). A summary of these findings can be found in Table 2.

A chi-square test was conducted to evaluate whether the CD group, in comparison to the CT group, had a significantly different proportion of participants who were enrolled as students. A significant chi-square statistic was obtained, $\chi^2(1, N = 90) = 6.05$, $p = .014$, as the CD group had significantly more caregivers who were students (17.8%) than the CT group (2.2%). Comparisons between the two groups based on the average

number of hours that participants spent in school (ranging from one hour to 41 or more hours) were not conducted as the sample size of students in each group was too low to conduct meaningful analyses and abide by limits of confidentiality. These findings are illustrated in Table 2.

A *t*-test was conducted to determine whether the average frequency of opportunities to socialize with friends or family (ranging from daily to never) was significantly different in the CD group ($M = 3.93$; $SD = 1.64$) than in the CT group ($M = 2.42$; $SD = 1.03$). As frequency of socialization was grouped into 7 categories, a mean between 3 and 4 indicates that the average frequency of socialization for the CD group was between *several times per month* and *once per month*. In contrast, a mean between 2 and 3 indicates that the average frequency of socialization for the CT group was between *weekly* and *several times per month*. The *t* statistic was significant, $t(74.09) = -5.22$, $p < .01$ (2-tailed, unequal variance assumed), indicating that the average frequency of socialization was higher among participants in the CT group than in the CD group. As demonstrated in Table 2, a *z*-test of column proportions with a Bonferroni correction revealed that participants in the CT group reported significantly more opportunities for socialization on a weekly basis ($p < .05$). Conversely, the CD group was significantly more likely to report that their frequency of socialization with friends or family occurred on an annual basis.

Table 2. Caregivers Engaging in the Daily Activities

Daily activities	CT group (n = 45) (%)	CD group (n = 45) (%)
Caregiving hours per day		
1- 5 hours	26.7	17.8
6- 10 hours	26.7	22.2
11- 15 hours	11.1	22.2
16- 20 hours	13.3	24.4
21 or more hours	22.2	13.3
Working for pay		
Yes	66.7*	57.8
No	33.3	42.2*
Hours per week working for pay		
1- 10 hours	10.0	7.7
11- 20 hours	10.0	19.2
21- 30 hours	20.0	7.7
31- 40 hours	50.0	50.0
41 or more hours	10.0	15.4
Student		
Yes	2.2	17.8*
No	97.8*	82.2
Socialization		
Daily	17.8*	0.0
Weekly	42.2*	22.2
Several times per month	22.2	26.7
Once per month	15.6	17.8
Once per year	2.2	13.3*
More than one year has passed since last socialization	0.0	8.9*
Never	0.0	11.1*

Note. * $p < .05$

Caregiving

Caregivers of typical children who participated in the present study reported that they cared for up to 4 children in the home, who were between the ages of 3 and 12 years old. In comparison, caregivers of children with disabilities reported caring for up to 4 typical children and 3 children with disabilities in the home between the ages of 3 and 12

years old. As demonstrated in Table 3, both the CT and CD groups consisted of the same proportion of participants who identified as single (11.1%) and cohabitating with another caregiver (88.9%).

Participants in the CD group reported that they cared for children with a wide variety of disabilities and many children had comorbid conditions. As the present study utilized a small sample, the various diagnoses were grouped into two broader categories of mental and physical disorders. In the present study, caregivers of children with disabilities reported that their children with disabilities had been diagnosed with 107 conditions in total, in which 96.26% were primarily psychological disorders and 15.89% were primarily physical disorders. These broader categories were used to describe the sample, but analyses could not be conducted to determine the effects of the child's diagnosis on the mental and physical health, stress and needs of the caregivers as the sample size was low and the categorization of disabilities was subjective. This is only one way to conceptualize the diagnoses and the author has recognized the significant limitations of using these categories. For example, some diagnoses were counted in both categories because they have the potential to cause severe physical and psychological impairments. Therefore, a list of diagnoses per family has been provided in Appendix P.

A chi-square test was conducted to evaluate whether caregivers of children with disabilities and caregivers of typical children had a different relationship to their child. A non-significant chi-square statistic was obtained, $\chi^2(4, N = 90) = 5.3, p = .258$, indicating that the CD and CT groups were similar on the basis of the caregiver's relationship to the child. As can be seen in Table 3, the CD and CT groups primarily consisted of biological parents (86.7% and 97.8% respectively).

Table 3. Caregivers' Relationships

Caregiving Information	CT group (<i>n</i> = 45) (%)	CD group (<i>n</i> = 45) (%)
Caregiver status		
Single	11.1	11.1
Cohabiting with another caregiver	88.9	88.9
Relationship of caregiver to child		
Biological parent	97.8	86.7
Adoptive parent	0.0	6.7
Step-parent	0.0	2.2
Other family member	2.2	2.2
Foster parent	0.0	2.2

All children with disabilities were enrolled in the Specialized Services program funded by FSCD, although only 88.9% of participants reported the number of therapy hours per month that their children received. A text box was used to collect responses to this survey item, but 13.3% of participants did not answer the question in a meaningful way that could be analysed. The findings illustrated that 15.6% typical children were also receiving therapy. As expected, children with disabilities received more therapy per month ($M = 18.48$, $SD = 21.42$) than children without disabilities ($M = 4.36$, $SD = 6.24$). It should be noted that an extreme outlier in the CD group was removed from the analysis to ensure that the average number of therapy hours that was reported was a more accurate reflection of the sample as a whole. Moreover, participants were asked to report the total number of therapy hours that their children received, thus the average number of therapy hours per child is unknown. The survey question was structured in this way to maintain simplicity and anonymity of the responses, although this limited the author's ability to conduct more precise analyses. Further analyses were not deemed necessary as this was beyond the scope of the present study.

The final two questions in this section asked participants to report if the caregivers in the home received therapy and to report the number of therapy hours per month that they received. The findings demonstrated that 15.6% of caregivers of children with disabilities and 2.2% of caregivers of typical children received therapy. Analyses were not conducted to determine the average number of therapy hours per month that caregivers received as the sample size was limited. Participant responses were difficult to interpret as this question relied on manually recorded responses, rather than response choices.

Centre for Epidemiological Studies – Depression Scale (CES-D)

A *t*-test was conducted to determine whether depression scores in the CD group ($M = 26.67$; $SD = 14.75$, range 4 to 54) were significantly different than the CT group ($M = 11.64$; $SD = 9.47$, range 0 to 34). There were 43 cases in the CD group and 42 cases in the CT group that were available for analysis. The *t* statistic was significant, $t(71.83) = -5.6$, $p < .01$ (2-tailed, unequal variance assumed), indicating that caregivers of children with disabilities had significantly higher depression scores than caregivers of typical children. Thus, hypothesis 1, which stated that caregivers of children with disabilities will have significantly different levels of depression in comparison to caregivers of typical children, was supported. Average CES-D scores for the CT group were below the suggested cut-off of 16, indicating that, collectively, caregivers of typical children did not tend to meet criteria for clinical depression. Conversely, average CES-D scores for the CD group were well above the suggested cut-off of 16, suggesting that caregivers of children with disabilities not only tended to meet criteria for clinical depression, but may have also experienced a greater severity of depression.

A one-way analysis of variance (ANOVA) was conducted to evaluate the relationship between the number of children with disabilities that participants cared for and the severity of depression symptomology among caregivers. The independent variable, number of children with a disability, had three levels: typical children only, one child with a disability and two or three children with a disability. The dependent variable was average CES-D scores to determine the presence and severity of depression symptoms among participants. The means and standard deviations for each group are shown in Table 4. The ANOVA was significant, $F(2, 18.78) = 12.33, p < .01$, indicating that depression scores were significantly different based on whether participants cared for a typical child(ren), one child with disabilities, or two to three children with disabilities. Follow-up pairwise comparisons were conducted to evaluate pairwise differences among the means. As variances among the three groups were unequal, the Games-Howell test was used for post-hoc comparisons.

As demonstrated in Table 5, significant differences in depression scores were found between caregivers of typical children ($M = 11.64, SD = 9.47$) and caregivers of one child ($M = 25.51, SD = 14.35, p < .001$) and two to three children with disabilities ($M = 31.75, SD = 16.39, p = .024$). Mean depression scores of caregivers appeared to increase concomitantly as the number of children with disabilities living in the home increased, i.e., the greater the number of disabled children in the home, the greater the caregiver's depression scores. However, there was not a statistically significant difference in depression scores between caregivers who had one child with disabilities versus two to three children with disabilities.

Table 4. Caregivers' Depression Scores

Children in home	<i>n</i>	<i>M</i>	<i>SD</i>
Typical children	42	31.64	9.47
1 child with disabilities	35	45.51	14.35
2 or 3 children with disabilities	8	51.75	16.39

Note. Depression was measured using the Center for Epidemiological Studies – Depression Scale (CES-D; Radloff, 1977).

Table 5. Mean Difference of Caregivers' Depression Scores

Children in home	Children in home	<i>M</i>	<i>SE</i>
Typical children (<i>n</i> = 42)	1 child with disabilities (<i>n</i> = 35)	-13.87*	2.83
	2 or 3 children with disabilities (<i>n</i> = 8)	-20.11*	4.77
1 child with disabilities	Typical children	13.87*	2.83
	2 or 3 children with disabilities	-6.24	4.85

Note. Depression was measured using the Center for Epidemiological Studies – Depression Scale (CES-D; Radloff, 1977). * $p < .01$.

State-Trait Anxiety Inventory (STAI)

Two *t*-tests were conducted to determine whether state and trait anxiety symptoms were significantly different among caregivers of children with disabilities in comparison to caregivers of typical children. The *t* statistic for state anxiety was significant, $t(78.93) = -6.23$, $p < .01$ (2-tailed, unequal variances assumed), indicating that the CD group had significantly higher levels of state anxiety ($M = 51.82$, $SD = 12.13$, range 29 to 74), in comparison to the CT group ($M = 37.73$, $SD = 8.92$, range 23 to 57). There were 45 cases in the CT group and 44 cases in the CD group that were included for analysis.

Moreover, the *t* statistic for trait anxiety was significant, $t(85) = -5.24$, $p < .01$ (2-tailed, equal variances assumed), indicating that the CD group had significantly higher levels of trait anxiety ($M = 52.8$, $SD = 13.96$, range 26 to 76), compared to the CT group

($M = 38.86$, $SD = 10.56$, range 20 to 62). Thus, hypothesis 2, which stated that caregivers of children with disabilities will have significantly different levels of anxiety in comparison to caregivers of typical children, was supported.

Normative (reference) data provided by Spielberger, Gorsuch, Lushene, Vagg, and Jacobs (2015) was used to compare the average state and trait anxiety scores of the CD and CT groups to a sample which represented the population of female working adults between the ages of 19 and 39. This reference group was selected for comparison as it most closely matched the sample of the present study. A one-sample t test was conducted to determine whether the average state anxiety scores of the CT group ($M = 37.73$, $SD = 8.92$) differed significantly from the reference group ($M = 36.17$, $SD = 10.96$). The t statistic was not significant, $t(44) = 1.18$, $p = .246$ (2-tailed), indicating that state anxiety scores of the CT group were similar to the reference sample. A one-sample t test was conducted to determine whether the average state anxiety scores of the CD group ($M = 51.82$, $SD = 12.13$) differed significantly from the reference group ($M = 36.17$, $SD = 10.96$). The t statistic was significant, $t(43) = 8.56$, $p < .01$ (2-tailed), indicating that the CD group had significantly higher state anxiety scores than the reference sample.

A one-sample t test was conducted to determine whether the average trait anxiety scores of the CT group ($M = 38.86$, $SD = 10.56$) differed significantly from the reference group ($M = 36.15$, $SD = 9.53$). The t statistic was non-significant, $t(42) = 1.68$, $p = .10$ (2-tailed), indicating that the CT group had similar trait anxiety scores to the reference sample. A one-sample t test was conducted to determine whether the average trait anxiety scores of the CD group ($M = 52.8$, $SD = 13.96$) differed significantly from the reference group ($M = 36.15$, $SD = 9.53$). The t statistic was significant, $t(43) = 7.91$, $p < .01$ (2-

tailed), indicating that the CD group had significantly higher trait anxiety scores than the reference sample.

Physical Health

Chi-square tests were conducted to evaluate whether physical health was significantly different among caregivers of typical children and caregivers of children with disabilities. There were 42 cases in the CT group and 43 cases in the CD group that were available for analysis. The findings suggest that caregivers of children with disabilities experienced overall reduced physical health in comparison to caregivers of typical children. There was an elevated proportion of participants in the CD group, in comparison the CT group, who experienced each of the 17 physical health conditions. As illustrated in Table 6, chi-square analyses revealed that caregivers of children with disabilities, in comparison to caregivers of typical children, were significantly more likely to experience 10 of the 17 physical health conditions, including asthma (32.6% versus 11.9%), arthritis or rheumatism (39.5% versus 11.9%), back problems excluding arthritis (46.5% versus 21.4%), high blood pressure (32.6% versus 4.8%), sinusitis (20.9% versus 4.8%), diabetes (11.6% versus 0%), epilepsy (14% versus 0%), heart disease (14% versus 0%), stomach or intestinal ulcers (25.6% versus 4.8%), and a bowel disorder (27.9% versus 2.4%). Thus, hypothesis 3, which stated that caregivers of children with disabilities will have a significantly different quantity of physical health concerns in comparison to caregivers of typical children, was supported.

Table 6. Caregivers Reporting a Physical Health Condition

Physical Health Conditions	CT group (<i>n</i> = 42) (%)	CD group (<i>n</i> = 43) (%)	Chi-square tests
Food allergies	21.4	31.8	χ^2 (1, <i>N</i> = 86) = 1.18, <i>p</i> = .277
Any other allergies	38.1	53.5	χ^2 (1, <i>N</i> = 85) = 2.03, <i>p</i> = .154
Asthma	11.9	32.6*	χ^2 (1, <i>N</i> = 85) = 5.22, <i>p</i> = .022
Arthritis or rheumatism	11.9	39.5*	χ^2 (1, <i>N</i> = 85) = 8.46, <i>p</i> = .004
Back problems, excluding arthritis	21.4	46.5*	χ^2 (1, <i>N</i> = 85) = 5.95, <i>p</i> = .015
High blood pressure	4.8	32.6*	χ^2 (1, <i>N</i> = 85) = 10.74, <i>p</i> = .001
Migraine headaches	33.3	53.3	χ^2 (1, <i>N</i> = 85) = 3.51, <i>p</i> = .061
Chronic bronchitis or emphysema	2.4	7.0	χ^2 (1, <i>N</i> = 85) = 1, <i>p</i> = .317
Sinusitis	4.8	20.9*	χ^2 (1, <i>N</i> = 85) = 4.93, <i>p</i> = .026
Diabetes	0.0	11.6*	χ^2 (1, <i>N</i> = 86) = 5.19, <i>p</i> = .023
Epilepsy	0.0	14.0*	χ^2 (1, <i>N</i> = 85) = 6.31, <i>p</i> = .012
Heart disease	0.0	14.0*	χ^2 (1, <i>N</i> = 85) = 6.31, <i>p</i> = .012
Cancer	2.4	11.6	χ^2 (1, <i>N</i> = 85) = 2.77, <i>p</i> = .096
Stomach or intestinal ulcers	4.8	25.6*	χ^2 (1, <i>N</i> = 85) = 7.11, <i>p</i> = .008
Effects of a stroke	0.0	7.0	χ^2 (1, <i>N</i> = 85) = 3.04, <i>p</i> = .081
Urinary incontinence	4.8	9.3	χ^2 (1, <i>N</i> = 85) = .668, <i>p</i> = .414
A bowel disorder	2.4	27.9*	χ^2 (1, <i>N</i> = 85) = 10.69, <i>p</i> = .001

Note. Scale items were extracted from the National Population Health Survey (NPHS; Statistics Canada, 2012). * *p* < .05.

Additional Mental and Physical Health Questions

There were 42 cases in the CT group 44 cases in the CD group that were available for analysis. Three chi-square tests were conducted to evaluate whether a significantly different proportion of caregivers of children with and without disabilities would report having a diagnosis of a mood or anxiety disorder, or fibromyalgia. Only 2.35% of participants in both the CD (*n* = 43) and CT groups (*n* = 42) reported having a diagnosis of chronic fatigue syndrome. A significant chi-square statistic was obtained for the presence of a mood disorder, χ^2 (1, *N* = 86) = 5.78, *p* = .016, as the CD group was significantly more likely to report that they have been diagnosed with a mood disorder

(22.7%), in comparison to the CT group (4.8%). Moreover, a non-significant chi-square statistic was obtained for the presence of an anxiety disorder, $\chi^2(1, N = 86) = 3.2, p = .074$. The proportion of participants with an anxiety disorder was elevated in the CD group (27.3%), in comparison to the CT group (11.9%), but the difference was not statistically significant ($p = .074$). Finally, a non-significant chi-square statistic was obtained for the presence of fibromyalgia, $\chi^2(1, N = 86) = 2.67, p = .102$, although the proportion of participants with a diagnosis of fibromyalgia was elevated in the CD group (11.4%), in comparison to the CT group (2.4%), but the difference was not statistically significant. A summary of these findings can be found in Table 7 below.

Table 7. Caregivers Reporting a Mental Health and/or Physical Health Diagnosis

Diagnosis	CT group (n = 42) (%)	CD group (n = 44) (%)
Mood disorder	4.8	22.7*
Anxiety disorder	11.9	27.3
Fibromyalgia	2.4	11.4
Chronic fatigue syndrome	2.4	2.3

Note. * $p < .05$.

Perceived Stress Scale (PSS)

A *t*-test was conducted to determine whether the stress levels of caregivers of children with disabilities ($M = 23.34; SD = 9.28$, range 2 to 39) were significantly different in comparison to caregivers of typical children ($M = 15.33; SD = 7.52$, range 3 to 31). The *t* statistic was significant, $t(84) = -4.38, p < .01$ (2-tailed), indicating that caregivers of children with disabilities experienced significantly higher levels of stress in comparison to caregivers of typical children. There were 44 cases in the CD group and 42

cases in the CT group that were available for analysis. Thus, hypothesis 4, which stated that caregivers of children with disabilities will have significantly different levels of stress in comparison to caregivers of typical children, was supported.

The author compared participants' results with the reference group data from Cohen, Kamarck, and Mermelstein (1983) for female participants, as the majority of participants in the presented study were female. A *t*-test was conducted to determine whether the stress levels of caregivers of typical children ($M = 15.33$; $SD = 7.52$) were significantly different than the reference sample ($M = 13.7$, $SD = 6.6$). The *t* statistic was non-significant, $t(41) = 1.41$, $p = .167$ (2-tailed), indicating that caregivers of typical children experienced similar levels of stress in comparison to the reference sample. A *t*-test was conducted to determine whether the stress levels of caregivers of children with disabilities ($M = 23.34$; $SD = 9.28$) were significantly different than the reference sample ($M = 13.7$, $SD = 6.6$). The *t* statistic was significant, $t(43) = 6.89$, $p < .01$ (2-tailed), indicating that caregivers of children with disabilities experienced significantly greater levels of stress than the reference sample.

Family Support Index (FSI)

The FSI was only completed by caregivers of children with disabilities to contribute to an understanding of the types of services that caregivers use and feel that they need, but do not currently have access to. The proportion of caregivers of children with disabilities with unmet supports needs was calculated by subtracting the proportion of the CD group that reported *using* a specific service from the proportion of the CD group that felt that they *needed* the service. There were 41 cases that were available for analysis. As demonstrated in Table 8, a proportion of the CD group had unmet needs for

Table 8. Support Services Used or Needed by Caregivers

FSI Items	Need (n = 41) (%)	Use (n = 41) (%)	Unmet Needs (n = 41) (%)
In-home respite care	75.6	36.6	39.0
In-home nursing or other specialized care	14.6	4.9	9.7
Home services	70.7	9.8	60.8
Physical therapy	68.3	31.7	36.6
Occupational therapy	85.4	56.1	29.3
Speech therapy	70.7	61.0	9.7
Psychological services or behaviour therapy	82.9	73.2	9.7
Information or training for activities of daily living	70.7	39.0	31.7
Social or recreational activities	87.8	26.8	61.0
Educational or academic support	100.0	70.7	29.3
Counselling or psychotherapy for child(ren)	58.5	17.1	41.4
Counselling or psychotherapy for other family members	65.9	9.8	56.1
Support meeting with other families	70.7	12.2	58.5
Psychiatrist visit for medication	36.6	26.8	9.8
Day or partial hospital program	14.6	4.9	9.7
Transportation assistance	48.8	12.2	36.6
Information about or help obtaining benefits	46.3	7.3	39.0
Out of home respite care	70.7	24.4	46.3
Information about or help obtaining residential services	17.1	2.4	14.7
Information about or help obtaining psychiatric services	39.0	17.1	21.9
Legal assistance	24.4	0.0	24.4
Emergency residential services	14.6	0.0	14.6
Crisis intervention	31.7	7.3	24.4
Alcohol/drug abuse treatment for other family members	19.5	0.0	19.5
Advocacy when dealing with service programs	70.7	12.2	58.5
Routine medical check-up	82.9	65.9	17.0
Routine dental check-up	87.8	46.3	41.5
Hospitalization for psychiatric care	12.2	4.9	7.3

Note. Scale items were extracted from the Family Support Index (Heller & Factor, 1993). The proportion of caregivers of children with disabilities with unmet supports needs was calculated by subtracting the proportion of the CD group that reported *using* a specific service from the proportion of the CD group that felt that they *needed* the service.

each of the 28 support services that were listed in the survey. Thus, hypothesis 5, which stated that caregivers of children with disabilities will report that they have at least one unmet support need, was supported.

The five support services which had the highest proportion of caregivers of children with disabilities who reported an unmet need in that area included: social or recreational activities for the child(ren) (61%), home services such as housekeeping (60.8%), support meeting with other families to discuss caring for a child(ren) with disabilities (58.5%), advocacy when dealing with service programs (58.5%) and counselling or psychotherapy for other family members (56.1%). Caregivers reported unmet needs for many services that may benefit them more directly, such as counselling or psychotherapy for the family, alcohol or drug abuse treatment for the family, support meetings with other families with children with disabilities and respite care.

Socialization

A correlation matrix was conducted to determine if any of the variables studied were significantly associated with depression, anxiety and stress. The findings suggest that income, education level, hours worked per week, number of children with a disability living in the home, total number of children living in the home, caregiver status (single or cohabitating), and total therapy hours per month for the child were not significantly associated with depression, anxiety or stress among caregivers. In contrast, frequency of socialization with friends or family was significantly negatively associated with depression ($r = -0.61, p < .001$), state anxiety ($r = -0.63, p < .001$), trait anxiety ($r = -0.60, p < .001$) and stress ($r = -0.57, p < .001$).

A one-way analysis of covariance (ANCOVA) was conducted to evaluate whether

there was a difference in depression scores between the CT and the CT groups while controlling for the effect of socialization. There were 42 cases in the CT group and 43 cases in the CD group that were available for analysis. There was a significant main effect of socialization, $F(1, 82) = 22.84, p < .01$, partial $\eta^2 = .218$, indicating that socialization affected depression scores regardless of which group participants were in. There was also a significant main effect of group, $F(1, 82) = 8.69, p < .01$, partial $\eta^2 = .096$, indicating depression scores were affected by the group that participants were in, even when the effect of socialization was controlled for. The interaction effect between group and socialization was also significant, $F(2, 82) = 30.44, p < .01$, partial $\eta^2 = .426$, undoubtedly because available socialization rises significantly based on caregiver group as reported earlier. As a result, caregiver group membership exerts a moderating effect in the strength of the relationship between socialization and depression scores. However, the assumption of homogeneity of slopes was violated in this ANCOVA so these results should be interpreted with caution.

A one-way analysis of covariance (ANCOVA) was conducted to evaluate whether there was a difference in state anxiety scores between the CD and CT groups while controlling for socialization. There were 45 cases in the CT group and 44 cases in the CD group that were available for analysis. There was a significant main effect of socialization, $F(1, 86) = 26.36, p < .01$, partial $\eta^2 = .235$, indicating that socialization impacted state anxiety scores regardless of which group participants were in. There was a significant main effect of group (CT or CD) on state anxiety scores, while controlling for socialization, $F(1, 86) = 12.91, p < .01$, partial $\eta^2 = .13$, indicating that state anxiety scores were affected by the group that participants were in, even when controlling for the

effect of socialization. Finally, there was a significant interaction effect between socialization and group for state anxiety scores, $F(2, 86) = 37.3, p < .01$, partial $\eta^2 = .465$, indicating that socialization moderates the effect of group on state anxiety scores.

A one-way analysis of covariance (ANCOVA) was conducted to evaluate whether there was a difference in trait anxiety scores between the CD and CT groups while controlling for socialization. There were 43 cases in the CT group and 44 cases in the CD group that were available for analysis. There was a significant main effect of socialization, $F(1, 84) = 23.29, p < .01$, partial $\eta^2 = .217$, indicating that socialization impacted trait anxiety scores regardless of which group participants were in. There was a significant main effect of group (CT or CD) on trait anxiety scores, while controlling for socialization, $F(1, 84) = 6.56, p = .012$, partial $\eta^2 = .072$, indicating that trait anxiety scores were affected by the group that participants were in, even when controlling for the effect of socialization. Finally, there was a significant interaction effect between socialization and group for trait anxiety scores, $F(2, 84) = 30.33, p < .01$, partial $\eta^2 = .41$, indicating that socialization moderates the effect of group on trait anxiety scores.

A one-way analysis of covariance (ANCOVA) was conducted to evaluate whether there was a difference in stress scores between the CD and CT groups while controlling for socialization. There were 42 cases in the CT group and 44 cases in the CD group that were available for analysis. There was a significant main effect of socialization, $F(1, 82) = 16.93, p < .001$, partial $\eta^2 = .17$, indicating that socialization impacted stress scores regardless of which group participants were in. There was non-significant main effect of group (CT or CD) on stress scores, while controlling for socialization, $F(1, 82) = 1.25, p = .27$, partial $\eta^2 = .015$, indicating that stress scores were not affected by the group that

participants were in, even when controlling for the effect of socialization. Finally, there was a non-significant interaction effect between socialization and group for stress scores, $F(1, 82) = .12, p = .73$, partial $\eta^2 = .002$, indicating that socialization and group (CD or CT) did not have an interaction effect on stress scores. However, the assumption of homogeneity of slopes was violated in this ANCOVA so these results should be interpreted with caution.

Summary

In summary, the present study found support for the following five hypotheses:

- 1) Caregivers of children with disabilities will have significantly different levels of depression in comparison to caregivers of typical children.
- 2) Caregivers of children with disabilities will have significantly different levels of anxiety in comparison to caregivers of typical children.
- 3) Caregivers of children with disabilities will report a significantly different quantity of physical health concerns in comparison to caregivers of typical children.
- 4) Caregivers of children with disabilities will have significantly different levels of stress in comparison to caregivers of typical children.
- 5) Caregivers of children with disabilities will report that they have at least one unmet support need.

The findings of this study indicate caregivers of children with disabilities experience elevated levels of stress, depression, anxiety, physical health problems and unmet needs, in comparison to caregivers of typical children. The survey response rate was low; however, sufficient data was collected that a large proportion of the data was normally distributed, and the findings of this study are supported by the literature.

Additionally, this study has contributed to the literature by analyzing several interrelated variables (e.g., stress, physical health, anxiety, depression, unmet needs) that have previously been studied separately. An interesting finding of the present study was that socialization played an important role in supporting the psychological and physical health and stress of caregivers of children with disabilities.

Chapter 5: Discussion

This study is the first of its kind to explore the mental and physical health, stress and needs of caregivers of children with disabilities enrolled in family-centered wraparound service programs in Alberta, Canada. Overall, the results indicate that caregivers of children with disabilities face unique challenges and experience an exorbitant amount of stress, which appears to have detrimental effects on their own psychological and physical health. Overall, caregivers of children with disabilities experienced higher levels of stress, mental and physical health problems and unmet needs, in comparison to the average parent of a child without disabilities. This section will provide an overview of the conclusions and interpretations of the results, while drawing comparisons to the pre-existing research that has provided the rationale for this research. Furthermore, the limitations of the present study will be discussed and recommendations for future research will be delineated.

Previous research has demonstrated that caregivers of children with disabilities face a unique set of challenges and stressors which have been shown to impact their psychological and physical health (Brehaut et al., 2004; Grant et al., 2013; Jackson et al., 2010). At the outset of this study, the author intended to develop a better understanding of the experiences of caregivers of children with severe disabilities enrolled in family-centered wraparound services in Alberta, Canada. Thus, the purpose of the present study was to expand on previous findings and to investigate the psychological and physical health, stress and needs of caregivers of children with disabilities.

Demographic Information

The present study compared two samples of caregivers of children with and

without disabilities, who were similar in age. Both groups primarily consisted of Caucasian participants, although they differed in the ethnic groups that were represented by the remainder of the sample. These differences in the ethnicities of participants are likely attributed to the inherent limitations of a small sample. An unusual finding was that the CD group consisted of more male participants than the CT group. This may have occurred because the organizations, who offered Specialized Services programs, had supported the study by actively encouraging both male and female clients to participate. A possible explanation is that male participants may be more likely to take part in a study about caregivers if they are actively recruited by an organization, rather than passively, such as by the use of a poster or social media advertisement. Another possibility is that raising a child with disabilities may be more demanding and, therefore, provoke more father involvement. Thus, male caregivers may have felt more drawn to participate in the study because the topic of the study resonated with them. Furthermore, the CT group had an overall higher education level than the CD group. As the average education level of both groups were similar, it can be speculated that these differences may have also been attributed to the use of a small sample size.

Daily Activities

The demographic items in the survey also revealed that caregivers of children with and without disabilities spend approximately the same amount of time caring for their child(ren), although the mean category represented a wide range of caregiving hours. Furthermore, a similar proportion of participants in both groups reported that they were employed and that they were working approximately the same number of hours per week. There were more students in the CD group, in comparison to the CT group. As the

CD group reported an overall lower education level in comparison to the CT group, it would be interesting to know why these caregivers were more likely to complete their education at a later date. For example, their reasons for returning to school may include a desire to improve their career and financial outlook, or perhaps a desire to complete courses that were previously interrupted by a life event, such as parenthood or the onset of mental health concerns.

Caregivers of children with disabilities, on average, spent significantly less time socializing with friends and family in comparison to caregivers of typical children. This is a concerning finding because the literature has demonstrated that support programs, such as parent-to-parent support, can reduce stress by increasing socialization and emotional support (Banach, Iudice, Conway, & Couse, 2010; Mathiesen, Frost, Dent, & Feldkamp, 2012). Socialization is also an important protective factor for caregivers of children with disabilities because it has been associated with reduced stress and improved psychological and physical health (Brehaut et al., 2004; Kimura & Yamaoka et al., 2015; Kimura & Yamazaki, 2013). Moreover, the present study demonstrated that socialization moderates the impact of caring for a child with disabilities on mental health outcomes.

Caregiving

The present study also gathered information about the caregiving experience to develop a better understanding of the context that influences the psychological and physical health, and stress of caregivers of children with disabilities. The CT group reported that they cared for up to four typical children, whereas the CD group cared for up to four typical children and three children with disabilities. Thus, it can be inferred that the CD group experienced greater parenting demands than the average parent. While

there was a non-significant difference between caregivers who had one child with disabilities and caregivers who had two to three children with disabilities, a trend was observed in which depression scores among caregivers increased as the number of children in the home with disabilities increased. This finding is consistent with previous research, which has found that caregivers who have multiple children with disabilities can experience higher levels of depression and anxiety (Almansour, Alateeq, Alzahrani, Algeffari & Alhomaidan, 2013; Kimura & Yamazaki, 2013).

Furthermore, the CD and CT groups had similar proportions of single and cohabitating caregivers. While the majority of participants in the CD group were cohabitating caregivers, which has been shown to be a protective factor against stress and depression, it is nonetheless important that these families learn strategies to cooperate, engage in healthy communication, share caregiving tasks, and provide mutual emotional support and compassion in order to truly benefit from having multiple caregivers in the home (Almansour et al., 2013; Azeem et al., 2013, Laxman et al., 2015; Yamaoka et al., 2015). Moreover, single caregivers may benefit from programs such as respite care or domestic services in order to reduce the stress associated with balancing a large number of commitments simultaneously (Heller et al., 1999). It is especially important to support single caregivers because they are at a higher risk of social isolation and severe depression (Kimura & Yamazaki, 2013).

As expected, the majority of caregivers in both groups were biological parents of the children in their care. The CD group also included step-parents, adoptive and foster parents. Both groups had a small proportion of caregivers, who identified as another family member who primarily cared for the child. As caregivers of children with

disabilities have been shown to experience more mental and physical health issues, it is possible that these circumstances affected the ability of some parents to care for their children (Brehaut et al., 2004; Grant et al., 2013; Jackson et al., 2010). In these cases, the child may have been placed in a foster home or with an adoptive family, as children with disabilities are at a higher risk of entering the child welfare system, in comparison to typical children (Brown, & Rodger, 2009). This finding further highlights the importance of supporting the psychological and physical health, stress and needs of caregivers of children with disabilities, while simultaneously increasing their capacity to effectively care for their children.

The remaining demographic questions were related to therapy services for the children and caregivers. As the CD group was enrolled in the Specialized Services program, it was expected that children in this group would have a greater exposure to therapy than the CT group. On average, 89.9% of children with disabilities received approximately 18.48 hours of therapy per month. Conversely, only 15.6% of typical children received, on average 4.36 hours of therapy per month. This finding illustrates the added commitments that caring for a child(ren) with disabilities can entail, such as attending more therapy appointments for the child. Although therapy for the child can improve the daily functioning and well-being of families of children with disabilities, Osborne, McHugh, Saunders, and Reed (2008) have demonstrated that therapy effectiveness can suffer if caregivers experience an exorbitant amount of stress. Therefore, families of children with disabilities would benefit most from programs that support the mental and physical health and stress of the caregivers, while simultaneously providing therapy for the child(ren) with disabilities (Osborne et al., 2008).

Therapy for the Caregivers

Therapy can benefit all caregivers, but it can be especially supportive for caregivers of children with disabilities, who are more susceptible to psychological and physical health concerns and stress (Brehaut et al., 2004; Grant et al., 2013). In this study, a mere 15.6% of caregivers of children with disabilities were seeking therapy for themselves. It would be of interest to know the reasons why such a small proportion of the CD group were actively participating in therapy. There are potentially many barriers that would discourage caregivers from seeking therapy such as fatigue and lack of motivation (which can be related to depression), anxiety, lack of transportation, financial restrictions, legal concerns (how it may reflect on a parenting assessment), lack of awareness of mental health concerns and the benefits of therapy, low self-esteem, shame, embarrassment, language barriers and/or stigma (Heller et al., 1999; Kimura, & Yamazaki, 2013; You & McGraw, 2011). Thus, caregivers of children with disabilities may benefit from supports that extends beyond referrals to community supports. Specifically, caregivers of children with disabilities may be more inclined to access therapy for themselves if service providers are able to reduce barriers which discourage them from seeking mental health support.

Hypothesis Testing

Hypothesis 1. Hypothesis one stated that caregivers of children with disabilities will have significantly different levels of depression in comparison to caregivers of typical children. Overall, caregivers of children with disabilities demonstrated clinical levels of depression, whereas caregivers of typical children did not meet the criteria for depression. This finding is even more concerning because the CD group demonstrated

elevated depression scores suggesting that they experienced a greater severity of depression. This finding is supported by the literature, which has also found that depression severity can increase if a caregiver is single or has multiple children with disabilities (Almansour, Alateeq, Alzahrani, Algeffari & Alhomaïdan, 2013; Azeem et al., 2013; Grant et al., 2013; Kimura & Yamazaki, 2013; Laxman et al., 2015; You & McGraw, 2011). As expected, caregivers of children with disabilities were more likely to have a diagnosis of depression, in comparison to caregivers of typical children.

Hypothesis 2. The second hypothesis stated that caregivers of children with disabilities will have significantly different levels of anxiety in comparison to caregivers of typical children. The findings of this study also revealed that caregivers of children with disabilities had elevated levels of state and trait anxiety in comparison to the CT group and the reference group provided by the creators of the scale. According to percentile ranks provided by Spielberger, Gorsuch, Lushene, Vagg, and Jacobs (2015), the average state anxiety score of the CD group fell in the 91st percentile of anxiety scores from the reference sample, while the average trait anxiety score of the CD group fell in the 93rd percentile of anxiety scores from the reference sample. This finding has been supported by the literature, which has demonstrated a positive relationship between depression and anxiety levels among caregivers of children with disabilities (Almansour, Alateeq, Alzahrani, Algeffari & Alhomaïdan, 2013; Azeem et al., 2013; Grant et al., 2013). As caregivers of children with disabilities reported that they generally experience high levels of anxiety in their daily life, it is essential that service providers support caregivers to self-regulate so that they can attend, participate and benefit from support services that are provided to them. The proportion of participants with an anxiety disorder

was elevated in the CD group, in comparison to the CT group, but not statistically different. As this study has already established that caregivers of children with disabilities are less likely to seek therapy for themselves, it is possible that many caregivers are experiencing mental health concerns that are undetected and undiagnosed.

Hypothesis 3. The third hypothesis tested in this study was that caregivers of children with disabilities will report a significantly different quantity of physical health concerns in comparison to caregivers of typical children. In this study, caregivers of children with disabilities reported more physical health problems than caregivers of typical children. Caregivers in the CD group were significantly more likely to experience 10 of the 17 physical health conditions, including asthma, arthritis or rheumatism, back problems excluding arthritis, high blood pressure, sinusitis, diabetes, epilepsy, heart disease, stomach or intestinal ulcers, and a bowel disorder. These findings have been supported by Brehaut et al. (2004) and Lee, Park, Matthews, and Hsieh (2017), who also used the NPHS to measure physical health. There were only a few differences between the findings of the present study and the research conducted by Brehaut et al. (2004), such that previous research has also found that the CD group were significantly more likely to experience non-food allergies, migraine headaches, and cancer. Conversely, the present study found that the CD group was significantly more like to experience epilepsy, which was not supported by the previous study. The present study also analyzed the proportion of caregivers who experience fibromyalgia and chronic fatigue syndrome, however there were non-significant differences between the CT and CD groups.

As previous studies have suggested that physical health problems are frequently related to psychological health concerns, such as depression and stress, it is crucial that

organizations provide services that are able to accommodate and support the physical limitations and needs of caregivers of children with disabilities (Brehaut et al., 2004). This finding supports the notion that the mental and physical health of caregivers can be mediated by support services that provide respite care, domestic services, counselling for the caregivers, and encouragement of partner involvement in caregiving tasks (Laxman et al., 2015).

Hypothesis 4. The fourth hypothesis stated that caregivers of children with disabilities will have significantly different levels of stress in comparison to caregivers of typical children. In this study, caregivers of children with disabilities experienced significantly higher levels of stress in comparison to caregivers of typical children. This finding has also been supported by the literature, such that caregivers who experienced high levels of stress, frequently experienced higher levels of anxiety, depression, and physical health problems (Almansour, Alateeq, Alzahrani, Algeffari & Alhomaidan, 2013; Azeem et al., 2013; Brehaut et al., 2004; Grant et al., 2013; Kimura & Yamazaki, 2013; Laxman et al., 2015; You & McGraw, 2011). The present study has also validated these findings. Bazzano et al. (2015) and Bobbitt et al. (2016), who also used the Perceived Stress Scale to measure stress levels of caregivers of individuals with disabilities, found that caregivers of individuals with disabilities experienced high levels of stress. Bazzano et al. (2015) and Lo, Chan, Szeto, Chan, & Choi (2017) also took a solution-focused approach, whereby they found that yoga and mindfulness-based stress reduction techniques significantly reduced stress and increased well-being among caregivers. Thus, service providers can improve the quality of life of this population by supporting caregivers to engage in community programs that involve exercise,

movement, and mindfulness activities (Bazzano et al., 2015; Lo, Chan, Szeto, Chan, & Choi, 2017; Rayan & Ahmad, 2017).

Hypothesis 5. The fifth hypothesis stated that caregivers of children with disabilities will report that they have at least one unmet support need. In this study, caregivers of children with disabilities expressed having a variety of unmet needs. There were similarities between the findings of the present study and a previous study conducted by Heller, Miller and Hsieh (1999) who also used the Family Support Index to evaluate caregiver needs. In both studies, the greatest proportion of caregivers reported ‘social and recreational activities for the child’ as being an unmet need. The present study, in comparison to the previous study conducted by Heller, Miller and Hsieh (1999), included a higher proportion of caregivers of individuals with disabilities who reported that they needed support in the areas of ‘advocacy when dealing with service programs’ and ‘alcohol or drug abuse treatment for another family member’. These differences illustrate the unique experiences and challenges that caregivers face when caring for an individual with disabilities. Furthermore, it would be expected that there may be some differences in the findings of these two studies as the present study focused on caregivers of children, whereas the previous study investigated the experiences of caregivers of adults with disabilities. Moreover, the two studies were separated by an extended period of time. Nonetheless, the findings of both studies highlight the importance of addressing unmet needs and reducing barriers to service use, such as providing financial support to cover the costs associated with support services in the community (Heller, Miller, & Hsieh, 1999). The unmet needs identified in the Family Support Index provide valuable insight as to how service providers can support caregivers of children with disabilities in

a holistic way that includes reducing stress and enhancing socialization, communication, relationships, confidence, parenting effectiveness, family cohesion and child well-being. These findings suggest that caregivers of children with disabilities may benefit from a wide array of services, that extend beyond therapeutic supports for the child(ren).

Summary

This paper presented a variety of strengths and coping skills that caregivers of children with disabilities possess, as well as various challenges related to the added stress of caring for a child with special needs. Caregivers of children with disabilities may struggle to balance more commitments in their lives than the average parent, such as more children to care for, more therapy, medical, and/or school appointments for their children with disabilities, being a student, working for pay, more medical and therapy appointments for themselves, domestic duties, and spending quality time with their partner. Thus, there could be a bidirectional relationship between stress and support-seeking behaviours, in which their high levels of stress aggravate their physical and mental health, which in turn, discourages them from seeking support and socializing with friends and family. Then, as the individual becomes more isolated, their psychological and physical health, and stress becomes exacerbated. The present study found that decreased opportunities for socialization were significantly associated with increased anxiety, depression and stress. This scenario could potentially explain the high rates of psychopathology, stress and physical health problems, and the low rates of anxiety diagnoses and therapy engagement, among caregivers of children with disabilities in the present study.

Defining Disability

The theoretical models and varied definitions of the term disability also added another layer to this research. As qualitative studies presented in this paper demonstrated that caregivers of children with disabilities often feel dismissed, stereotyped and stigmatized (Berghs et al., 2016), it appears to be highly important to describe disabilities in a way that includes these attitudinal and environmental factors. Although many organizations appear to rely on a medical model, which describes pathologies, physical or mental conditions and limitations in functioning, the bio-psycho-social model proposed by the World Health Organization (2018) appears to be a more holistic way of understanding disabilities (World Health Organization & the World Bank, 2011). It is important for organizations to reflect on the way in which they describe disabilities, as their mission statement and definition will set the tone of the services that they provide. For example, if an organization describes disabilities as an interaction between environmental, attitudinal and personal challenges that can reduce an individual's participation in society, then this encourages support workers and families of children with disabilities to learn about the contextual factors that may impact an individual's perception or experience of having a disability. This conversation would enable support workers and families affected by disabilities to collaboratively engage in problem solving discussions to identify ways of reducing the barriers caregivers face when accessing support, engaging in self-care and advocating for their child with disabilities. Furthermore, it encourages organizations to train their staff members how to accommodate or meet the needs of families of children with disabilities.

This study also discussed the moral model, which may be highly relevant for

some clients who may experience shame in their communities, especially if they have been blamed by family or friends for causing their child's disability (Durham & Ramcharan, 2018). As You and McGraw (2011) described in their study, some parents, such as Korean mothers, may be profoundly affected by the social isolation that rejection from their community has caused. This form of social rejection can become internalized and evolve into a deep depression or state of suicidal ideation (You & McGraw, 2011). The literature clearly supports the notion that the way in which a caregiver interprets their experience can have a profound impact on their psychological and physical health, stress and needs (Hill & Rose, 2009; Masulani-Mwale, Kauye, Gladstone, & Mathanga, 2018; Minnes, Perry, & Weiss, 2015; Song, Mailick, Greenberg, Ryff, & Lachman, 2016; You & McGraw, 2011). Therefore, the author would recommend that support workers should consider these theoretical models and support caregivers of children with disabilities to understand how their perceptions and thought patterns can have profound effects on their health and sense of well-being.

Lastly, this research explored the human rights model, which suggests that accessibility, respect and equal opportunities do not simply reflect the needs of individuals with disabilities, rather, they are human rights (Berghs et al., 2016). When professionals and organizations reflect on their best practices through the lens of a human rights model, it can improve the services they provide by increasing the ethical considerations that contribute to policy development and reform. It would be especially beneficial for communities to have meetings or focus groups to discuss what professionals and families of children with disabilities deem to be human rights versus additional needs. As demonstrated by Ryan and Quilan (2017), many families of children

with disabilities feel the need to fight for the rights of their children. This type of language suggests that families of children with disabilities may already feel that their human rights or the human rights of their children with disabilities have been violated. This provides support workers and society as a whole an opportunity to reflect and discuss the human rights of individuals who are affected by disabilities to ensure that support services are empathic and ethical.

Overall, these conceptual frameworks can assist professionals to understand disabilities from different perspectives. As the definition of disabilities is subjective, it is highly important to allow families of children with disabilities to define their own experiences and to share their personal perspectives with the disability support organizations who provide services to them.

Future Research

Based on the findings of the present study, and in keeping with the ongoing needs of parents of children with disabilities, several areas for future research emerge. First, it would be of interest to expand what is known about the relationship between stress and the physical health of caregivers and to develop strategies to support caregiver physical health. Moreover, service providers may benefit from more diversity in the research as to develop a better understanding of experiences of parents of children with different types of disabilities. Caregivers of children with disabilities may also benefit from empirical studies which evaluate whether parental needs are being met within the services that are offered to them to ensure that programs are both effective and supportive. As the literature has demonstrated that caregivers across the globe are experiencing high levels of psychopathology, stress and physical health concerns, it would be advantageous for

future research to explore the effects of culture on the needs and values expressed by families of children with disabilities. This would enable service providers to improve their cultural competence, effectiveness and ethical conduct when supporting families of different cultural backgrounds.

Lastly, there appears to be a strong gender bias in the research as very few studies explore the male caregiving experience. The present study also consisted of a predominantly female sample, despite rigorous efforts to recruit male caregivers of children with disabilities. It is possible that males are less likely to participate in a study if recruitment efforts primarily target community organizations that support families and social media users, as was the case in the present study. It is essential that service providers have access to research that highlights the male experience of caring for a child with disabilities to ensure that support programs are appropriate and individualized for all caregivers. Thus, future researchers may want to explore recruitment strategies that may increase male participations rates in studies about the caregiving experience. For example, it may be beneficial to recruit participants in areas that males frequent, such as support groups for fathers, gyms, sports events, or to place advertisements in washrooms, restaurants, bars or magazines which target male interests. Media advertisements may also be more effective if they consist of television and radio advertisements, rather than social media posts.

Recommendations for Service Providers

The literature clearly demonstrates that there are many ways in which service providers can increase the support they provide to caregivers of children with disabilities, such as providing access to a multidisciplinary team to provide professional support

(McConkey, Gent, & Scowcroft, 2013), financial assistance (Heller et al., 1999), cognitive-behavioural therapy (Wong, Ng, Ip, Chung, & Choi, 2018), parent-to-parent support (Banach, Iudice, Conway, & Couse, 2010; Mathiesen, Frost, Dent, & Feldkamp, 2012), mindfulness-based stress reduction techniques (Bazzano et al., 2015; Lo, Chan, Szeto, Chan, & Choi, 2017; Rayan & Ahmad, 2017), access to a key worker (Ryan & Quilan, 2017), and parent training programs (Leung, Chan, Lam, Yau, & Tsang, 2016; McConkey, Gent, & Scowcroft, 2013; Roux, Sofronoff & Sanders, 2013). Furthermore, the present study suggests that caregivers of children with disabilities would benefit from support which specifically targets their anxiety, depression, stress, physical health problems, socialization, and unmet needs. Potential programs that can be used to support these concerns include free or subsidized counselling services, respite care services, yoga, mindfulness, and exercise classes, parent support groups, psychoeducation seminars, transportation services to increase accessibility and access to a key worker to support the family in navigating the social services system and accessing available supports.

Furthermore, service providers may find it useful to have the key worker ask all clients to complete a questionnaire to identify potential unmet needs. When barriers to well-being are identified, such as financial strain, lack of transportation or health concerns, key workers can support the family to access services or enroll in programs that specifically target these areas of concern. If service providers are unaware of the context which reduces the overall functioning and well-being of the caregivers, support services may contribute to the stress of parents, and may consequently feel counterproductive. Thus, it is essential that service providers understand the overall needs of a family before providing services to increase the potential effectiveness of the intervention.

This paper has demonstrated the need for individualized services. The author recommends asking clients to discuss their personal interpretation of the term disability, describe how their culture and/or religion may impact their experience of raising a child with disabilities and express how certain structural, social and environmental factors may affect them, such as their gender, socioeconomic status, exposure to stigmatization or accessibility concerns. Organizations that serve families of children with disabilities may find it useful to use focus groups to determine some of the most common needs of families in their area and one-on-one discussions with parents to explore more personal and sensitive topics. This paper has demonstrated how important it is for caregivers of children with disabilities to feel heard and to be acknowledged for the wisdom and knowledge they possess from raising a child with special needs.

Limitations

There are inherent limitations with using a cross-sectional survey design, such as a non-response bias, an inability to draw conclusions about causation and a response bias (e.g., social desirability bias or extreme responses). Moreover, it may be beneficial for future researchers to expand the response options if using closed questions on a survey. The present study was limited in that small nuances in the data could not be captured or analyzed as the response categories were sometimes too broad to provide sufficient context or information. The present study was also limited in that it utilized a convenience sample, it was conducted by a novice researcher and the success of the data collection process was dependant on the literacy and technological abilities of the participants. Another limitation was the potential for survey fatigue as participants were asked to complete a lengthy survey lasting 10 to 15 minutes. Despite extensive

recruitment efforts, the sample size fell short of the target sample size, perhaps because the study had little direct benefit for respondents, or because respondents were already overwhelmed with activities demanding their attention. Future studies like the present study may benefit from funding so that respondents can receive financial remuneration for their participation.

The current state of the literature presents several limitations which are important to consider. The present study attempted to address some of these concerns by incorporating a variety of scales which measured stress, psychological and physical health and caregiver needs to develop a more holistic understanding of the caregiving experience. Furthermore, a gender-neutral operational definition of *caregiver* was used to encourage both male and female caregivers to participate in the study. Several different recruitment strategies were employed to obtain a diverse sample that included children with a variety of disabilities and families of different cultural backgrounds. Although there were a few male participants and several different ethnic groups represented in the present study, the sample was still limited by being predominantly representative of Caucasian females. Thus, it can be argued that there were not enough males in the study to generalize the results to the male population of caregivers. A diverse selection of disabilities among the children was represented by the present study, although meaningful comparisons between the different groups of disabilities could not be conducted as the present study utilized a small sample. Finally, there is a dearth of research in a couple of areas that were also not addressed by the present study, such as the relationship between high levels of stress and increases in physical health problems among caregivers, and solution-focused strategies and programs to improve the

psychological and physical health, and stress levels of this population. Thus, caregivers of children with disabilities may benefit from research being conducted in these areas in the future.

Summary

In summary, caregivers of children with disabilities experience higher levels of stress than the average parent which has been shown to negatively impact their psychological and physical health (Brehaut et al., 2004; Grant et al., 2013; Jackson et al., 2010). Many factors have been found to contribute to caregiver stress, including social isolation (Kimura & Yamazaki, 2013) and disrupted family cohesion (Mitchell, Szczerepa, & Hauser-Cram, 2016). A review of the literature has shown that high parental stress and reduced psychological well-being are associated with increased child behaviour problems (Neece et al., 2012) and reduced effectiveness of therapeutic interventions for the child (Osborne et al., 2008). The present study aligns with previous findings by Azeem et al. (2013) who found that high proportions of mothers and fathers of children with intellectual disabilities met DSM-IV criteria for depression, anxiety or both (89% and 77% respectively). Among female caregivers, 40% were diagnosed with depression, 35% with anxiety and 13% with both depression and anxiety. Among male caregivers, 31% were diagnosed with depression, 42% with anxiety and 3% with both depression and anxiety (Azeem et al., 2013). The present study also found that caregivers, primarily mothers, of children with disabilities experienced high levels of depression, anxiety and stress, although gender comparisons were not conducted due to a low sample size.

This study has supported previous findings which indicate that caregivers of

children with disabilities experience an array of unmet needs that may suppress their ability to achieve a state of health and well-being (Bobbitt et al., 2016; Heller et al., 1999). Thus, families of children with disabilities may benefit as a whole from support services that extend beyond therapeutic interventions for the child, such as parent-to-parent support, mindfulness, parent training programs, respite care and therapy for the caregivers (Bazzano et al., 2015; Heller et al., 1999; Lo, Chan, Szeto, Chan, & Choi, 2017; Rayan & Ahmad, 2017).

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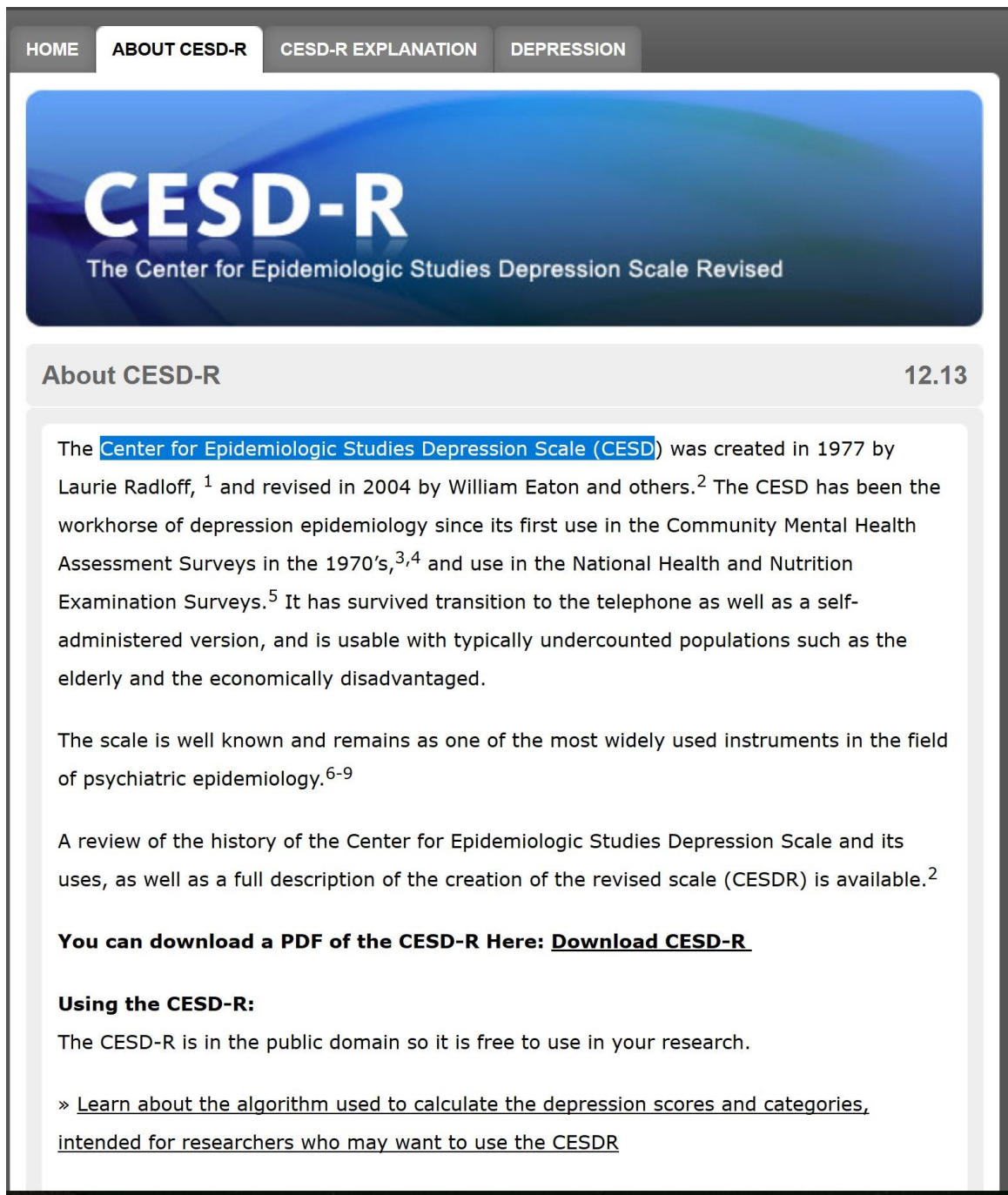
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Appendix A:

Permission to Use Center for Epidemiologic Studies Depression Scale



HOME ABOUT CESD-R CESD-R EXPLANATION DEPRESSION

CESD-R

The Center for Epidemiologic Studies Depression Scale Revised

About CESD-R 12.13

The [Center for Epidemiologic Studies Depression Scale \(CESD\)](#) was created in 1977 by Laurie Radloff,¹ and revised in 2004 by William Eaton and others.² The CESD has been the workhorse of depression epidemiology since its first use in the Community Mental Health Assessment Surveys in the 1970's,^{3,4} and use in the National Health and Nutrition Examination Surveys.⁵ It has survived transition to the telephone as well as a self-administered version, and is usable with typically undercounted populations such as the elderly and the economically disadvantaged.

The scale is well known and remains as one of the most widely used instruments in the field of psychiatric epidemiology.⁶⁻⁹

A review of the history of the Center for Epidemiologic Studies Depression Scale and its uses, as well as a full description of the creation of the revised scale (CESDR) is available.²

You can download a PDF of the CESD-R Here: [Download CESD-R](#)

Using the CESD-R:

The CESD-R is in the public domain so it is free to use in your research.

» [Learn about the algorithm used to calculate the depression scores and categories, intended for researchers who may want to use the CESDR](#)

Retrieved from <http://cesd-r.com/about-cesdr/>

Appendix B:

Permission to Use the State-Trait Anxiety Inventory

For use by Em Pijl only. Received from Mind Garden, Inc. on November 20, 2017

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within one year of November 20, 2017**

**State-Trait Anxiety Inventory
for Adults™
Instrument and Scoring Key**

Developed by Charles D. Spielberger

in collaboration with R.L. Gorsuch, R. Lushene, P.R. Vagg, and G.A. Jacobs

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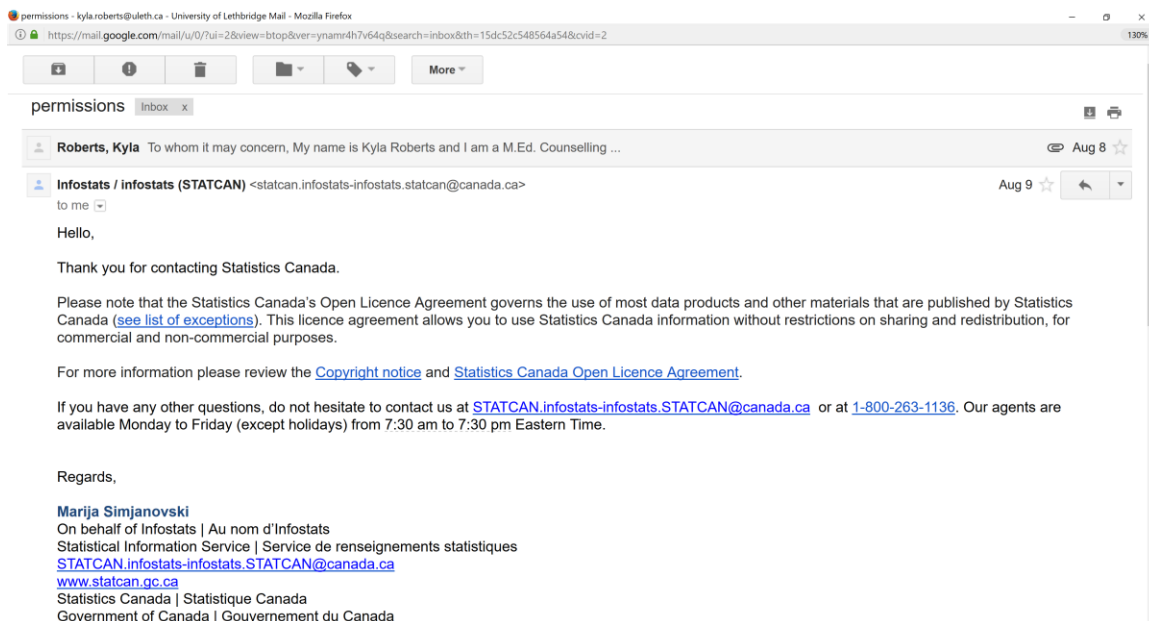
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Appendix C:

Permission to Use the National Population Health Survey



Appendix D:

Permission to Use the Perceived Stress Scale

Permissions for the use of the Perceived Stress Scale - kyla.roberts@uleth.ca - University of Lethbridge Mail - Mozilla Firefox

https://mail.google.com/mail/u/0/?ui=2&view=bt&ver=ynamr4h7v64q&search=inbox&th=15db4e559066e60a&ccid=1

130%

Permissions for the use of the Perceived Stress Scale Inbox x

Roberts, Kyla <kyla.roberts@uleth.ca> Aug 5 ☆ ↶ ⌵
to scohen ⌵

Hello Dr. Cohen,
My name is Kyla Roberts and I am a M.Ed. Counselling Psychology student at the University of Lethbridge. I am currently working on my thesis and would like to administer the Perceived Stress Scale to approximately 120 caregivers. I was wondering what the permissions of use are pertaining to this scale. Our study is not funded so I am seeking gratuitous assessments unless I can acquire funding in the near future.

Thank you for your time and cooperation and best of luck with your future endeavours.

Sincerely,
...

Sheldon Cohen <scohen@cmu.edu> Aug 5 ☆ ↶ ⌵
to me ⌵

Kyla, You are welcome to use the PSS for your project. sc

From: Roberts, Kyla [mailto:kyla.roberts@uleth.ca]
Sent: Saturday, August 05, 2017 8:15 PM
To: Sheldon Cohen
Subject: Permissions for the use of the Perceived Stress Scale
...

Roberts, Kyla <kyla.roberts@uleth.ca> Aug 5 ☆ ↶ ⌵
to Sheldon ⌵

Wonderful! Thank you and enjoy your evening!

Appendix E:

Permission to Use the Expanded Version of the Family Support Index

permissions for the use of the Family Support Index - kyla.roberts@uleth.ca - University of Lethbridge Mail - Mozilla Firefox
https://mail.google.com/mail/u/0/?ui=2&view=bt&ver=ynamr4h7v64q&search=inbox&th=15dc5a1eec8bae3b&cvid=3 130%

permissions for the use of the Family Support Index Inbox x

Roberts, Kyla <kyla.roberts@uleth.ca> Aug 9 ☆ ↶ ▾
to Theller ▾

Hello Dr. Heller,
My name is Kyla Roberts and I am a M.Ed. Counselling Psychology student at the University of Lethbridge. I am currently working on my thesis and will be examining the mental and physical health, stress and needs of caregivers of children with disabilities. I am contacting you because I would like to know the permissions of use pertaining to the Family Support Index as I would like to include it in my study. The study is currently not funded so I am seeking a gratuitous assessment of caregiver needs.

Thank you for your time and cooperative and best of luck with your future endeavors.

Sincerely,
...

Heller, Tamar <theller@uic.edu> Aug 9 ☆ ↶ ▾
to me ▾

Yes that is fine.

From: Roberts, Kyla [mailto:kyla.roberts@uleth.ca]
Sent: Wednesday, August 09, 2017 1:15 AM
To: Heller, Tamar <theller@uic.edu>
Subject: permissions for the use of the Family Support Index

...

Roberts, Kyla <kyla.roberts@uleth.ca> Aug 9 ☆ ↶ ▾
to Tamar ▾

Great! Thank you. Have a wonderful day :)

Appendix F:

Center for Epidemiologic Studies - Depression Scale

Center for Epidemiologic Studies Depression Scale (CESD)

Below is a list of the ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

1 = Rarely or None of the Time (Less than 1 Day)

2 = Some or a Little of the Time (1-2 Days)

3 = Occasionally or a Moderate Amount of Time (3-4 Days)

4 = Most or All of the Time (5-7 Days)

During the past week:

	Rarely or none of the time (less than 1 day)	Some or a little of the time (1-2 days)	Occasionally or a moderate amount of time (3-4 days)	Most or all of the time (5-7 days)
1. I was bothered by things that usually don't bother me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I did not feel like eating; my appetite was poor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I felt that I could not shake off the blues even with help from my family or friends.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I felt that I was just as good as other people.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. I had trouble keeping my mind on what I was doing.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. I felt depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I felt that everything I did was an effort.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I felt hopeful about the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I thought my life had been a failure.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I felt fearful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. My sleep was restless.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I was happy.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I talked less than usual.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I felt lonely.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. People were unfriendly.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I enjoyed life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I had crying spells.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I felt sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I felt that people dislike me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I could not get "going".	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Appendix G:

State-Trait Anxiety Inventory

SELF-EVALUATION QUESTIONNAIRE STAI Form Y-1

Please provide the following information:

Name _____ Date _____ S _____
 Age _____ Gender (Circle) **M** **F** T _____

DIRECTIONS:

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you feel *right now*, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

VERY MUCH SO
 MODERATELY SO
 SOMEWHAT
 NOT AT ALL

- | | | | | |
|--------------------------|---|---|---|---|
| 1. I feel calm..... | 1 | 2 | 3 | 4 |
| 2. I feel secure | 1 | 2 | 3 | 4 |
| 3. I am tense | 1 | 2 | 3 | 4 |
| 4. I feel strained | 1 | 2 | 3 | 4 |
| 5. I feel at ease | 1 | 2 | 3 | 4 |

Appendix H:
National Population Health Survey

NATIONAL POPULATION HEALTH SURVEY (NPHS)

Now I'd like to ask about certain chronic health conditions which you may have. We are interested in "long-term conditions" that have lasted or are expected to last 6 months or more and that have been diagnosed by a health professional.

Do you have:

- A. Food allergies? **Yes / No**
- B. Any other allergies? **Yes / No**
- C. Asthma? **Yes / No**
- D. Arthritis or rheumatism? **Yes / No**
- E. Back problems, excluding arthritis? **Yes / No**
- F. High blood pressure? **Yes / No**
- G. Migraine headaches? **Yes / No**
- H Chronic bronchitis or emphysema? **Yes / No**
- I. Sinusitis? **Yes / No**
- J. Diabetes? **Yes / No**
- K. Epilepsy? **Yes / No**
- L. Heart disease? **Yes / No**
- M. Cancer? **Yes / No**
- N. Stomach or intestinal ulcers? **Yes / No**
- O. Effects of a stroke? **Yes / No**
- P. Urinary incontinence? **Yes / No**
- Q. A bowel disorder such as Crohn's Disease or colitis? **Yes / No**

Appendix I:

Perceived Stress Scale

PERCEIVED STRESS SCALE

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate by circling *how often* you felt or thought a certain way.

Name _____ Date _____

Age _____ Gender (Circle): **M** **F** Other _____

0 = Never 1 = Almost Never 2 = Sometimes 3 = Fairly Often 4 = Very Often

- | | | | | | |
|--|---|---|---|---|---|
| 1. In the last month, how often have you been upset because of something that happened unexpectedly? | 0 | 1 | 2 | 3 | 4 |
| 2. In the last month, how often have you felt that you were unable to control the important things in your life? | 0 | 1 | 2 | 3 | 4 |
| 3. In the last month, how often have you felt nervous and "stressed"? | 0 | 1 | 2 | 3 | 4 |
| 4. In the last month, how often have you felt confident about your ability to handle your personal problems? | 0 | 1 | 2 | 3 | 4 |
| 5. In the last month, how often have you felt that things were going your way? | 0 | 1 | 2 | 3 | 4 |
| 6. In the last month, how often have you found that you could not cope with all the things that you had to do? | 0 | 1 | 2 | 3 | 4 |
| 7. In the last month, how often have you been able to control irritations in your life? | 0 | 1 | 2 | 3 | 4 |
| 8. In the last month, how often have you felt that you were on top of things? | 0 | 1 | 2 | 3 | 4 |
| 9. In the last month, how often have you been angered because of things that were outside of your control? | 0 | 1 | 2 | 3 | 4 |
| 10. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them? | 0 | 1 | 2 | 3 | 4 |



info@mindgarden.com

www.mindgarden.com

References

- The PSS Scale is reprinted with permission of the American Sociological Association, from Cohen, S., Kamarck, T., and Mermelstein, R. (1983). A global measure of perceived stress. *Journal of Health and Social Behavior*, 24, 386-396.
- Cohen, S. and Williamson, G. Perceived Stress in a Probability Sample of the United States. Spacapan, S. and Oskamp, S. (Eds.) *The Social Psychology of Health*. Newbury Park, CA: Sage, 1988.

Appendix J:**Expanded Version of the Family Support Index**

The questions in section II are about services families use to help care for a relative with a disability. Each question has two parts:

Do you **NEED** this service? Circle either **Yes** or **No**

Do you **USE** this service? Circle either **Yes** or **No**

1. In-home respite care (someone to look after your child(ren) at home)? **Yes / No**
2. In-home nursing or other specialized care? **Yes / No**
3. Home services (such as housekeeping)? **Yes / No**
4. Physical therapy? **Yes / No**
5. Occupational therapy? **Yes / No**
6. Speech therapy? **Yes / No**
7. Psychological services or behaviour therapy? **Yes / No**
8. Information or training to help your child(ren) in activities of daily living? **Yes / No**
9. Social or recreational activities for your child(ren)? **Yes / No**
10. Educational or academic support for child(ren)? **Yes / No**
11. Counseling/psychotherapy for your child(ren)? **Yes / No**
12. Counseling/psychotherapy for other family members? **Yes / No**
13. Support meeting with other families to discuss caring for child(ren) with disabilities?
Yes / No
14. Psychiatrist visit for medication? **Yes / No**
15. Day/partial hospital program? **Yes / No**
16. Transportation assistance (not including school bus)? **Yes / No**
17. Information about or help obtaining benefits such as food vouchers, utility assistance,
income support or health care? **Yes / No**
18. Out of home respite care? **Yes / No**
19. Information about, or help obtaining residential services? **Yes / No**
20. Information about, or help obtaining psychiatric services? **Yes / No**

21. Legal assistance? **Yes / No**
22. Emergency residential services? **Yes / No**
23. Crisis intervention? **Yes / No**
24. Alcohol/drug abuse treatment for other family members? **Yes / No**
25. Advocacy (help and support) when dealing with service programs? **Yes / No**
26. Routine medical checkup for child(ren) (not for a specific problem)? **Yes / No**
27. Routine dental checkup for child(ren) (not for a specific problem)? **Yes / No**
28. Hospitalization for psychiatric care? **Yes / No**

Appendix K:
Letter of Support from Pacekids



September 7, 2017

Kyla Roberts
c/o University of Lethbridge
Via e-mail (kyla.michelle.roberts@gmail.com)

Dear Kyla

Pacekids Programs is pleased to support your thesis research on the mental and physical health, stress and needs of caregivers of children with disabilities.

The results on this research not only has the potential to help the families we work with, but it may also influence the types of programming we provide and how we extend supports to families.

When specific information about the research and how families can participate, we will forward the information to our 400+ families with encouragement for them to participate. We will also share the call for participants on our social media channels.

For this support, we only ask for a copy of the findings once they are available.

If you have any questions or concerns about our support, please don't hesitate to contact me directly at lori.james@pacekids.ca or 587-390-0125.

Kind regards

Lori James
Managing Director, FSCD Programs



Pacekids Programs 808 5th Avenue NE, Calgary, AB T2E 6Y4
Phone: 403.234.7876 Fax: 403.685.3146 Email: info@pacekids.ca
www.pacekids.ca

Pacekids is a non-profit, registered charitable organization since 1994 #89131 3363 RR0001



Appendix L:

Poster to Advertise the Study



Are you a parent/caregiver of a child with or without disabilities?

You are invited to participate in a 15-minute online survey that will assess the mental and physical health, stress and needs of parents/caregivers of children with and without disabilities. Participation is voluntary and anonymous.

We would like to hear from you if you are:

- A parent/caregiver of a child without disabilities (aged 3-12)
- A parent/caregiver of a child with disabilities (aged 3-12) enrolled in a Specialized Services program in Alberta

For more information, please go to: http://scholar.ulethbridge.ca/em_pijl/students

This research study has been approved by the University of Lethbridge Human Subject Research Committee.



To go to the survey:

https://uleth.qualtrics.com/jfe/form/SV_8GNABoFdko3E1bT

1/20 chance of winning one of four \$50 Amazon gift cards as a thank-you for your participation!



Supervisor: Em Pijl, PhD, RN, Faculty of Health Sciences
em.pijl@uleth.ca 403-332-5232

Principal Investigator: Kyla Roberts, B.A., M.Ed. student
kyla.roberts@uleth.ca



Appendix M:

Advertisement for Recruitment by E-mail and Social Media

Participants needed! 15 minutes of your time for a 1/20 chance of winning one of four \$50.00 Amazon gift cards

In 2006, a national survey revealed that 3.7% of Canadian children under the age of 15 had one or more disabilities. As many Canadian families are affected by childhood disabilities, it is essential that social service providers understand the complex experiences and challenges that these families face in order to develop effective support services for this population. The literature has strongly demonstrated that caregivers of children with disabilities, in comparison to caregivers of neurotypical children, experience an exorbitant amount of stress, which can have detrimental effects on their physical and psychological health. The purpose of this survey is to investigate the psychological and physical health, stress and needs of caregivers of children with disabilities. Please see the poster below for more information. Thank you for your time and cooperation.

To go to the survey: https://uleth.qualtrics.com/jfe/form/SV_8GNABoFdko3ElbT

Appendix N:**Lottery Contact Information Form****Lottery Contact Information Form**

Please complete the contact information form below ONLY if you would like to be entered in the draw to win one of four \$50 Amazon gift cards:

Please write your FIRST name: _____

Please write your LAST name: _____

Please write your E-MAIL address: _____

Please write your PHONE number: _____

To satisfy federal legal requirements with respect to lotteries, receipt of the prize must depend to some extent on skill. To be eligible to claim the prize, if you win, please answer the following question:

1 + (2X10)≡

Thank you for your participation!

Appendix O:**Consent Form and Letter of Invitation****PARTICIPANT (ADULT) CONSENT
FORM AND LETTER OF INVITATION****THE PSYCHOLOGICAL AND PHYSICAL HEALTH, STRESS AND NEEDS OF
CAREGIVERS OF CHILDREN WITH DISABILITIES ENROLLED IN FAMILY-
CENTERED SUPPORT PROGRAMS**

You are being invited to participate in a study entitled “The Psychological and Physical Health, Stress and Needs of Caregivers of Children with Disabilities Enrolled in Family-Centered Support Programs” that is being conducted by Kyla Roberts who is a graduate student in the Faculty of Education at the University of Lethbridge. You may contact the student researcher at kyla.roberts@uleth.ca if you have questions about this study or if you are interested in receiving a summary of the findings upon completion (available after September 2018).

As a graduate student, Kyla is required to conduct research as part of the requirements for a degree in Master of Education Counselling Psychology with a focus on addiction and mental health. It is being conducted under the supervision of Dr. Em Pijl. You may contact Dr. Pijl at 403-332-5232. Two other researchers, Dr. Kellett and Dr. Piquette, will be active consultants and committee members throughout the study. If you have any questions about their involvement, you may contact Dr. Peter Kellett at 403-329-2643 and Dr. Noella Piquette at 403-394-3954.

The purpose of this research project is to expand on previous findings and to investigate the psychological and physical health, stress and needs of caregivers of children with disabilities who are enrolled in family-centered support programs in Alberta, Canada.

Research of this type is important because the literature in this field, although limited, has strongly demonstrated that caregivers of children with disabilities, in comparison to caregivers of children without disabilities, experience an exorbitant amount of stress, which can have detrimental effects on their physical and psychological health. To the knowledge of the author, this study will be the first of its kind to explore the mental and physical health, stress and needs of caregivers of children with disabilities enrolled in family-centered wrap-around service programs in Alberta, Canada.

You are being asked to participate in this study because you have identified as a caregiver of a child (or children) with disabilities enrolled in a Specialized Services program or a caregiver of a child (or children) without disabilities. The present study will be comparing the experiences of caregivers of children with disabilities to caregivers of children without disabilities to better understand how caring for a child with disabilities may deviate from the typical caregiving experience.

If you agree to voluntarily participate in this research, your participation will include an online or paper survey that will take approximately 15 minutes to complete.

Participation in this study may result in emotional discomfort or distress. To prevent or deal with these risks, a list of mental health specialists within the city of Lethbridge is included in this consent form to support you emotionally and psychologically. Moreover, the results of this study may reach policy makers and service providers. Thus, it is important to note that your participation in this study has the potential to influence future program development and policy reform.

Your participation may improve our understanding of the psychological and physical health, stress and needs of caregivers of children with disabilities. As a thank you for your participation, if you choose you may enter your name and contact information into a separate online form at the end of the survey, to win one of four \$50 Amazon gift cards. The draw is online and completely separate from the survey and your personal information will not be connected in any way. If you choose to participate in the lottery, your contact information will only be accessed if you win; the information will then be destroyed. The same rules of confidentiality will apply to any information that is collected for the purpose of the draw. The odds of winning the draw are 1 chance in 25 (assuming 100 participants complete the survey). If you choose to withdraw from the study and still wish to have your name entered in the draw to win one of four \$50 Amazon gift cards, you may contact the student researcher Kyla Roberts with your request at kyla.roberts@uleth.ca.

If you choose to complete a paper survey, you may also enter in the draw to win one of four \$50 Amazon gift cards by contacting the student researcher Kyla Roberts at kyla.roberts@uleth.ca and providing your name and contact information. If you choose to participate in the lottery, your contact information will only be accessed if you win; the information will then be destroyed. The same rules of confidentiality will apply to any information that is collected for the purpose of the draw. Your contact information will be kept separate from your completed survey. The odds of winning the draw are 1 chance in 25 (assuming 100 participants complete the survey).

Your participation in this research is completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or explanation by exiting the online survey or asking that your paper survey be discarded upon handing it back to the student researcher. Apart from paper surveys handed directly to the student researcher that will be destroyed at the request of participants, it will not possible to

remove the data submitted up to the point of withdrawal because there is no personal identifying information in the survey that could be used to identify your specific responses. If you do not complete the survey, your data will be included in the study at the discretion of the student researcher and supervisor. Qualtrics Research Suite®, the online survey tool used in this study, will automatically save the data from partially completed surveys, even if the window on the computer screen has been closed.

In terms of protecting your anonymity, you will be assigned a numerical code and will have the contact information of my research supervisor, my own contact information, and the contact information for the University of Lethbridge Office of Research Ethics. Your identity will also be kept confidential from any other members of the research team including the supervisory committee.

Participation is voluntary and your responses will not be identified with you personally as the survey collects no identifying information; however, as with any online survey, neither anonymity nor confidentiality can be completely guaranteed.

The survey is being hosted on Qualtrics Research Suite® and their privacy policy can be accessed at <https://www.qualtrics.com/security-statement/>. Canadian data in Qualtrics Research Suite® is stored in Canada. The Suite is password protected and encrypted. SPSS Statistics® software will be used to analyze the data on a password-protected computer. Raw data organized in Excel® and SPSS will be kept on a password protected or encrypted USB key that will only be stored in a locked cabinet in Dr. Pijl's locked office or will be in the hands of the student researcher and/or the supervisor. Your confidentiality and the confidentiality of the data will be further protected by consent.

At the beginning of the online survey, consent will be obtained by the participants clicking a button stating that they agree to the conditions of participating in the study. Participants completing online surveys will not be asked to provide a name or signature, thus all survey responses will remain confidential, aside from the IP addresses associated with participant data.

Paper consent documents will require a printed name and signature, but these forms will be kept separate from the raw data to ensure that the confidentiality of participants is protected. Each paper survey will have a unique code on it so that a list can be kept linking participant names to numerical codes. This master list will be kept separate and secure from the signed consent forms and completed surveys for enhanced protection of confidentiality. Paper surveys will be kept in a locked cabinet in Dr. Em Pijl's locked office for up to five years. Upon concluding the research, all data from this study and copies of the consent forms will be destroyed within five years.

Other planned uses of this data and results of this study include being disseminated in journals (hard copies and online), within a written thesis (hard copies and online), at professional conferences and potentially at community events. Thus, the results of the study have the potential to reach policy makers and service providers. Upon concluding the research, all data from this study and copies of the consent forms will be destroyed

within five years. In addition to being able to contact the researcher Kyla Roberts and, if applicable, the supervisor Dr. Pijl at the above phone numbers, you may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Office of Research Ethics at the University of Lethbridge at research.services@uleth.ca or 403-329-2747.

This study will solely reflect the interests of the researchers involved and is not representative the opinions of Family Support for Children with Disabilities (FSCD), Pacekids or the various organizations which provide Specialized Services to the community.

For paper surveys only:

Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers. [A signature will only be required on paper surveys and the consent form will be kept separate from the raw data. At the beginning of the online survey, consent will be obtained by the participants clicking a button stating that they agree to the conditions of participating in the study.]

You must be between the ages of 18 and 65 to participate in this survey.

For online surveys only:

If you wish to participate in the survey, please proceed to the questions now at https://uleth.qualtrics.com/jfe/form/SV_8GNABoFdko3ElbT . Submission of your responses will be accepted as implied consent to participate. Thank you in advance for your participation

For paper surveys only:

<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
----------------------------	------------------	-------------

A copy of this consent will be left with you, and a copy will be taken by the researcher

Referral Phone Numbers for Lethbridge

Lethbridge Counselling Services: 403-942-0452

Associates' Counselling Services Inc: 403-381-6000

Crossroads Counselling Centre: 403-327-7080

YWCA Lethbridge & District: 403-329-0088

Distress Line of South Western Alberta: 403-327-7905 OR 1-888-787-2880

Lethbridge Family Services: 403-327-5724

University of Lethbridge Counselling Services: 403-317-2845

Family Centre: 403-320-4232

Referral Phone Numbers, Texting and Online Chat Services for Calgary

Calgary Counselling Centre: 403-265-4980

Canadian Mental Health Association: 403-297-1700

Distress Centre (24/7 crisis line): 403-266-1601

Distress Centre (online chat):

<http://m2.icarol.com/ConsumerRegistration.aspx?org=2181&pid=1&cc=en-US>

Distress Centre (counselling): 403-266-4357

Wood's Homes (Eastside Family Centre): 403-299-9696

Wood's Homes (24/7 crisis line): 403-299-9699 or 1-800-563-6106

Wood's Homes (texting crisis services): 587-315-5000

Appendix P:**Conditions Reported by the Caregivers of Children with Disabilities**

The following information was entered by respondents who were parents of at least one child with a disability. Respondents indicated in a text box the disorders affecting their child(ren).

Participant 1: Fetal Alcohol Spectrum Disorder (FASD), Autism Spectrum Disorder (ASD), speech disorder

Participant 2: Chromosomal deletion disorder

Participant 3: FASD, Attention-Deficit/Hyperactivity Disorder (ADHD), Social Inhibition Disorder, learning disabilities, Posttraumatic Stress Disorder (PTSD), Generalized Anxiety Disorder (GAD)

Participant 4: Asperger's syndrome, developmental delay

Participant 5: ASD

Participant 6: Angelman syndrome, ASD

Participant 7: ASD

Participant 8: Scoliosis, ADHD, Oppositional Defiant Disorder (ODD)

Participant 9: ADHD, PTSD

Participant 10: Asperger's syndrome, ADHD, ODD, anxiety, sensory processing issues

Participant 11: ASD

Participant 12: ASD

Participant 13: Microcephaly

Participant 14: ASD

Participant 15: Down syndrome

Participant 16: Microcephaly

Participant 17: ASD, Global Developmental Delay (GDD)

Participant 18: ASD, Sensory Processing Disorder (SPD), speech disorder

Participant 19: Tourette's syndrome, ADHD, OCD, ODD, anxiety, learning disability

Participant 20: Pervasive Developmental Disorder

Participant 21: ASD

- Participant 22: Angelman Syndrome
- Participant 23: Chromosomal deletion disorder
- Participant 24: ASD, ODD, selective mutism
- Participant 25: Speech disorder
- Participant 25: Speech disorder
- Participant 26: Ehlers-Danlos Syndrome
- Participant 27: Hypoplastic left heart syndrome and pulmonary hypertension
- Participant 28: Down syndrome
- Participant 29: GDD, sleep apnea, gastroesophageal reflux disease, chromosomal disorder
- Participant 30: Cerebral palsy, ASD
- Participant 31: ADHD, ODD
- Participant 32: Epilepsy, developmental delay, progressive ataxia
- Participant 33: ASD
- Participant 34: ASD
- Participant 35: FASD
- Participant 36: ADHD, ODD
- Participant 37: ADHD, ASD, ODD
- Participant 38: GDD, GAD
- Participant 39: ASD, speech disorder, sensory processing disorder, anxiety
- Participant 40: FASD, PTSD, Reactive Attachment Disorder (RAD)
- Participant 41: GDD
- Participant 42: FASD, ADHD, ODD, RAD, PTSD
- Participant 43: ADHD, ODD, ASD
- Participant 44: Arthrogryposis multiplex congenita, chromosomal deletion disorder
- Participant 45: Non-progressive hydrocephalus ex-vacuo