STRESS IN CAREGIVERS OF PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES:

THE ROLE OF SUPPORT

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ABSTRACT

Caregivers of individuals with Intellectual and Developmental Disabilities (IDD) experience high rates of stress, which leads to difficulties for both caregivers and care receivers. A relationship was found between caregiver stress and unmet needs for support or services. This study used the General Social Survey: Caregiving and Care Receiving to explore caregiver service needs, service access and relationship between services and stress. Results from this study found an increase in caregiver stress was related to an increased need for services. Caregiver stress was increased in people who received formal support services and was decreased in people who had informal support. Caregivers who received funding were more likely to report they were stressed. Compared to formal support and demographic factors, caregivers who received informal support were 2.85 times more likely to report not experiencing stress related to caregiving duties.

DEDICATION

This thesis is dedicated to my grandmother Esther Georgina Mercer, who taught me that it is never too late to achieve your dreams.

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Chapter 1: Introduction

The Center for Disease Control defines developmental disabilities (DD) as “a group of conditions due to impairment in physical, learning, language or behavior areas. These conditions begin during the developmental period, may impact day- to- day functioning, and, usually last throughout a person’s lifetime” (Center for Disease Control, 2015, para. 1). Examples of DD include conditions such as cerebral palsy, spina bifida and, autism spectrum disorders. The prevalence rate of DD is estimated to be approximately 15% (CDC, 2015).

The most common DD is intellectual disability (ID) (May Institute, 2010). ID is a disorder that results in deficits in two areas as measured by standardized tests. The first is intellectual functioning. Individuals who meet the criteria for ID have an Intellectual Quotient (IQ) of 70 or below. ID is categorized by severity based on the individual’s IQ score. The second deficit is in adaptive functioning or adaptive behaviour (American Psychiatric Association, 2013). “Adaptive behavior is the collection of conceptual, social, and practical skills that are learned, and performed by people in their everyday lives (American Association of Intellectual and Developmental Disabilities, 2013, para. 4).” Adaptive behaviour consists of three categories of skills. The first is conceptual skills, which includes language, literacy, and understanding of concepts such as money, time, numbers, and self-direction. The second category is social skills, which includes interpersonal skills as well as community safety skills, such as obeying rules, and avoiding victimization. The third category is practical skills. This includes activities of daily living, or personal care, the ability to take care of one’s health, manage one’s money, follow a schedule or routine, safety skills, and occupational skills (American Association of Intellectual and Developmental Disabilities, 2010). For an individual with ID, deficits in adaptive behaviour limit functioning in one or more activities of daily living, and are present across several environments (American Psychiatric Association, 2013).

The worldwide prevalence of ID varies based on geographic region. Approximately one to three percent of the world's population has an ID (Hughes, 2006; Maulik, Maya, Colin, Tarun, & Shekhar, 2011). The highest rates of ID are in developing countries (Maulik, et al. 2011).

In the literature, there are several terms used to refer to this population. For the purposes of this research the term intellectual and developmental disabilities (IDD) will be used as an umbrella term for conditions that fall into the category of intellectual or developmental disabilities. Throughout the following chapters research pertaining to the following conditions will be discussed: ID, DD, Autism Spectrum Disorders (ASD) both with and without ID, and other related conditions.

1.1 Personal Experience

The journey to complete this master's thesis has been long and not without many challenges. For almost 10 years I have been a behaviour management specialist, where I have worked with numerous individuals with IDD and their caregivers to reduce challenging behaviour, increase skills and improve their quality of life. During this time, I have become familiar with a number of barriers that individuals with IDD and their caregivers face when trying to access services.

One area where this is apparent is with respect to their mental health needs and mental health services. Individuals with IDD are at increased risk for developing mental health concerns compared to the general population (Cooper, Smiley, Morrison & Williamson, 2007; Einsfeld, Ellis & Emerson, 2011; Harris, 2006). From my work experience I have seen this to be the case. Despite this knowledge I have seen individuals with IDD and their caregivers struggle when trying to obtain an accurate mental health diagnosis, receive appropriate treatment and obtain the necessary services. It was very clear to me that mental illness among people with IDD is very misunderstood and often missed, impacting the individual’s quality of life.

The impact of this experience on caregivers was also apparent through my work experience. I have sat with many parents or caregivers as they have cried about the stress of caring for an individual with IDD along with the additional challenges of a mental health diagnosis and/or challenging behaviour. From these conversations, one theme that frequently occurred was the stress caregivers faced when trying to access services to improve their situations.

These experiences led me to have an interest in contributing to the research for people with IDD and comorbid mental health diagnoses. The goals of the initial study were to examine the service needs identified by caregivers, their experiences (satisfaction or dissatisfaction) with the services received, and the barriers that prevented them from accessing services. The design of the original study was a mixed methods phenomenological study, using a modified version of the Need for Help Questionnaire (Douma, Dekker & Koot, 2006). After two years of trying to recruit participants to participate in online surveys or in person questionnaires I was unable to recruit a sufficient number of participants. As a result, I changed my study and used data from the Caregiving and Care Receiving survey from the General Social Survey completed by Statistics Canada. While this change in direction differs from the original study, it still allowed me to examine the main objective, caregiver stress and its relationship to support and access to services.

1.2 Support Needs of Individuals with IDD

The support needs of individuals with IDD are individual and vary based on the person's level of cognitive impairment, as well as available supports and abilities (Harris, 2006). Some individuals with mild IDD can live independently. However, the majority of individuals with IDD, as a result of their deficits in adaptive behaviour, will require support for the rest of their lives (Hughes, 2006).

In addition to needing support for adaptive deficits, individuals with IDD often have additional challenges. One example of this is higher than average rates of comorbid mental illness. Mental illness co-occurs with IDD at rates of approximately 30-40% (Cooper, Smiley, Morrison & Williamson, 2007; Einsfeld, Ellis & Emerson, 2011; Harris, 2006), compared to rates of 20% in the general population (Public Health Agency of Canada, 2002). Second, challenging behaviour occurs more frequently among individuals with IDD. Challenging behaviours refers to behaviours that are culturally abnormal, and occur at such intensity, frequency, and duration that it causes harm to the individual or others and/or impacts their quality of life by limiting their use of community facilities (Emerson 2001).

Given the unique challenges and care needs of individuals with IDD, it is not surprising that it can have an impact on parents and caregivers overall quality of life. Providing care for persons with IDD is known to increase stress. Dykens and Lambert (2013) measured the amount of stress in mothers of children and adults with IDD using the biomarker cortisol. The results indicated that 63% of mothers had cortisol levels that indicated higher stress levels. Increased caregiver stress has implications for both the caregiver the care receiver. A high stress level among caregivers was associated with anxiety, depression, and physical health problems (Chou, Pu, Fu, Kroger, 2010; Gallagher & Whiteley, 2012).

Many caregivers of individuals with IDD expressed a high need for service to cope with caregiving challenges. Despite this high need for services, many caregivers reported not receiving the necessary services (Douma, et al., 2006; Weiss & Lunsky, 2010). Research has shown caregivers who reported more unmet service needs or a need for a greater amount of service reported higher caregiver burden, stress, and poor mental health (Caldwell, 2008; Williamson & Perkins, 2014). Additionally, caregivers who reported difficulties with physical and/or mental health were more likely to seek out of home placement for their care receivers (Williamson & Perkins, 2014).

1.3 Purpose of this Study

Given the high rates of stress among caregivers of individuals with IDD, specifically those who reported unmet need for services it is important to understand this relationship to effectively reduce caregiver stress. The overall goal of this study was to explore the role of support for caregivers of individuals with IDD. This study examined what services a sample of Canadian caregivers of individuals with IDD needed, what services they accessed, and the barriers to accessing those services. In addition, this study explored the relationship between caregiver stress with need for service, services received, and caregiver/care receiver characteristics. For the purposes of this study, support is separated into two categories: informal and formal support. Informal support included support provided by family, friends, volunteers, and anyone else who provided support without receiving pay. This is also referred to as social support in the research literature. Formal support refers to support provided through government services, and individuals who are paid to provide services.

This study used data from the General Social Survey, Caregiving and Care Receiving. The Caregiving and Care Receiving survey was used to collect information on caregiving and care receiving for Canadians with a variety of health conditions such as aging, terminal illness, physical disability, and developmental disability. The primary use of this data was for government departments to assist in the development of policies and programs that meet the needs of Canadian caregivers (Statistics Canada, 2016). Academic researchers have also used this data from the Caregiving and Care Receiving survey as a secondary data source. Published research with this database has been used to provide an overview of Canadian caregivers, the fiscal impacts of caregiving, the impact of caregiving on employment, and the impact of caring for aging family members (Jacobs, Lilly, Ng & Coyte, 2013; Turcotte, 2013).

Findings from the Caregiving and Care Receiving study estimated that approximately 28% of the population provided care to family members or friend (Turcotte, 2013). The majority of caregivers who provided two or more hours of support a week were caring for their children. Those caregivers who provided care to a close family member such as a spouse or child reported more health and psychological problems. These problems were reported to be a result of the intensity of care provided (Turcotte, 2013). Of those caregivers who participated in this survey, 22% provided care to an individual because of a developmental problem or disability. These caregivers provided more care than other caregivers in this survey, averaging at least 10 hours of care a week. Most of these caregivers were parents providing care to their own children (Sinha, 2012; Turcotte, 2013). Despite these results, no previous study has looked specifically at the needs of this subpopulation. The current study isolated the data specific to caregivers of individuals with IDD for the analysis.

This study examined the following research questions:

1) What services do caregivers of individuals with developmental disabilities need and what services did they access?
2) What was the relationship between caregiver need for support and self-reported stress?

3) How did formal and informal support influence self-reported caregiver stress in combination with demographic factors?

1.4 Theoretical Framework

This research study examined participants' experiences through Bronfenbrenner's Bioecological Model of Human Development. This model views human development as being influenced by interactions between the individual and systems within their environment (Bronfenbrenner, 1977). Bronfenbrenner (1977) defined the ecology of human development as "the scientific study of the progressive, mutual accommodation, throughout the life span, between a growing human organism and the changing immediate environments in which it lives, as this process is affected by relations obtaining within and between these immediate settings, as well as the larger social contexts, both formal and informal, in which the settings are embedded" (p. 514). Bronfenbrenner divided the ecological environment into four levels: Microsystem, Mesosystem, Exosystem, and Macrosystem (Bronfenbrenner, 1977).

The Microsystem includes the relationships between the person and the environment. This refers to an immediate setting containing that person where participants engage in particular activities or roles (Bronfenbrenner, 1977). The Mesosystem refers to the interrelationship between settings containing the person at a particular point in their development. The Exosystem is considered an extension of Mesosystem. This includes other specific social structures, both formal and informal, that does not contain the person but encompasses and influences the immediate settings where the person is found. This includes the major institutions of society such as healthcare, schools, and work place. The fourth and final level, the Macrosystem, refers to the institutional patterns of the culture or subculture. This ideology influences all other systems previously mentioned (Bronfenbrenner, 1977).

Bronfenbrenner later modified his theory to become the Bioecological Model. In this model, he emphasized the importance of the developing person. Bronfenbrenner based this on two propositions. The first proposition is that “human development takes place through processes of progressively more complex reciprocal interaction between an active evolving biopsychological human organism and the persons, objects, and symbols in its immediate external environment (Bronfenbrenner, 1999, p. 5).” These reciprocal interactions are what Bronfenbrenner called proximal processes (Broderick & Blewitt, 2010; Bronfenbrenner, 1999).

The second proposition is that the individual’s development is impacted through the joint function of several factors. These include: the characteristics of the developing person, the environment, developmental outcomes, and social influences occurring within the historical period (Bronfenbrenner, 1999). Proximal processes are interactive, meaning the individual both influences and is influenced by the proximal processes (Broderick & Blewitt, 2010). Recognizing the importance of biological factors, Bronfenbrenner also discussed distal processes in his revised version of his theory. Distal processes include biological or physiological elements within the person. Proximal processes are modified by distal processes (Broderick & Blewitt, 2010).

Bronfenbrenner’s revised Bioecological Theory focuses on four factors, which he termed: process-person-context and time. Process refers to the interactions between the developing person and the objects and symbols in the environment. The person refers to the biological as well as personality characteristics or temperament of the individual. Context refers to the systems previously described: Microsystem, Exosystem and Macrosystem. Finally, time refers to the significance of the timing of events during the person's development, as well as the historical context of that time period. This is referred to as the chronosystem (Bronfenbrenner, 1999; Tudge, Mokrova, Hatfield, & Karnik, 2009).

Although this study is not a developmental psychology study, Bronfenbrenner's model is applicable to this research. Many individuals with IDD require a significant amount of support from their families, as well as external sources, often extending into their adult years. Rillotta, Kirby, Shearer and Nettelbeck (2012) stated, "Outcomes for families are important to the provision of services because families, rather than institutions, are increasingly considered the primary support unit" (2011, p.71). Bronfenbrenner (1999) emphasized that the lives of all family members are interdependent. Family stress was found to have a disruptive effect on the developing child. This stress does not only occur within environments involving the individual but also from other settings where caregiver interactions occur that do not involve the individual (Bronfenbrenner, 1986). Therefore, we cannot study caregiver stress and its impact on the person with IDD, without considering the impacts of external influences (Exosystem and Macrosystem).

There have been arguments made for using an ecological perspective to examine and assess caregiver needs. An ecological framework shows that the needs of caregivers and care receivers are intertwined and shows how decisions made in the policy sectors that provide services to these individuals have a profound effect on their lives

(Eckenweiler, 2007). Williamson and Perkins (2014) recommended that comprehensive assessment of caregiver needs should use the Bioecological Model. They argued a caregiver assessment that used an ecological approach will highlight both the needs of the caregiver and the care receiver.

Chapter 2: Review of the Literature

This chapter reviews the literature relevant to this study. The first part of this literature review provides an overview of stress and its impact on caregiving. The remaining sections of this chapter are divided into four sections of Bronfenbrenner's Bioecological Model: the Macrosystem, the Exosystem, the Microsystem, and the Person. The factors that contribute to caregiver stress at each level are discussed. The barriers to accessing services are also examined at the Macrosystem level. It should be noted that most caregivers of people with IDD are their parents; therefore, the research pertaining to both parenting and caregiving for people with IDD have been included in this study. Throughout this section the term parent and caregiver are used interchangeably.

2.1 Stress

Stress is traditionally defined in one of two ways. The first definition defines stress as a stimulus or a stressor, which is an event that happens to a person that causes stress. The second is a response involving physiological arousal and negative affect such as anxiety (Folkman, 2013). Stress was defined by Lazerus and Folkman (1984) as "a relationship between the person and the environment that is appraised as taxing or exceeding his or her resources and endangering his or her well-being" (p. 21). This definition is considered to be the hallmark of stress and coping theory (Folkman, 2013).

People differ in their sensitivity and vulnerability to specific events as well as their interpretations and reactions. Therefore, Lazerus and Folkman (1984) stated that people make what is called an appraisal. Appraisal is when an individual continuously evaluates a situation to determine how it is progressing in relation to their personal goals, values and beliefs (Folkman, 2013). Experiencing a situation as stressful varies from one person to the next, and is dependent on a number of factors (Lazerus & Folkman, 1984).

Impact of stress on the caregiver. Having a child with a disability impacts the parents and the family as a whole. Parents of children with IDD often experience guilt and blame for causing the disability. Siblings of individuals with IDD often receive less attention and time from their parents. In addition, they are often expected to provide care for their sibling. This demand increases as the sibling ages (Griffiths, et al., 2002).

Given the additional challenges of caring for an individual with IDD it is not surprising that caregivers expressed increased stress that impacts physical and mental health. Research in this area found that caregivers reported high rates of stress, more physical health problems, and high rates of depression (Chou, et al., 2010; Gallagher & Whiteley, 2012; McStay, et al., 2014). Long term or chronic stressors wear the person down psychologically and physically, making them susceptible to future illnesses (Lazerus & Folkman, 1984). This can be problematic for caregivers of individuals with IDD because most caregivers provide support to individuals with IDD for many years. More than half (55%) of the parents interviewed by Murphy, Christian, Caplin and Young (2006) indicated their physical and emotional health had been impacted because of the demands of caregiving.

2.2 Coping

Coping is what an individual does in response to stressful situations. It is the process of changing cognitive and behavioural efforts to manage demands that are appraised as exceeding the person’s resources. Coping refers to anything that a person does regardless of how well it works. (Lazarus & Folkman, 1984).

In their work, Lazarus and Folkman (1984) identified two types of coping: emotion-focused and problem-focused. Emotion-focused coping involved using cognitive processes that focus on lessening emotional distress. Emotion-focused coping was most likely to be used in situations where an appraisal has been made that nothing can be done to modify or change the situation. Specific emotion-focused coping strategies included: avoidance, minimization, distancing, selective attention, positive comparisons and gaining positive value from negative events. These types of coping are used to maintain hope and optimism, not for self-deception or reality distortion (Lazarus & Folkman, 1984).

The second type of coping was problem-focused. This type of coping was directed at defining the problem, generating alternatives, examining the alternatives in terms of cost/benefit, choosing among the alternatives, and acting. This type of coping is more likely to be used in situations where an appraisal has been made that the situation is amenable to change. Problem-focused coping included problem solving strategies as well as strategies that are directed inward. Some specific problem-focused strategies included: motivational/cognitive changes such as shifting level of aspiration, developing new standards of behaviour, and learning new skills or procedures (Lazarus & Folkman, 1984). Research on coping amongst caregivers of people with IDD found that problem-focused coping resulted in better outcomes for caregivers (Lai & Oei, 2014). Emotion-focused coping, on the other hand, resulted in higher stress levels, depression, anxiety, anger, and negative affect (Lai & Oei, 2014; Lin, Orsmond, Coster, & Cohn, 2011).

2.3 The Macrosystem

The Macrosystem refers to the institutional patterns of the culture or subculture. It is the information or ideology that influences all other systems. The place or priority that the person has in the Macrosystem influences how they are treated and interact with each other (Bronfenbrenner, 1977). Individuals with IDD, along with their caregivers, are often devalued in society and this likely impacts their access to support needed to reduce caregiver stress. This section of the literature review examines the role that the social movement, normalization, has played in caregiving for individuals with IDD. In addition, this section looks at attitudes and structure of services, and how this impacts access to services.

Normalization movement. The normalization principle was used as a means to prevent, minimize or reverse social devaluation of a group of people. It was developed as a systematic theory that can be applied to human services. Normalization promoted the opportunity for people with disabilities to be integrated into valued social roles. This included living in normative housing in the community, being educated with the rest of their peers, working in the same facilities as others, and being involved in the same activities as other members of society (Wolfensberger & Tullman, 1982).

The normalization movement changed how individuals with IDD received services in the community. The most notable change that impacted caregiving was deinstitutionalization, or the movement of individuals with ID from institutional settings to community housing (Hughes, 2006). Prior to deinstitutionalization, it was common for families to place children with IDD in institutions at birth. As a result of the normalization movement, however, IDD was no longer seen as a medical condition requiring treatment in an institutional setting (Ouellette-Kuntz, Garcin, Lewis, Minnes, Martin & Holden, 2005). After the closure of institutions, caregiving responsibilities for individuals with IDD were placed on families (Ouette-Kuntz, et al., 2005). Individuals with IDD typically require lifelong intervention and supports (Hughes, 2006). This means that many individuals with IDD are being supported by families well into their adult years.

Barriers to accessing services. Previous research has identified several barriers that people with IDD's and their caregivers faced when trying to access services. These barriers can be divided into two categories: societal attitudes towards people with IDD, and the structure of services. These two categories will be discussed in the following sections.

Attitudes towards people with IDD. While the normalization movement did shift attitudes about people with IDD, there are still stereotypes and biases that exist towards individuals with IDD and their caregivers. Family caregivers who participated in Chadwick and colleagues (2013) study stated they felt attitudes towards people with ID had changed. Many participants, however, reported that members of the public still seemed awkward, scared or embarrassed around their family member with ID. These caregivers were upset by negative experiences towards their family member with ID such as: exclusion, ignoring, bullying, and being made fun of by others (Chadwick et al., 2013). The participants also found that there was a lack of societal awareness of the challenges that families faced in supporting a family member with an ID. This was especially true if the disability was not physically evident to others. In this case the individual was viewed as difficult and people assumed the caregiver had poor parenting skills (Chadwick et al., 2013).

Public attitudes. Morin, Rivard, Crocker, Boursier and Caron (2013) conducted a study of public attitudes towards ID. Participants completed the Attitudes towards Intellectual Disability Questionnaire (Findler, Vilchinsky & Werner, 2007). They found that public attitudes were generally positive, an improvement compared to previous studies. However, they found that the general public held emotions and opinions that are in conflict with normalization, and contributed to the idea that individuals with ID cannot have a valid social role in society. Participants expressed pity towards people with ID and had reservations about their right to drink alcohol or have children.

Professional attitudes. It is to be expected that negative societal attitudes or biases would influence professionals who work with individuals with ID. It was also suggested that these biases or attitudes partly explained healthcare inequalities within this population (Lewis & Sternfert-Krose, 2010). Negative stereotypes that healthcare professionals have about individuals with ID influenced the services they provided to this population (Griffiths, et al., 2002).

Lewis and Sternfert-Kroese (2010) measured nurse’s attitudes and emotions towards two vignettes: one of a person with a physical disability and one of a person with an ID. The results of the study indicated that compared to the person with a physical disability, participants expressed significantly more negative attitudes and emotions towards the vignette of the person with ID. Age, gender or occupational status of the participants was found to have no impact on the results.

Service providers' attitudes not only provided a barrier for services but also the satisfaction the caregiver experienced from receiving the services. Participants interviewed by Faust and Scior (2008) stated they often felt let down, belittled and felt they were treated like "Neurotic parents" (p. 402) by service providers. Parents felt they needed to be threatening or yell at service providers to get results. Services provided were considered by some participants to be inadequate often infantilizing the youth and not paying attention to marked differences in ability in the ID population (Faust & Scior, 2008). Similarly, Weiss and Lunsky (2010) found that a large number of parents of individuals with ID who participated in their study expressed dissatisfactions with the services they received (Weiss & Lunsky, 2010).

Health disparities. Ouellette-Kuntz et al. (2005) defined health disparities as "population specific differences in health indicators. These differences may or may not be inequitable" (p. 59). The ID population experienced several health disparities. Griffiths, et al. (2002) stated that while individuals with ID have equal access to healthcare, they do not have equity of healthcare. Individuals with ID do not receive the same level of care as non-disabled persons.

Ouellette-Kuntz et al. (2005) stated that health disparities may have resulted from deinstitutionalization. Prior to deinstitutionalization individuals with IDD received specialized services. After deinstitutionalization, they accessed the same services as the general population. This is specifically the case when it comes to mental health or challenging behaviour. These systemic challenges lead to misdiagnoses, inappropriate treatments, and over-reliance on pharmacological interventions.

Structure of services. Another barrier for caregivers was how services were structured. Many caregivers indicated difficulty with the way services for people with IDD were structured. Parents interviewed by Faust and Scior (2008) felt overwhelmed by the multiple sites of service provision, each with a different philosophy and felt that there should be a clearer path to access necessary services. A few parents indicated that when services were eventually provided they were necessary and valuable. Similarly, parents interviewed by Chia and Lunsky (2003) expressed difficulty finding appropriate services or service providers. This was especially true once their children were past school age.

When services were found, caregivers and individuals often faced long wait times (Chia & Lunsky, 2003; Ward, Nichols & Freedman, 2010). This was usually because there were few health care professionals who were able to provide services to individuals with IDD. When these individuals received services they often did not feel their concerns were given adequate attention by service providers (Chia & Lunsky, 2003; Ward, Nichols & Freedman, 2010).

Barriers to accessing services and caregiver stress. The need to continually advocate for the care receiver was a significant source of stress for some caregivers and impacted their quality of life (Murphy et al., 2006; Yoong & Koritas, 2012). Parents often reported feeling they have to fight to get services and their situation had to reach a crisis point before services were delivered. They often felt their crisis was not taken seriously. Some parents reported that instead of receiving increased levels of support at times when needs were increased services were either inappropriate or withdrawn because of the presentation of the individual (Faust & Scior; James, 2013). Similarly, participants in Yoong and Koritas's (2012) study stated that they fought to receive services, funding, and equipment for their care receiver. They identified poor quality of services, poor communication between services, and lack of continuity of care. Several participants identified difficulties with government and bureaucracies for not providing funding to meet their needs.

2.4 The Exosystem

The Exosystem refers to the interactions between the person's microsystems. An example relevant to this study was the interaction between the individual's caregiver with health and social services. These interactions did not directly involve the individual (Bronfenbrenner, 1977). Bronfenbrenner (1999) noted that stress within a family can have disruptive effects on the person. This stress often resulted from external environments or the Exosystem. It has already been identified that caregivers of individuals with IDD faced increased challenges and levels of stress. These same caregivers are expected to support individuals with IDD into adulthood. Therefore, it can be assumed that these caregivers required more support to successfully care for individuals with IDD. This section of the literature review examined the caregiver's need for services, its relationship to stress, and the impact of formal and informal support on caregiver stress.

Caregiver need for service. Douma, et al. (2006) interviewed 289 caregivers of individuals with mild to moderate ID residing in the Netherlands, who reported emotional or behavioural problems in their child. The purpose of the study was to determine what types of services these caregivers needed, and whether or not their needs were met. To obtain this information the authors developed the Need for Help Questionnaire. This survey was based on an extensive literature review and semi-structured interviews with eight caregivers of dually diagnosed children and seven service providers (Douma, et al., 2006).

The Need for Help Questionnaire started with a screening question that asked parents how their child was doing with regards to their emotional and/or behavioural functioning in the past year. The questionnaire then examined the need for specific supports. The areas included: (1) a friendly ear for the parents to talk to, (2) information, (3) activities for child, (4) respite, (5) practical/material help, (6) child mental health care, and (7) parent counselling. The participants were then asked if each of their needs were met or unmet. If their needs were not met participants were asked to select the reasons for not receiving supports. The researchers also examined the influence of several contextual barriers (Douma, et al., 2006).

The results of the study indicated that parents need for services was very diverse. Approximately 88% of parents needed some support as a result of their child’s emotional or behavioural challenges, with 67.4% stated needing three or more types of support. The most frequent supports needed were: a friendly ear to talk to, information, parent counselling, and child mental health care. The reasons identified by participants for not seeking help included: (1) wanting to solve the problem on their own, (2) problem not considered serious enough to seek help, (3) not knowing where to find support, and (4) considering the problem to be temporary. Needs that were most likely to be met were: a friendly ear to talk to (75.3%) respite care (61.1%), and information (51.3%). In contrast, less than 43% of participants reported receiving practical/material help, child mental health care, activities for the child, and parent counselling (Douma, et al., 2006).

Weiss and Lunsky (2010) expanded on the study completed by Douma, et al. (2006). They used a modified version of the Need for Help Questionnaire with a sample of Canadian parents of individuals of children and adults with ID's who experienced a behavioural crisis in the past year. In addition to the Need for Help Questionnaire, participants were asked two open-ended questions. Overall, the participants in this study indicated that they had received the services they needed. However, when the participants were asked to rate their satisfaction with services received, many reported low levels of satisfaction (Weiss & Lunsky, 2010).

Other studies have found that caregiver's of individuals with IDD's need for supports were varied. Syveda, Weiss and Lunsky (2011) used the Brief Family Distress Scale (BFDS) to measure distress among families of individuals who have dual diagnosis (Weiss & Lunsky, 2011). The results of the study indicated the top priorities or needs identified by participants in order of importance were: information on family member's treatment progress, counselling to cope with symptoms or behaviours, information on treatment options, and activities for their family member.

Relationship between support and caregiver stress. Williamson and Perkins (2014) conducted a review of the research to determine family caregiver outcomes with existing services and supports for families with IDD in the US. The findings indicated that family caregiver’s relationships with services or supports were related to their mental health. Specifically, caregivers who report more unmet service needs or a need for a greater amount of service reported significantly higher caregiver burden and stress.

Similarly, Caldwell (2008) compared the physical and mental health status of women providing care to adult relatives with developmental disabilities to the general female population. Among other factors the study examined the relationship between caregiver physical and mental health and several factors, including unmet service needs and health care access. Unmet service needs and poor access to health care were found to be contributing factors to poor mental health for caregivers.

Support and coping. Support was found to be an effective coping strategy for caregivers. There were two different types of support that have been identified in the research, namely, formal and informal support. Formal support referred to services provided by paid staff. Informal support was provided by family, friends, and other sources of unpaid support. Both formal and informal support services, and their relationship to stress and coping, will be discussed in the following sections.

Formal support. Formal support services have an influence on both the amount of stress caregiver’s experience, as well as their ability to cope with stress. Lai and Oei (2014) found that availability of treatment services and referrals to support resources influenced both caregiver stress as well as their ability to cope with stress. In Lai & Oei’s (2014) review of parental coping literature they found that the most effective coping strategy for parents of children with ASD was problem-focused coping strategies. Problem-focused coping strategies included strategies such as: setting up treatment plans, and mobilizing support from others (Lai & Oei, 2014). These types of strategies were received through the use of formal support services. The types of formal support strategies discussed in the following sections include: home support or respite and financial support.

Home support or respite. Caregivers often expressed a need for respite services. The caregivers interviewed by Murphy et al. (2006) stated a lack of respite hours was a barrier to addressing their own self-care. Caregivers felt time away from caregiving would help to minimize burnout. Other studies also found that caregivers considered respite to be one of the most useful services they received (Dillenburger & Mckerr, 2010). Chou, Tzou, Pu, Kroger and Lee (2008) examined the effects associated with respite care for caregivers in Taiwan. Prior to using respite care, caregivers expressed a significant amount of caregiver burden and stress. Over half of the caregivers stated they had considered placing the care receiver in a 24-hour residential setting. After receiving respite, 71.3% of caregivers reported they felt either somewhat better or very much better in relation to overall caregiving burden. Factors that influenced the success of respite care included practicing a religion. There was lower satisfaction from respite care if the caregivers used it for any reason other than to have a short break.

In contrast, Hoare, Harris, Jackson and Kerley (1998) explored families' knowledge, use, and views of respite and the relationship between stress characteristics of the child and caregiver in relation to respite usage. Caregivers of children with severe/profound ID were selected from the UK to take part in the study. The findings indicated that those caregivers who used respite reported significantly more stress. When asked about their ability to cope now or in the future, non-respite users were more optimistic than respite users. Greater respite use was also significantly related to higher reported stress.

One possible reason for increased stress related to caregiving may be that the process of arranging services caused stress for caregivers. It was difficult for parents to find qualified respite care providers that they could trust (Chia & Lunsky, 2003; Murphy et al., 2006). Caregivers who did receive respite care often found that respite hours were used to care for other family members, not to rest themselves. Additionally, the work involved to plan for respite outweighed the benefits of respite (Murphy et al., 2006). A lack of flexibility was another concern that was identified by caregivers. If caregivers needed respite they had to arrange for it in advance. This did not account for emergencies (Yoong & Koritsas, 2012). Finally, caregivers receiving respite services reported higher rates of stress because they provided care to individuals with IDD who were more challenging, and reported higher rates of stress overall.

A large number of studies in this area indicated that caregivers needed and valued respite. However, respite services were not always readily available. If caregivers did have access to respite services, the respite available or funding was not sufficient enough to meet the caregiver’s needs. A review of respite services for caregivers of individuals with ID noted that respite services were more likely to be limited to adults over the age of 20 and for individuals who had severe or profound ID (McConkey, Kelly & Craig, 2010). This limited respite services for a number of other caregivers who might not have meet these criteria.

Financial support. The financial burden of medical expenses and other costs for caring for a person with IDD contributed to caregiver stress (Murphy et al., 2006; Serrata, 2012). Syveda, et al. (2011) measured caregiver stress in relation to a number of factors in a group of Canadian caregivers whose relative was referred to a mental health service for individuals with ID. Participants in the study completed the Brief Family Distress Scale (Weiss & Lunsky, 2011) to measure perceived level of crisis. The results of this study indicated that financial and employment difficulties caused the most distress for caregivers (Syveda, et al., 2011).

Informal support. Lai and Oei (2014) concluded from their review of the research that the second most useful coping strategy for caregivers of individuals with ASD was social support. Social support refers to informal support services. Caregivers of individuals with ID often express feelings of loneliness or social isolation (Chadwick et al., 2013; Griffiths, et al., 2002). Therefore, it is not surprising that social support has been reported by caregivers to be the most helpful in times of stress (Lai & Oei, 2014). As well, restricted access to social support as a result of caregiving responsibilities, have been found to increase parental stress (Cramm & Niebor, 2011).

Several studies show that social support is negatively correlated with stress in caregivers of individuals with IDD (Ben-Zur, Duvdevany & Lury, 2005; Hassell, Rose & McDonald, 2005; Hill & Rose, 2009). Feldman, McDonald, Serbin, Stack, Secco and Yu (2007) found social support was the only factor that mediated and marginally moderated the relationship between child behaviour problems and caregiver depressive symptoms.

Informal sources of support such as, family, friends, community, and support groups were found to reduce negative emotions for caregivers (Murphy et al., 2006).

However, other studies have found conflicting results. Plant and Saunders (2007) examined informal social support as moderators for caregiver stress. The factors examined were: family support, friend support, external/professional support, and positive coping strategies. There was no significance found between any of these factors and caregiver stress (Plant & Saunders, 2007). The sources of informal support discussed in the following sections include support provided by: family and friends, community, volunteer services, spiritual or cultural community, and support groups.

Support from family, friends and community. The caregivers in Murphy et al.'s (2006) study highly valued sources of informal support provided by of friends, extended family, and peer organizations. Some participants stated a quick phone call to a friend was effective in reducing stress. Unfortunately, caregivers felt they did not receive much support from their extended family, or the community at large (Chia & Lunsky, 2003). Participants from Yoong and Koritsas's (2012) study stated that the demands of caregiving limited the amount of time that they were able to spend with family members and friends. Many felt they were limited to friendships with other caregivers.

As parents of individuals with IDD age, siblings were often involved in their care. This demand increased as their sibling aged (Griffiths, et al., 2002). Seeking support from their children may actually increase caregiver stress. Parents often felt guilty about asking their other children to assist in their sibling's care (Yoong & Koritsas, 2012). The majority of older caregivers in Ireland who participated in Dillenburger and McKerr's

(2010) study did not made long term future plans for their adult child with a disability. A significant stressor for these participants was thinking about asking siblings to provide care. Caregivers felt they didn't want to burden them with the responsibility of providing care.

Religious support or spiritual coping. Spiritual coping was another type of informal support caregivers used to reduce stress. This included optimism and religious focused coping (Lai & Oei, 2014). Religion or spirituality was a source of support that often helped reduce stress in caregivers of individuals with IDD. A minority of the parents interviewed by Faust and Scior (2008) stated they found strength to cope with their children's behavioural and mental health concerns in their religious beliefs.

Luther, Canham, and Cureton (2005) found that while parents of children with Autism who participated in their study ranked spiritual support as high for coping with stress, low numbers of participants reported accessing spiritual support. The authors suggested that this may be because many parents with children with ASD may have found it difficult to access spiritual support because of the demands of caring for their child. For example, their child's need for constant supervision may have interfered with their ability to attend religious/spiritual services or events.

For some caregivers, holding certain religious beliefs may have contributed to increased stress. Caregivers from Taiwan who participated in the study by Wei et al. (2012) indicated that those who believed in Karma felt guilt about having to care for a person with a disability. They believed that their misfortune was a consequence of their actions.

Support groups. Support groups with other caregivers of individuals with IDD were found to be helpful to reduce caregiver stress and support resilience (Murphy et al., 2006; Yoong & Koritsas, 2012). Some caregivers identified being a part of a support network with other caregivers as one of the most positive experiences of providing care to a person with IDD (Yoong & Koritsas, 2012).

Wei, et al. (2012) examined the effectiveness of a support group of family caregivers in Taiwan providing care to family members with ID. The authors measured physical and psychological health of the caregivers before and after the support group and at four-week follow-up. The caregivers participated in an eight-week support group. Psychological health was measured using the 90 question Derogatis Symptoms Checklist (Zheng, 1987). Social support was measured using the Inventory of Socially Supportive Behaviours (Barrera & Ainlay, 1983) and the Social Support Questionnaire (Yang, 1998). There were four types of social support measured: emotional support, positive social interactions, information support, and material aid support. There were no significant differences between the control group and experimental group in measures of physical and psychological health at the beginning of the study. However, after the intervention, the experimental group showed statistically significant differences in depressive and anxious symptoms, as well as improvement in all four areas of social support. At follow-up, three of the four areas maintained significant improvement, with the exception of positive social interactions. The authors suggested that in order for improvements in positive social interactions to be maintained it would be necessary for caregivers to have continued involvement in the support group (Wei et al., 2012).

2.5 The Microsystem

The Microsystem was identified as the interaction of the person with the other systems. These interactions directly involved the person (Bronfenbrenner, 1977). This section of the literature review examined the caregiver characteristics that contribute to stress. There were several caregiver characteristics identified that were related to higher rates of caregiver stress. These included: gender, education level, income, co-residence with the care receiver, and marital status.

Gender. Gender of the caregiver was found to impact caregiving stress. One reason for this may be through secondary factors like adherence to traditional gender roles. Typically, fathers assumed the role of breadwinner and focused on work, while mothers took on more responsibility for caregiving (Lai and Oei, 2014; Murphy et al., 2006). Results from the General Social Survey, Caregiving and Care Receiving found that caregivers were slightly more likely to be female (54%). However, what differed was the type and amount of care provided by males and females. Approximately 20% of females spent 20 or more hours per week completing caregiving tasks, compared to 17% of males. Female caregiving duties were more likely to be assisting in personal care, medical treatments, and housework. Males were more likely to assist in house maintenance and outdoor work (56% of males completed these tasks, compared to 35% of females) (Sinha, 2012).

Gender also influenced how caregivers coped with stress through the types of coping strategies they used. Lai and Oei (2014) conducted a review of studies examining coping strategies of parents of individuals with autism spectrum disorders. They found that mothers tended to use coping strategies that have been found to be effective such as: social support, problem focused coping and spiritual coping. Fathers tended to use emotional coping, such as suppressing frustration or avoidance, which was found to be less effective.

Gender not only influenced caregiving and coping with associated stress, but it also influenced involvement in research related to caregiving. Heller, Caldwell, and Factor (2007) conducted a review of the research of aging caregivers of individuals with IDD. Some consistent findings in the research were that fathers were not only less likely to be primary caregivers but they were less likely to be included in research studies on the impact of caregiving. Having a low number of fathers involved in research makes it difficult to draw definite conclusions about the role of caregiver gender in the caregiving experience.

Education level. Studies in this area have also found conflicting results. Some studies found that caregiver's education level negatively correlated with caregiver psychological well-being and stress (Ben-Zur, et al., 2005; Cramm and Nieboer, 2011). However, caregivers who participated in the study conducted by Hoare et al. (1998) with higher levels of education reported significantly higher levels of stress. The authors suggested that this could be because caregivers with higher levels of education have a clearer understanding of their child's future (Hoare et al., 1998).

Caregiver's education level may influence other factors that contribute to stress. Results from the study conducted by Brandon (2011) found that if caregivers, specifically female caregivers, have a higher level of education it was more likely that they worked outside of the home, compared to mothers without post-secondary education. This may lower caregiver stress by increasing employment status and thereby increasing social contacts through the workplace.

Income. Research on caregiver stress and its relationship to income found that typically caregivers with higher incomes reported lower levels of stress and higher quality of life (Dardas & Ahmed, 2014; Ben-Zur, et al., 2005). Parents with higher incomes also used more diverse problem strategies, less escape-avoidance behaviour, and less responsibility acceptance behaviour, resulting in better coping (Dardas & Ahmed, 2014). It was also been suggested that caregivers may have a better sense of control over their situation and their child's future when they have a higher income (Ben-Zur, et al., 2005).

It was noted in the research that caregivers of individuals with IDD often reported financial stresses and lower socioeconomic status (Murphy et al., 2006; Syveda, et al., 2011; Yoong & Koritsas, 2012). There were a couple of reasons suggested for this discrepancy. One was that caregivers often reduced work hours or stopped employment to meet the needs of providing care to an individual with IDD (Syveda, et al., 2011; Brandon, 2011). Secondly, caregivers of individuals with IDD often had more expenses to meet the needs of caring for an individual with IDD (Murphy et al., 2006; Yoong & Korsitas, 2012). Caregivers from the Yoong and Koritsas's (2012) study stated they were struggling to make ends meet and to save money because of the cost of equipment for the care receiver. Most of their money went to meeting the care receiver's needs.

Co-residence with care receiver. One factor found to be related to caregiver stress and influence mental health outcomes was co-residence with the care receiver (Seltzer, Floyd, Song, Greenberg & Hong, 2011; Williamson & Perkins, 2014). Co-residence of the care receiver with IDD with their parent was prevalent especially during midlife and in the early years of old age (Seltzer et al., 2011). In particular, when compared to other types of IDD, people with ASD were more likely to live with a parent or guardian (87.1%), and only less likely to have ever lived independently (16.6%) (Anderson, Shattuck, Cooper, Roux & Wagner, 2014).

Ben-Zur, et al. (2005) administered questionnaires to mothers of adult children with ID residing in Israel to assess mental health resources and stress. Half the sample of mothers who participated had children who were placed outside of the home. There were several measures used to assess mental health and related factors. Mental health was measured using the Mental Health Inventory – Short Version. This questionnaire had 38 items rated on a six point Likert scale (Veit & Ware, 1983). Stress of caring for a child with an ID was measured using the 52-item Questionnaire on Resources and Stress. This questionnaire contained four scales: Parent and Family Problems, Parental Pessimism, Child's Characteristics and Child's Physical Incapacitation. Participants answered agree or disagree for each item (Friedrich, Greenberg & Crnic, 1983). The Interpersonal Support Evaluation List measured perceived social support, and contained 40 items that made up four subscales: belonging, appraisal, self-esteem, and tangible support (Cohen, Gottlieb & Underwood, 2000). Hardiness was measured using 50 items from the questionnaire that measure the three components of hardiness determined by Kobasa (1979): Commitment, Challenge, and Control. The results of the study indicated that mothers who placed their adult children out of the home expressed more stress than those whose adult children continued to reside at home with them. This was related to stress that specifically corresponded with the physical incapacitation subscale, or disability related stress (Ben-Zur, et al., 2005).

Co-residence with the care receiver has been found to influence other factors that led to increased caregiver stress. Parents who participated in the study conducted by Seltzer et al. (2011), whose adult children with IDD continued to live at home with them, reported a lower socioeconomic status (incomes below $44 000.00) compared to parents whose adult children resided in their own home. Additionally, co-residence with the care receiver impacted coping by reducing parent's access to informal social support. Parents whose adult children with IDD continued to live with them were less likely to visit with friends and relatives compared to parents whose adult children with IDD did not live with them (Seltzer et al, 2011).

Marital status. Caring for or parenting an individual with IDD has been found to increase stress because of the influence that marital status has on other factors known to influence stress. Parish, Rose, Swaine, Dababnah and Mayra (2012) examined the financial well-being of three groups of mothers in the United States: single mothers with a child with DD, single mothers without a child with DD, and married mothers with a child with DD. The findings indicated that single mothers of persons with DD were more likely to be living below the US poverty line when compared to both single mothers of people without IDD and married mothers (Parish, et al., 2012).

Financial difficulties were impacted by the ability of caregivers to secure and maintain employment. The demands of caring for an individual with IDD impacted on finding and securing employment. It also resulted in caregivers having to cut back on their hours of paid work and/or retiring early (Yoong & Koritsas, 2012). More than half of the parents who participated in the study conducted by Syveda, et al. (2011) had to quit jobs due to caregiving demands and as a result had difficulty paying bills. Single mothers of children with IDD were less likely to be employed compared to married mothers of children with IDD and single mothers of children without IDD (Gordon, Rosenman & Cuskelly, 2007).

The stress of caring for a child with an IDD can impact marriage. There has been a relationship found between stress and marriage quality among couples who have children with IDD. Kersh et al. (2006) found that parents of children with DD reported lower quality marriages compared to couples in the general population. Having a lower quality of marriage was also found to influence parenting stress in both mothers and fathers who participated in this study.

2.6 The Person

When Bronfenbrenner (1999) revised his ecological model to the current Bioecological Model he emphasized the importance of both distal and proximal processes on the development of the individual. Distal processes refer the person’s genetics or biology. Proximal processes are reciprocal interactions between the person and other persons, objects and symbols in the environment (Broderick & Blewitt, 2010; Bronfenbrenner, 1999). Individuals with IDD have additional challenges and require more demanding of care as a result of their condition, this can influence how caregivers respond to them.

It should be noted that proximal processes are not unidirectional; they are influenced by interactions in both directions (Bronfenbrenner, 1999). The previous sections of the literature review emphasized the impact of Exosystem and Macrosystem factors on caregiver stress. The next section looks at the impact of stress on the care receiver and the factors or distal processes that contribute to caregiver stress.

Impact of caregiver stress on the care receiver. Carona, Silva, Crespo, and Canavarro (2014) found that caregiving burden negatively correlated with quality of life for both parents and children. Caregiver stress impacts the care receiver in several ways. One being that people with IDD are at higher risk of being the victims of abuse. High levels of parental stress can increase this likelihood (Algood, Hong, Gourdine & Williams, 2011). In addition, poor caregiver health can contribute to recurrent hospitalizations and out of home placements for the care receiver (Murphy et al., 2006). There were several characteristics of care receivers identified in the literature that were related to caregiver stress. The characteristics examined in this study were: severity of IDD, gender, and employment status. These will be discussed in more detail in the following sections.

Severity of IDD. Studies found that the greater the severity of the disability, the lower the functional behaviour of the person, or more complex needs were related to higher caregiver stress and burden (Chou et al., 2010; Hoare et al., 1998; Williamson & Perkins, 2014). Plant and Saunders (2007) found that level of disability was a predictor of caregiver stress. In addition to severity of the IDD diagnosis there were additional challenges that co-existed within the individual with IDD that contributed to caregiver stress. These were challenging behaviour and/or comorbid mental illness.

Challenging behaviours and comorbid mental illness occur frequently among individuals with IDD. Caregivers who cared for individuals with IDD and caregivers of persons with dual diagnosis or challenging behaviour reported poorer physical health, more chronic medical conditions and higher rates of depression or anxiety compared to caregivers of individuals with a sole diagnosis of IDD (Faust & Scior, 2008; Miodrag & Hodapp, 2010; Woodman & Hauser-Cram, 2013). Challenging behaviour also made parents feel less effective in their parenting abilities. Woodman and Hauser-Cram (2013) found that mothers of adolescents with DD who displayed challenging behaviour felt less effective as parents, compared to parents of children with DD who didn’t have challenging behaviour. This lack of parenting efficacy also contributed to increased caregiver stress and mental health concerns.

Gender. Gender of the care receiver was another factor that was studied for its impact on caregiver stress. Gender of the care receiver was related to caregiver stress and caregiver coping (Ben-Zur, et al., 2005; Lai & Oei, 2014). Gender of the individual with IDD may be related to other factors that impacted caregiver stress. Deb, Thomas and Bright (2001) conducted a study that examined the prevalence of challenging behaviours, and its relationship to other factors including gender. They found that 60.4% of the individuals had challenging behaviours. While IDD’s are more prevalent among males, females had significantly higher rates of challenging behaviour (Deb, et al., 2001).

2.7 The Chronosystem

The chronosystem was included in Bronfenbrenner's model to represent the influence of time. This included the historical context as well as the passage of time, and life transitions (Bronfenbrenner, 1999). For this study, the historical context was discussed in the first section of this chapter, the Macrosystem, when we discussed the social movement normalization and subsequently the process of deinstitutionalization. This shifted the caregiving role from institutions to the family and had a direct impact on caregiving (Ouellette-Kuntz et al., 2005). The following sections will look at the role of age of caregiver and care receiver and the importance of life transitions.

Age. Age of both the caregiver and care receiver was found to be related to caregiver stress. In her book, Shifren (2009) wrote about the importance of using a lifespan perspective to examine caregiving and its impacts on the caregiver. Caregiving is not solely an adult activity, as adolescents and even young children can be involved in caregiving. Becoming a caregiver at certain times will impact the person's current and future development. Shifren (2009) examined the impacts of caregiving at each developmental age period as follows.

Caregiving during childhood and adolescence (under 18) while rare can occur. This may occur more frequently among families who have a member with IDD, where siblings may be expected to assist in caregiving. Most young caregivers started providing care in early to mid-adolescence. Caregiving in childhood and adolescence was found to have positive or negative implications. Caregiving at a young age can strengthen resiliency to adversity as an adult. If the young caregiver has a positive experience they may seek other opportunities to fulfill a caregiving role through friendships or a future career (Shifren, 2009).

Stress from caregiving provided other stressors during adolescence such as concerns about their body and development during puberty. The caregiving role also impacted adolescent identity development, causing future impacts by not allowing them to contemplate a variety of options related to: career, relationships etc. Their identity can become based on a narrower view of themselves such as how they are perceived or viewed by others and their current experiences. It may also limit the options they see for themselves in the future (Shifren, 2009).

Young adulthood (18-39) has unique challenges for caregiving. Emerging adulthood (18-25) is often identified in developmental psychology as a distinct period of development. Emerging adulthood was seen as an important time where individuals have varied life experiences and changes in world views. Many emerging adults moved out of their family home and attended post-secondary or worked for the first time. If an emerging adult was a caregiver, however, these experiences were delayed (Shifren, 2009).

Young adults are considered to be more stable in their relationships, careers, and living situations compared to adolescents or emerging adults. As a result, it is assumed that young adults will feel less stressed compared to adolescent or emerging adult caregivers because they have more life experiences to help with decision making pertaining to caregiving, especially pertaining to medical decisions (Shifren, 2009).

Previous and current experiences pertaining to caregiving can influence how the young adult perceives caregiving. Those who had positive experiences may thrive in their caregiving roles. They may choose careers that place them in the caregiving role. Alternately, if caregiving experiences were negative the young adult may choose to delay marriage or parenthood. Young adults may have their own children to care for and have to balance the caregiving roles with parenting (Shifren, 2009). In the case of parents of individuals with IDD some had to balance caring for their child with IDD along with caring for their other children.

Caregivers in middle and older adulthood also faced unique challenges. Caregivers in middle adulthood (40-65) had to balance many responsibilities: work, child rearing, relationships, community related activities, and caring for aging parents in addition to caregiving. One positive aspect of caregiving at this age was middle adult caregivers had the most social support available to them. Older adult caregivers (65+) had to cope with a decline in physical and cognitive abilities that may impact caregiving. While people can become grandparents in earlier stages in their life, most people are likely to be grandparents after age 60. This means that grandparent caregiving is most common during this developmental phase (Shifren, 2009).

Caregiver age. Some studies found that caregiver age influenced stress and mental health outcomes (Dardas & Ahmad, 2014; Williamson & Perkins, 2014). Dardas and Ahmad (2014) studied the relationship between parent characteristics, coping strategies used and three stress subscales: The Parenting Stress Index-Short Form (Abidin, 1995), the Revised Ways of Coping Checklist Revised (Folkman & Lazarus, 1988), and The World Health Association Quality of Life Index (WHO, 1996). The results indicated that two factors: being an older parent and, having more time since ASD was first diagnosed in their child, were significantly associated with lower parent distress scores and higher quality of life. In contrast, Caldwell (2008) found no significant differences in mental health between midlife and older caregivers of individuals with developmental disability. However, the study found that caregivers at both midlife and early old age had worse mental health outcomes compared to national norms.

One reason proposed for why age is related to stress is as caregiver's age, they encounter two major transitions in caregiving. One being that the individual with developmental disability transitions to adulthood. Second, the aging caregiver is no longer able to provide care (Caldwell, 2008). One common concern that caregivers have as they age is about what will happen to their children with IDD when they die Dillenburger & McKerr, 2010; Murphy et al., 2006). This uncertainty about the future was found to increase emotional stress and anxiety in caregivers (Murphy et al., 2006). Some caregivers even expressed a desire for the care receiver to pass away before them because they would rather not think about what will happen to them when they are no longer around to provide care (Dillenburger & McKerr, 2010; Yoong and Koritsas, 2012).

A second reason proposed for the relationship between caregiver age and stress is related to coping skills. As parents or caregivers get older they transition to the use of less effective coping strategies. Lai and Oei (2014) found in their research that younger parents tended to use problem focused coping while older parents tended to use emotion focused coping more often.

A third reason for caregiver stress increasing as caregiver's age is the impact that long term caregiving has on stress and mental health. Most caregivers of individuals with IDD are parents who provided care for the majority of the care receiver's life. Seltzer, et al. (2011) conducted a study to compare parents of children with and without IDD at two phases in life; mid-life and early old age. The findings indicated that in midlife parents of children with IDD were similar to parents of typically developing parents in symptoms of depression, and psychological well-being. By early old age, parents of children with IDD reported poorer health and mental health outcomes (Seltzer et al., 2011). Older caregivers who participated in the study conducted by Dillenburger and McKerr (2010) were more than twice as likely to experience psychological ill health compared to the same age adults in the general population.

Care receiver age. It is uncertain whether age of the care receiver impacts stress. Some studies have found that age of the care receiver was related to caregiver stress and impacted caregiver's ability to cope with stress (Lai & Oei, 2014). However, McStay et al. (2014) found in their research that age of the child was not significantly related to parenting stress. One reason that care receivers age may increase caregiver stress is changes in the care receiver. As the care receiver ages, their needs may become increasingly complex. Caregivers have to deal with declining health and changes in behaviour in addition to the existing needs of individuals with IDD. Long-term caregiving can have negative consequences for the caregivers, especially if the care receiver has complex needs or challenging behaviour (Hayley & Perkins, 2004).

2.8 Conclusion

Through the review of the literature we can see how the different levels of the Bioecological Model: the Person, Microsystem, Exosystem and Macrosystem have a direct impact on the person with IDD and their caregiver. In recent years, we have seen a shift in attitudes in how we view people with IDD. The normalization movement was the most significant shift, resulting in changes in how we deliver services to individuals with IDD. Despite the normalization movement, society still has biases and stereotypes about people with IDD. These affect professionals and how they deliver services to these individuals. In addition to professional attitudes, there are several barriers to accessing services.

The Exosystem examined the relationship between support and caregiver stress. It is not surprising that caregivers with adult children with IDD reported a high need for services. Caregivers’ needs for support were varied and dependent on individual circumstances. Additionally, need for support can change depending on circumstances, for example a caregiver will often require more support in times of crisis. The literature in this area has shown that there is a relationship between a need for support and caregiver stress. However, what is unclear is which type of support, formal or informal is most effective in reducing caregiver stress. Results from several studies often offered conflicting findings. What is apparent is the need for social support and its importance in reducing stress. Highlighted is the relevance of support groups of caregivers who can understand each other’s experiences.

At the Microsystem level, there were several caregiver characteristics that were found to influence caregiver stress. These included gender, age, income, employment status, and whether the individual resides with the care receiver. There are individual characteristics that influenced caregiver stress. In addition, caregiver stress impacts the quality of life of the individual with IDD, and vice versa.

Having an understanding of caregiver stress is important because it can impact the caregiver's ability to provide care and negatively impact the relationship between caregiver and care receiver (Miodrag & Hodapp, 2010). We see from this review of the literature, caregiver stress is a complex issue and one that is influenced by many factors. By taking the time to consider the factors through Bronfenbrenner's Bioecological Model, we can gain a better understanding of caregiver stress, and the factors that contribute to stress.

Chapter 3: Methodology

This study extracted data from the Public Use Microdata File of the General Social Survey, Cycle 26, 2012; Caregiving and Care Receiving. Smith (2008) stated that when using secondary data, one should consider the purpose of the original survey. The purpose of the original survey was to better understand the needs and challenges faced by those who give and receive care, and to help policy makers design programs to better meet their needs (Statistics Canada, 2016). The Caregiving and Care Receiving Survey is a subset of the General Social Survey (GSS). The objectives of the GSS were to gather data about social trends, to monitor changes in the living conditions of Canadians over time, and to gain information about social policy issues of interest (Statistics Canada, 2016). This survey corresponded well with the purpose of the current study, to determine how services/supports impacted caregiver stress, both individually and in combination with other factors.

Questions in the Caregiving and Care Receiving Survey covered the following topics: types and amount of care caregivers provided, and the types and amount of care received, and the unmet needs of caregivers and receivers. The survey was developed by staff at Statistics Canada using research and consultations with data users. The survey went through a pilot test in September 2011. The questionnaire was tested with randomly selected respondents in British Columbia, Alberta, and Quebec. Data collection and observations of this pilot test were conducted by survey team members. One-on-one in-depth qualitative interviews with respondents highlighted the questions that worked well and those that needed improvement. Where possible, feedback from these data users was incorporated into the original survey (Statistics Canada, 2016).

3.1 Secondary Data

This study used secondary data, or data that was collected for a different purpose that has been re-purposed for a different study (Goes & Simon, 2013). There are several advantages to using secondary data for research. One being that participant's identities kept confidential from the researcher as they do not collect the data (Smith, 2008). Additionally, it helps overcome the challenges with obtaining primary data, specifically participant recruitment, where researchers have to convince participants to respond to requests for data collection. Often in graduate studies, students are faced with difficulties recruiting participants and end up with smaller sample sizes than expected. This means that students have to modify analyzes to accommodate for the small sample size (Goes & Simon, 2013).

As discussed in chapter one, I originally tried to collect primary data for this study and was unable to collect an acceptable amount for analysis. Crinland, Jones, Caputi and Magee (2014) stated it is difficult to recruit families with a member with ASD using traditional methods such as flyers because parents do not have the time. Often, parents are dealing with other family responsibilities, in addition to caring for a child with ASD. Secondary data provided a solution to this problem as it provided access to a large pool of data collected on caregivers of individuals with IDD.

3.2 Survey Design

This survey used a cross-sectional design (Statistics Canada, 2016). Cross-sectional studies are those where the researcher collects the data at one point in time from people of different age groups (Leedy & Omrod, 2013). This design allowed for the measurement of the participants current beliefs attitudes or opinions. This type of design has the advantage of providing information about different age groups in a short amount of time (Cresswell, 2012). The disadvantage of cross-sectional studies is that it provides a snapshot of people's attitudes and beliefs at one point in time only, and cannot measure any changes that may occur through the person's development (Leedy & Omrod, 2013).

3.3 Participants

Participants of the Caregiving and Care Receiving survey were 25 000 randomly selected Canadians who met one of the following criteria: (1) receiving help or care due to a long-term health condition, disability or problems related to aging or (2) provided help or care to those with one of the previously stated conditions. The target population for this survey was individuals ages 15 and older, residing in one of the 10 provinces in Canada. This sample excluded those residing in the Yukon, Northwest Territories and full-time residents of institutions (Statistics Canada, 2016). This study focused on the needs of caregivers who reported caring for individuals they identified as having a developmental disability or developmental problem. Therefore, only the data from these participants was used for analysis. This reduced the sample size to 212 respondents.

Sampling. Participants were randomly selected from each of the 10 provinces. Statistics Canada divides each province further into strata, or geographical locations.

Random digit dialing was used to select the households in each stratum. Once the households were contacted a participant was randomly selected (Statistics Canada 2016).

To reach more participants for this survey a technique called rejective sampling was used. Rejective sampling is a technique used to increase the number of participants in hard to reach or small populations. All respondents were placed into one of four categories: caregiver, care receiver, both or neither. All caregivers and care receivers completed the long form interview. Those in the neither category were randomly assigned to either the long or short interview (Statistics Canada, 2016). Rejective sampling was then used to remove the poor performing data, or the outliers (Legg & Yu, 2010).

3.4 Data Collection

Interviews were completed at the four Statistics Canada regional offices and computer assisted telephone interviewing (CATI) was used to collect the data. Interviewers were Statistics Canada staff who had received training in telephone interviewing techniques using CATI and survey concepts and procedures. The majority of interviewers had prior experience administering telephone interviews. The survey could be completed in the language of the respondents choosing. Proxy interviews were allowed if one of the following criteria was met: the participant did not speak one of the official languages the survey was offered in, or, the participant could not take part in the interview because of health reasons. In these cases, another person in the household completed the interview on behalf of the participant. This only occurred in approximately 4% of the total interviews completed. Data for the Caregiving and Care Receiving survey was collected from March 2012 to January 2013. Data collection occurred in five waves, each lasting two months at a time (Statistics Canada, 2016).

Missing Data. Missing data was addressed in this study using a top down method. If participants did not answer a question but it was deemed to be consistent with their other responses it was coded as don't know. Refusals to answer questions were coded as not stated. If the response was considered off-path (i.e. a participant responded to a question for a sub-group in which they did not belong) it was coded as not asked. Statistics Canada did not use imputation for this survey because it was not appropriate for the types of questions used (Statistics Canada, 2013).

Weighting. Weighting is a statistical correction technique used to adjust survey data to improve the accuracy of survey estimates. The most common weight used in complex surveys is sampling weights. The principle behind weighting a sample is that each person in the sample represents several others not included in the survey in addition to him or herself (Bethlehem, 2008; Statistics Canada, 2016). The Caregiving and Care Receiving survey use two types of weights: person and household. The person weights are used for calculations using person characteristics, such as demographic data. Household weights were used for any calculations using household characteristics, such as household income (Statistics Canada, 2016). In addition to the person and household weights this survey also had available bootstrap weights. Bootstrapping is a technique that uses the variability within the sample to estimate the sample distribution (Mooney, 2008).

Weighting is necessary for survey designs because it helps reduce bias in survey results due to some groups being over or under-represented. It also allowed the researcher to generalize the findings of the results and to draw inferences about a larger population (Bethlehem, 2008; Rodgers-Farmer & Davis, 2001). One of the downsides of survey weights, however, is it can inflate significance because it increases the variance. This is especially the case with some of the current statistical software used for research analyses (Winship & Radbill, 1994). In preliminary calculations for this research it seemed that the significance was inflated when the person weights were used. The goal of this study; however, was not to draw inferences about the larger population of caregivers of individuals of IDD in Canada, but to focus on the participants in this study. Keeping this goal in mind and the inflated significance, this researcher made a conscious decision not to use person weights in any of the data analyses.

3.5 Variables and Analysis

Macinnes (2017) stated that when using secondary data variables often need to be deleted, transformed and/or recoded in order to complete meaningful data analysis. This was the case with several of the variables used in this study. In order to prepare this dataset for analysis the researcher completed the following steps: (1) any variables not relevant to this data analysis were deleted, (2) only those cases where the caregiver stated they provided care to an individual with a developmental disability or problem were filtered out from the original data set, and (3) several variables were recoded to allow for better analysis and interpretation of the results. The following sections provide a description of each of the variables and if and how they were recoded. Appendix A provides a summary table of the variables, the original coding, and any recoding that was completed.

Dependent variable: self-reported stress. The dependent variable used was self-reported stress. This was measured using the question, “How stressful have your caregiving responsibilities been during the past 12 months?” Participants responded using a Likert scale with the following 4 options: (1) very stressful, (2) stressful, (3) somewhat stressful, and (4) not at all stressful (Statistics Canada, 2012). This variable was re-coded to a dichotomous variable: (1) low or no stress, and (0) moderate to high stress, for the logistic regression analyses only.

Independent variables for research question two. Research question two was: “What is the relationship between caregiver need for support and self-reported stress?” There were three independent variables used for correlation analysis. These were: need for additional support, formal support, and informal support. A group of independent variables detailing type of support received, and need for support services were used for the two binomial logistic regression analyses. These variables are described in the next paragraph.

Need for additional support was measured using the question, “Is there any other type of support that you would like to have, to help with your caregiving duties?” Participants responded yes or no. *Formal support* was measured using the question, “During the past 12 months has your primary caregiver received help from professionals that are paid workers or part of organizations?” Participants responded yes or no.

Informal support was measured with the question, “Are there plenty of people you can rely on when you have problems?” Participants chose their response from three options: (1) yes, (2) more or less, and (3) no (Statistics Canada, 2012). The variable for informal support was recoded to a dichotomous variable with two options: (1) yes, or (2) no. All participants who answered more or less were merged with participants who answered yes.

Type of support received was measured using a series of questions. Participants were asked to consider the following options:

To accommodate your caregiving duties…

1. Has your spouse or partner modified their life and work arrangements?
2. Have your children provided you with help?
3. Have your extended family members provided you with help?
4. Have your close friends or neighbours provide you with help?
5. Have your community, spiritual, community or cultural or ethnic groups provided you with help?
6. Have you had occasional relief or respite care?
7. Have your family or friends provided you with financial support?
8. Have you received money from government programs?
9. Have you received any federal tax credits for which caregivers may be eligible?

The first option was not included in the analysis as it did not represent the type of support or services received. Options two to five were considered representative of informal support and options six to nine were representative of formal support (Statistics

Canada, 2012). Since options eight and nine both referred to government funding responses to both of these questions were combined.

Need for support or services were answered by a series of questions. Participants were asked to consider the following question and options provided:

What kinds of support, to accommodate caregiving duties would you like to have?

1. Home care/support provided to recipient
2. Financial support/government assistance/tax credit
3. Information/advice
4. Emotional support/counselling
5. Help from medical professionals
6. Occasional relief/respite care
7. Voluntary/community services
8. Other

Option eight (other) was not included in the analysis because the other responses by the participants were not provided (Statistics Canada, 2012).

Independent variables for question three. Research question three was: "How does formal and informal support influence self-reported caregiver stress in combination with demographic factors?" Question three used a binomial regression model for analysis. There were three categories of variables entered into the analysis: caregiver characteristics, care receiver characteristics, and formal/informal support.

Table 3.1

Description of Variables Entered into the Third Regression Model

Category	Variables
Caregiver Characteristics	Age Sex Marital Status Total Household Income Co-residence with Caregiver
Care Receiver Characteristics	Age Sex Severity of IDD
Formal and Informal Support	Formal Support Informal Support

Table 3.1 provides an overview of each category of variables used in the analysis. The first category was caregiver characteristics. These variables included age, sex, marital status, employment status, education, and household income. Several of these variables were recoded to complete more meaningful analysis, and to assist in interpretation of the results.

Age measured the caregiver age at time of survey. The participants were provided with 10 categories and were asked to state which category represented their current age. Age was recoded into the following categories based on those outlined by Shifren (2009): (1) adolescence (15-19), (2) early adulthood (20-39), (3) Middle adulthood (40-64), and (4) late adulthood (65 and over). *Sex* recorded the caregiver's sex as male or female. Participants were asked to report their *marital status* and were presented with the following options: (1) married, (2) living common-law, (3) widowed, (4) separated, (5) divorced, and (6) single, never married. This variable was recoded into two categories: (1) married or common-law, and (2) single. *Caregiver's education* was measured using the question, "What is the highest level of education that you have completed"? Participants were provided with seven options: (1) less than high school, (2) high school, (3) trade certificate or diploma, (4) college or CEGEP, (5) University certificate or diploma, (6) Bachelor's degree, and (7) above bachelor's degree. This variable was recoded into two types of responses: (1) less than high school or high school, and (2) post-secondary education. The variable *household income* was measured by asking participants to provide their best estimate of their total household income before taxes. A full breakdown of the categories provided for them to choose from can be found in Appendix A (Statistics Canada, 2012). Hodges and Brown (2015) calculated 5 quintiles to categorize Canadian household income levels into 5 categories. These were: (1) bottom 20 % - \$0 - \$38 754, (2) Lower middle \$38 755 – \$61 928, (3) Middle \$61 929 – \$88 074, (4) Upper Middle \$88 075 – \$125 009, and (5) and highest \$125 010 and up. These categories were calculated using Statistics Canada data on Canadian income in 2011 (Hodges & Brown, 2015). Based on these calculations the current data was recoded into 3 categories: (1) Low income – under \$ 39 000, (2) Middle income \$40 000 - \$79 999, and (3) Higher income - \$80 000 and over.

The second category of the regression model used care receiver characteristics. This included the variables age, sex, severity of IDD, employment status, and co-residence with the caregiver. *Age* measured the caregiver's age at time of survey. The caregiver selected from one of five age categories that represented the care receivers age.

Age was recoded into the following categories using those outlined by Shifren (2009): (1) childhood and adolescence (19 and under), (2) early adulthood (20 - 39), (4) Middle adulthood (40-64), and (5) late adulthood (65 and over). S*ex* measured the care receiver's sex as male or female. *Severity of IDD* was measured by the question, "would you say this person's main health condition is mild, moderate or severe?" Caregivers selected one of the three options provided. *Co-residence with caregiver* was derived from the original data. The original question for this variable was: "at the time you were providing help to _____________ how close did ________________ live to you?" Caregivers were provided with the following options: (1) in the same household, (2) in same building, (3) less than 10 minutes by car, (4) 10 minutes to less than 30 minutes by car, (5) 30 minutes to less than 1 hour by car, (6) 1 hour to less than 3 hours by car, and (7) 3 hours or more by car (Statistics Canada, 2012). For the purposes of this study this variable was recoded to form the new variable. All data from this question were combined into two categories: (1) co-residing with caregiver, and (2) not co-residing with caregiver.

The third category used variables that measured formal and informal support. *Formal support* was measured using the question, "During the past 12 months has your primary caregiver received help from professionals that are paid workers or part of organizations?" This variable was described in the previous section, independent variables for question two. *Informal support* used the same variable as the one described in the previous section, independent variables for question two (Statistics Canada, 2012).

3.6 Data Analysis

The Public Use Microdata File (PUMF) was downloaded from the Memorial University of Newfoundland Library webpage. Variables were selected and any irrelevant data was deleted from the data set. Descriptive statistics and correlational analysis was completed using The IBM Statistical Package for the Social Sciences (SPSS) version 24. The logistic regression models were completed using Stata version 12.

Research question one was analysed using descriptive statistics, percentages, frequency and means. Data was displayed using tables and graphs. Research question two was analyzed using bivariate correlations. Correlations were completed with the dependent variable self- reported stress with the independent variables need for support, informal support, and formal support. Spearman’s rho correlations were completed because the data was ordinal. The correlations were completed prior to any data recoding.

Binomial logistic regression analyses were used for research questions two and three. Binomial logistic regression analyses are completed when data meets the following criteria: (1) the dependent variable is categorical and consists of only two categories, and (2) the independent variables are categorical or continuous (Macinnes, 2017). Since the data in this study met these criteria, this type of analysis was selected. For research question two, two binominal regression models were calculated with the dependent variable self-reported stress, and the independent variables for type of support received and need for support/services.

For research question three, a third logistic regression model was completed to determine the impact of three categories of independent variables on the dependent variable caregiver self-reported stress. The three categories of variables were care receiver characteristics, caregiver characteristics, and formal/informal support. See section 3.5 and appendix A for a full description of the variables used in these analyses.

Prior to completing any analysis, several of the variables were recoded. See section 3.5 of this chapter for a complete description of recoding. In addition to this, several participants had missing data from questions that either were not asked or they chose not to answer. Some of this missing data was addressed through the use of imputation completed by Statistics Canada (see imputation in section 3.4 data collection). Any participants who had missing data in any of the variables used in the regression analyses not addressed through imputation were manually dropped. This resulted in a total number of 150 participants for the logistic regression analysis.

Additionally, effect size interpretations for each significant odds ratio were provided. Chen, Cohen and Chen (2010) provided a table with equivalencies between Cohen’s D and odds ratio values. This table was used as a reference to determine the effect size.

Chapter 4: Results

This study examined the relationship between formal support services and caregivers of individuals with developmental disabilities. More specifically, this study examined the following research questions: (1) What services do caregivers of individuals with developmental disabilities need and what services do they access? (2) What is the relationship between caregiver need for support and self-reported stress? and (3) How does formal and informal support influence self-reported caregiver stress in combination with demographic factors?

4.1 Overview of the Data

The response rate for this survey was 65.7%. After data collection, a total of 23093 respondents were included in the original data set; 10 771 responses were dropped by rejective sampling (Statistics Canada, 2016). Since this study was interested in caregivers of individuals with Intellectual and Developmental Disabilities (IDD), the respondents who stated they were providing care to someone with a developmental disability or problem, were isolated from the original data set. This resulted in a total of 212 responses used for this analysis.

4.2 Caregiver Characteristics

Table 4.1

Characteristics of Caregiver

Demographics	N	%
Age		
15 to 24	19	9.0
25 to 34	21	9.9
35 to 44	40	18.9
45 to 54	51	24.1
55 to 64	43	20.3
65 and over	38	17.9
Total	**212**	**100**
Gender		
Male	80	37.7
Female	132	62.3
Total	**212**	**100**
Marital Status		
Married	111	52.6
Living Common-law	18	8.5
Widowed	18	8.5
Separated	8	3.8
Divorced	18	8.5
Single, never married	38	18.0
Not Stated	1	0.5
Total	**212**	**100**
Level of education		
Less than High School	35	16.5
High School	62	29.2
Certificate/Diploma	18	8.5
College/CEGEP	38	17.9
University	4	1.9
Bachelor’s Degree	33	15.6
Above Bachelor’s	22	10.4
Total	**212**	**100**
Employed in last 12 months		
Yes	9	4.2
No	68	32.1
Not asked	135	63.7

Total	**212**	**100**
Total Household Income		
Under $39 999	49	24.1
$40 000 - $59 999	28	13.2
$60 000 - $79 999	23	10.8
$80 000 and more	75	35.3
Not Stated	20	9.4
Don’t Know	17	8.0
Total	**212**	**100**

Table 4.1 provides an overview of the caregiver demographic information. The majority of respondents (44.4%) were middle adulthood (ages 45-64). More than half were female (62.3%), and were married or in a common law relationship (61.1%). Approximately (47.7%) of caregivers had high school education or less. More than half (54.3%) of participants had post-secondary education, ranging from a trade certificate or diploma to university education. Only 4.2% of caregivers reported employment in the past six months, although 63.7% of caregivers who participated in this survey were not asked their employment status. Approximately 63% of caregivers surveyed reported total household incomes of $60 000 or more.

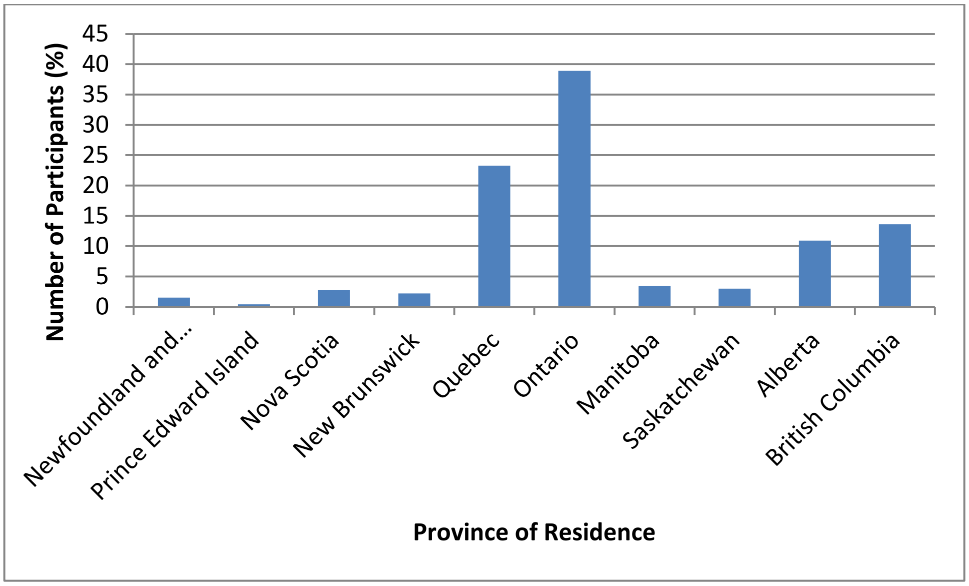

Figure 4.1. Participant's province of residence

Figure 4.1 illustrates the province of residence for the caregivers who participated in this study. From the diagram, we can see the majority of the provinces were evenly represented, the exception being Ontario, where 47% of the participants in this survey resided. The lowest numbers of participants were from Prince Edward Island (8%).

4.3 Care Receiver Characteristics

Table 4.2

Characteristics of Care Receiver

Demographics	N	%
Age		
14 years and younger	65	30.7
15 – 24	39	18.6
25 – 34	33	15.7
35 – 44	21	9.9
45 – 54	19	9.0
55 - 64	20	9.4
65 – 74	3	1.4
75 – 84	4	1.9
85 and older	4	2.4
Deceased	2	0.9
Not Stated	2	1.0
Total	**212**	**100**
Gender		
Male	134	63.2
Female	77	36.3
Not Asked	1	0.5
Total	**212**	**100**
Severity of Condition		
Mild	43	20.3
Moderate	90	42.5
Severe	73	34.4
Not Asked	2	0.9
Don’t Know	4	1.9
Total	**212**	**100**
Employment		
Employed	24	11.3
Not Employed	188	88.7
Total	**212**	**100**

Table 4.2 provides demographic information for the care receiver. Approximately 30.7% of the care receivers were 14 years or younger. The next largest age category for the care receiver was middle adulthood (25.5%). The majority of care receivers were

male (63.2%). A small proportion of the care receivers (20.3%) were reported by caregivers to have mild IDD, while the remaining care receivers were identified as moderate (42.5%), and severe (34.4%). The majority (88.7%) were not employed.

Relationship of Caregiver to Care Receiver

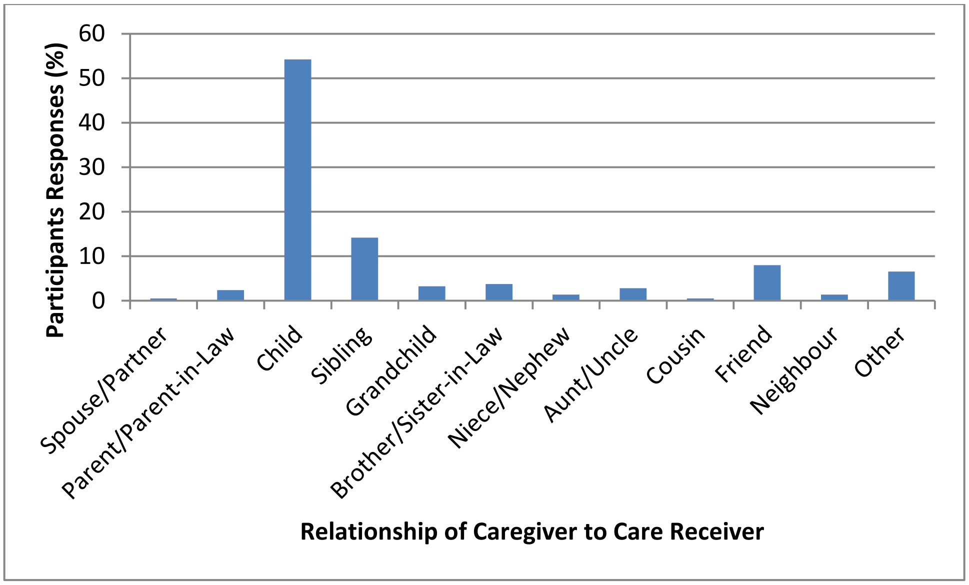

Figure 4.2. Relationship between caregiver and care receiver reported by participants

Figure 4.2 displays information about the relationship between the caregiver and care receiver. About half (54.2%) of care receivers were the son or daughter of the caregiver. Siblings were the next common relationship at 14.2%. Less commonly, care receivers were brother or sister in laws (3.8%), nephews or nieces (1.4%), or aunts and uncles (2.8%) of the caregivers. A small portion of the caregivers reported relationships to the care receiver other than those identified by the survey (6.6%).

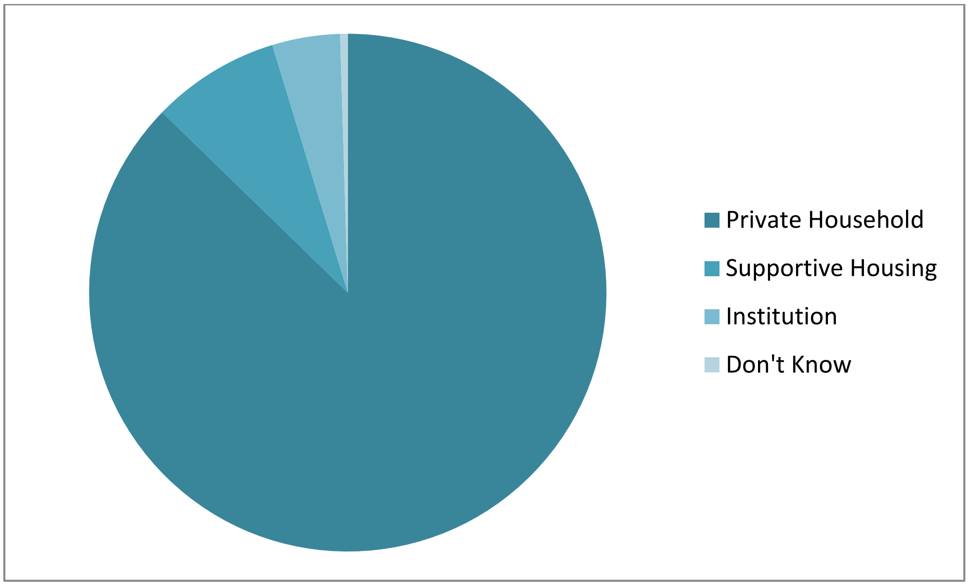

Figure 4.3. Living arrangement of care receiver

Figure 4.3 shows the living arrangements for the care receiver. The majority of care receivers lived in a private household (87.3%). Many of the care receivers lived in the same household or same building as their caregiver (60.4%), and (39.2%) lived away from their caregiver.

4.4 Self-Reported Caregiver Stress

Table 4.3

Level of Stress Related to Caregiving Responsibilities in the Past 12 Months

Level of Stress	N	%
Very Stressful	24	11.3
Stressful	39	18.4
Somewhat Stressful	74	34.9
Not at all stressful	43	20.3
Not Asked/Missing	32	15.1

Table 4.3 shows the distribution of self-reported stress over the past 12 months. The majority of caregivers experienced varying degrees of stress related to their caregiving responsibilities. The majority of participants reported some degree of stress in relation to their caregiving responsibilities, stating that they found them very stressful (11.3%), stressful (18.4%) or somewhat stressful. Only 20.3 % reported that their caregiving responsibilities are not at all stressful.

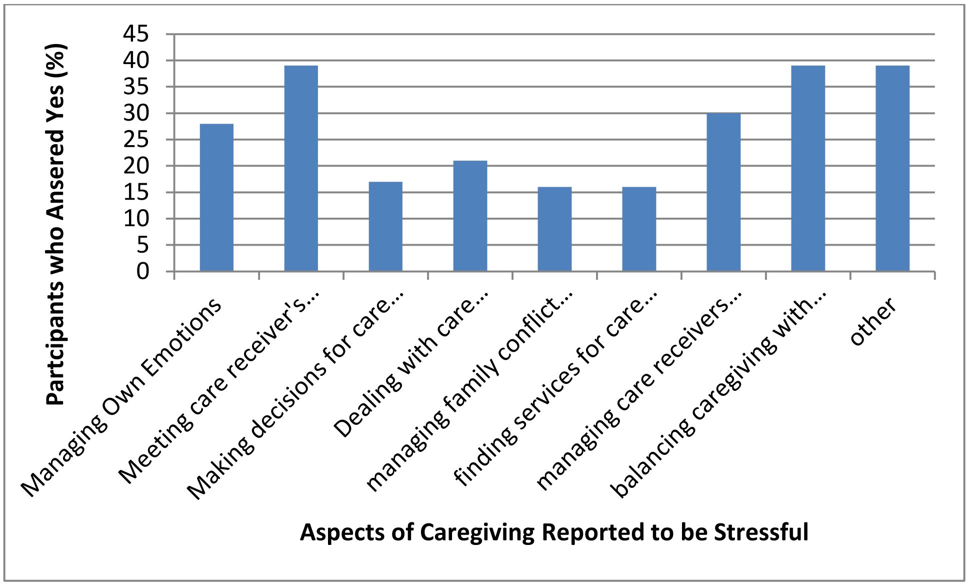

Figure 4.4. Specific aspects of caregiving that caregivers reported to cause stress

From figure 4.4 we can see that the three most frequently reported sources of stress reported by caregivers were: meeting care receiver's needs (29.3%), balancing caregiving with other responsibilities (29.3%), and other reasons (29.3%). The next most frequent source of stress was getting along with care receiver or managing care receiver's mood (22.6%). The least frequent sources of stress were managing family conflict and finding services for care receiver, both selected by 12% of participants.

4.5 Caregiver Need for and Access to Services

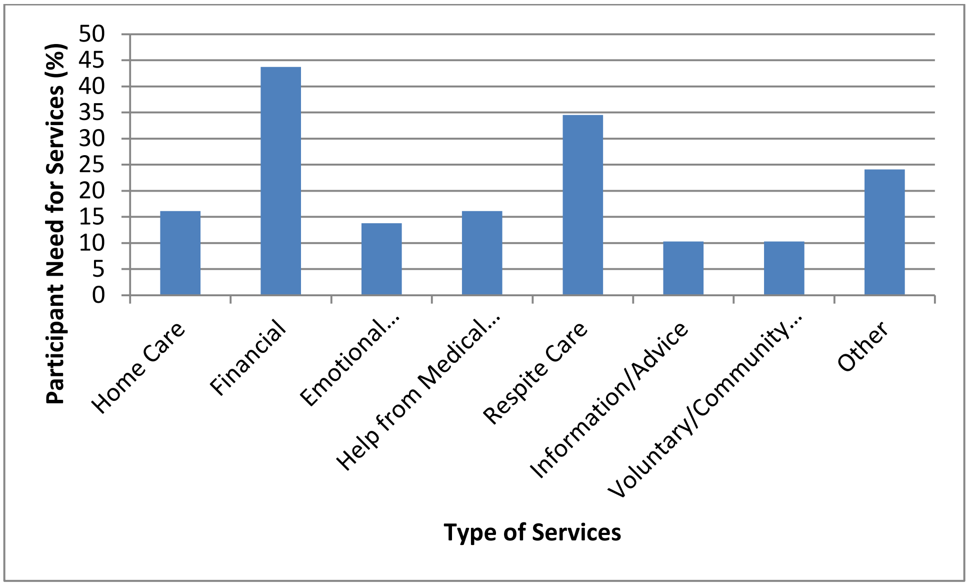

Figure 4.5. Types of services caregivers reported they would like to receive

Services Needed. When participants were asked if there was any other type of support they would like to have to help with their caregiving duties, 41% responded yes. Figure 4.5 shows the breakdown of the specific services caregivers would like to have. The service most commonly needed by caregivers surveyed was financial support through government assistance or tax credits (17.9%). The next highest service needed was occasional relief or respite care, with 14.2% of respondents indicating a need. The lowest needed services were information or advice, and voluntary or community services, both identified by 4.2 % of participants.

Services accessed. Of the participants who were asked the question, “During the past 12 months, has your primary care receiver received help from professionals that are paid workers or part of an organization?” The majority of participants (73.1%) stated they accessed formal support for their care receiver. On average, 33.5% of participants said that their care receiver received 5 or more hours of support a week from professionals.

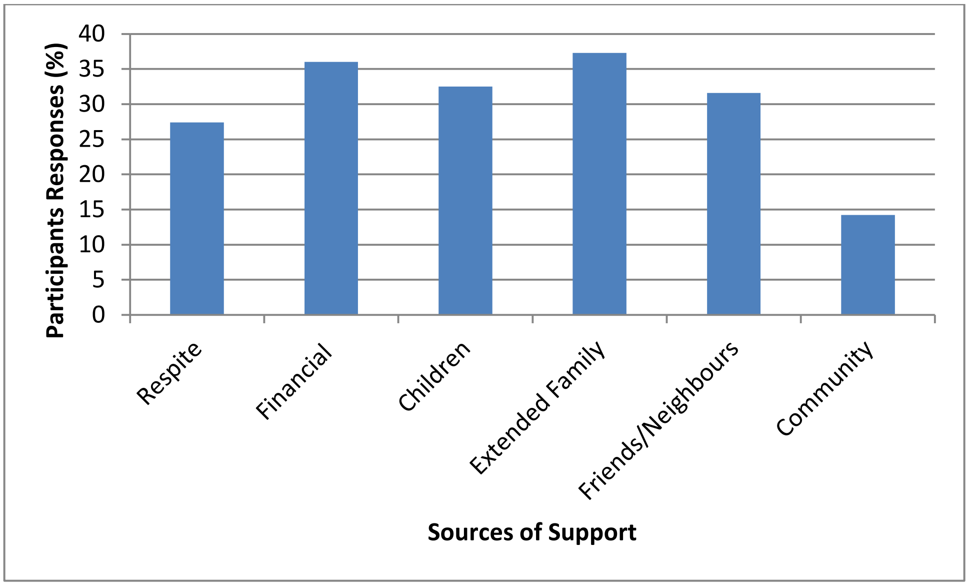

Figure 4.6. Sources of formal and informal supports accessed by caregivers

Figure 4.6 shows the types of support services accessed by caregivers. Formal support services included respite and financial services. The most commonly accessed service overall was financial support (36%). Financial support included money from government programs and federal tax credits. Only 27.4% of participants stated they accessed respite services.

Looking at informal sources of support, the most commonly accessed service was support from extended family (37.7%). Participants were almost as likely to seek support from their children (32.5%), as they were close friends or neighbours (31.6%). The least accessed type of support or service was community. This included support from the community, spiritual community, cultural or ethnic group. Participant's responses indicated that 14.2% had received financial assistance from friends or family members to accommodate caregiving duties and 85.8% did not receive financial support.

Barriers to accessing services. The response rate was very low for this question, with only seven participants who responded. The most common reason provided was professional help was not available (42.9%). Financial reasons included responses such as; the participants could not afford help, or help was too expensive. The third reason was family reasons, such as family members were too busy to help. Both financial and family reasons were reported by 28.6% of participants.

4.6 Relationship between Support and Self-Reported Caregiver Stress

Table 4.4

Results from Correlation Coefficients

Correlation Coefficient			
Need	0.408**		
Informal		-0.343**	
Formal			0.164*

**p<0.05 **p<0.01*

Self-reported stress and need for support. Spearman's rho correlation analysis was completed between the dependent variable self-reported stress and need for support, informal support and formal support. Table 4.4 shows the correlation coefficients for each of these correlations. The results indicated a positive correlation between need for support and self-reported stress r (210) = .408, $p < 0.001$, suggesting that as caregiver stress increased, so did their need for support.

Informal support and self- reported stress. A second Spearman's rho correlation was completed between caregiver stress and the question, "Are there plenty of people you can rely on when you have problems?" The results of the analysis found a negative correlation, r (179) = -0.343 $p < 0.01$, indicating that if caregivers have people to rely on when the have problems they report lower levels of stress.

Formal support and self-reported stress. Spearman's rho correlation analysis was completed with the dependent variable self -reported stress and the independent variable formal supports. The correlation analysis found a positive correlation between self-reported stress and the question: "During the past 12 months has your primary caregiver received help from professionals that are paid workers or part of organizations?” The results of the analysis showed a positive correlation between caregiver stress and care receiver receiving support from professionals, $r\ (171) = 0.164$, $p < 0.05$. This relationship shows that as formal support services increase so does their level of self-reported stress.

4.7 Type of Support Received and Self-Reported Stress

Logistic regression analysis was carried out to determine the relationship between type of support received and self- reported stress. Prior to completing the analysis variables were combined or recoded as needed. For a description of recoded variables see section 3.5 in chapter 3 methodology. Table 4.4 shows the results of the regression model and table 4.5 shows the demographics for the variables used.

Table 4.5

Summary of Logistic Regression Model with Type of Support as the Independent Variable and Self-Reported Stress as the Dependent Variable

Variables	Odds Ratio	Standard Error	Significance
Constant	0.353	0.208	0.077
Help from children (base = yes)	0.858	0.330	0.690
Help from family (base = yes)	1.278	0.535	0.558
Help from friends (base = yes)	1.329	0.535	0.516
Help from community (base = yes)	0.780	0.347	0.547
Respite (base = yes)	1.424	0.579	0.385
Informal financial support (base = yes)	2.541	1.359	0.081
Funding (base = yes)	2.673	1.059	0.013

Notes: number of observations = 150; log likelihood = -91.81, $x^2=17.45$*,* $p<0.02$*; pseudo* $R^2=0.0868$

Table 4.6

Demographics for the Logistic Regression Model with Type of Support as the Independent Variables and Self-Reported Stress as the Dependent Variable

Variables	Stressed	Not Stressed
Help from Children		
Yes	26	35
No	33	56
Help from family		
Yes	27	31
No	32	60
Help from friends		
Yes	23	24
No	36	67
Help from community		
Yes	15	44
No	20	71
Respite		
Yes	25	34
No	22	69
Informal financial Support		
Yes	13	46
No	7	84
Funding		
Yes	43	42
No	16	49

We can see from table 4.4 that this model was significant. However, the only independent variable that had a significant impact on caregiver stress was financial support. This included participants who indicated that they both received financial support from government programs and government tax credits. Caregivers who stated they did not receive funding were 2.67 times more likely to report lower levels of stress. The effect size for this finding suggests a moderate association between these two variables (Chen, Cohen & Chen, 2010). While not significant at the level of $p < 0.05$, there was also a trend for informal financial support, indicating that participants who received financial support from informal sources, such as family or friends, were 2.54 times more likely to report higher levels of stress (p = 0.081). The effect size for this finding also suggests a moderate association between these two variables (Chen, Cohen & Chen, 2010).

4.8 Need for Support/Services and Self-Reported Stress

A second logistic regression model was carried out to determine the caregivers need for support/services and self-reported stress. This model was not significant, indicating that specific unmet needs for services did not contribute to caregiver stress among the participants in this study.

4.9 Factors Influencing Caregiver Stress

A third binomial regression model was carried out with three sets of variables: caregiver characteristics, care receiver characteristics, and formal and informal support. Caregiver characteristics included the variables: age, sex, marital status, employment status in the last 12 months, household income, and level of education. Care receiver characteristics included the variables: age, sex, severity of condition, employment status, and co-residence with caregiver. Formal support (amount of support received from professionals) and informal support (do you have plenty of people to rely on when you have problems) variables were also added. Table 4.6 shows the results of the regression model and table 4.7 shows the demographics for the variables used in this model.

Table 4.7

Summary of Logistic Regression Model with the Independent Variables Caregiver Characteristics, Care Receiver Characteristics and Formal and Informal supports and the Dependent Variable Self-Reported Stress

Variables	Odds Ratio	Standard Error	Significance
Constant	0.206	0.188	0.083
Age of caregiver (base = 40-64)			
20-39	1.094	0.574	0.863
40-64			
65+	1.018	0.668	0.978
Sex of caregiver (base = female)			
Male	2.455	1.35	0.052
Female			
Marital status (base = married/common-law)			
Married/common-law			
Single	1.081	0.572	0.883
Education of Caregiver (base = high school/less)			
High School or less			
Post-Secondary	0.709	0.314	0.437
Age of Care Receiver (base = 20-39)			
Under 19	0.780	0.406	0.660
20-39			
40-64	4.956	3.167	0.012
Sex of Care Receiver (base = male)			
Male			
Female	1.789	0.836	0.213
Residence (base = same household)			
Same Household			
Different Household	2.643	1.363	0.059

Severity (base = moderate)	1.874	1.057	0.265
Mild			
Moderate	0.829	0.544	0.950
Severe			
Income (base = 40 000 – 79 999)			
Under 39 000	1.700	1.028	0.380
40 000 – 79 999			
Over 80 000	1.033	0.545	0.950
Formal Support (base = yes)			
Yes			
No	0.968	0.495	0.949
Informal Support (base = no)			
Yes	2.849	1.513	0.049
No			

Notes: number of observations = 135; log likelihood = -74.453, x^2*=33.59, p<0.004; pseudo* R^2*=0.184*

Table 4.8

Demographics for Logistic Regression Model with Independent Variables Caregiver Characteristics, Care Receiver Characteristics and Formal and Informal Supports and Dependent Variable Self-Reported Stress

Variable	Stressed	Not Stressed
Age of caregiver		
20-39	13	18
40-64	37	46
65+	5	16
Sex of caregiver		
Male	17	34
Female	38	46
Marital status		
Married/common-law	39	50
Single	16	30
Education of Caregiver		
High School or less	19	36
Post-Secondary	37	43
Age of Care Receiver		
Under 19	34	27
20-39	16	22
40-64	5	31
Sex of Care Receiver		
Male	38	50
Female	17	30
Residence		
Same Household	45	46
Different Household	10	34
Severity		
Mild	10	17
Moderate	25	41
Severe	20	22
Income		
Under 39 000	13	25
40 000 – 79 999	14	23
Over 80 000	28	32
Formal Support		
Yes	45	60
No	10	20
Informal Support		
Yes	40	70
No	15	10

Table 4.6 shows the overall model was significant, indicating that these factors influenced caregiver stress among the participants in this study. There were two significant factors in this model: informal support ($p<0.05$), and age of care receiver ($p>0.05$). Caregivers who accessed informal supports were 2.85 times more likely to report not feeling stressed than caregivers who do not access informal supports. The effect size for this finding suggests a moderate association for this relationship (Chen, Cohen & Chen, 2010). Also, caregivers who provided care to an individual with IDD between the ages of 40 and 65 were 4.956 times more likely to report not feeling stressed, compared to caregivers of individuals in the other two age categories. The effect size for this finding suggests a medium association for the relationship between these two variables (Chen, Cohen & Chen, 2010). There were two other factors approaching significance; namely, sex of the caregiver ($p = 0.052$), and residence of the care receiver ($p = 0.059$).

Chapter 5: Discussion

The purpose of this study was to examine caregivers of people with IDD, the types of services they needed, as well as the role that both formal and informal support played in caregiver stress. Specifically, this study attempted to answer the following research questions: (1) What services did caregivers of individuals with IDD need and what services did they access? (2) What was the relationship between caregiver need for support and self-reported stress? and (3) How did formal and informal support influence self-reported caregiver stress in combination with demographic factors? This chapter provides a discussion of the results of the research and its relationship to the relevant research in this field. The limitations of this research will be discussed, as well as suggestions for future research.

5.1 Self-Reported Caregiver Stress

Most caregivers reported that their caregiving responsibilities were very stressful, stressful or somewhat stressful. This is consistent with previous research that indicated that caregivers of individuals with IDD reported that their caregiving responsibilities cause increased stress. This study differed from findings of other studies in that only a small number of participants (11%) reported that their caregiving responsibilities were very stressful. In contrast, other studies found that caregivers of individuals with IDD reported high levels of stress related to caregiving (Chou, et al., 2010; Gallagher & Whiteley, 2012; McStay et al., 2014).

The most significant sources of stress reported by participants in this study were balancing caregiving with other responsibilities, and meeting care receiver's needs. Other research conducted in this area found that caregivers frequently reported difficulty caring for the individual with IDD and balancing caregiving responsibilities such as employment or time for self-care (Murphy et al., 2006). Given the high level of care needed for individuals with IDD, it is understandable that caregivers experienced stress about not being able to meet the needs of the care receiver.

Getting along with care receiver or managing care receiver's moods was the second highest rated source of stress. This corresponded with research that suggested that caregivers who provided services to care receivers who have more complex needs, such as challenging behaviour or comorbid mental health concerns, reported higher sources of stress (Faust & Scior, 2008; Miodrag & Hodapp, 2010; Woodman & Hauser-Cram, 2013).

Finding services for care receivers was selected by a very small number of participants as a source of stress. This was contradictory to other studies that found seeking and accessing services was a significant source of stress for caregivers (Caldwell, 2008: Williamson & Perkins, 2014). This indicated that the majority of caregivers who participated in this study were able to access services with few barriers or did not feel a need for additional services.

5.2 Theoretical Framework

This study used Bronfenbrenner's Bioecological Model of caregiving as a framework to examine the results. This theory considers how factors influence an individual at the different levels: the Person, the Microsystem, the Exosystem and the Macrosystem. This model is described in detail in chapter one; section 1.4. This analysis examined the interactions between each of the levels and their combined impact on caregiver stress. The following sections will use this framework to discuss the results.

Exosystem and macrosystem. The Exosystem and Macrosystem are the third and fourth levels of the Bioecological Model. The Macrosystem refers to the institutional patterns of the culture or subculture. The Exosystem refers to the interrelationship between the caregiver and the main institutions in society (Bronfenbrenner, 1977). In this study, the main institutions are the health and social services. The following paragraphs examined the findings relevant to the Exosystem and Macrosystem.

Caregiver service needs. Caregivers ranked financial services (17.9%) as the most needed service. This is consistent with the study completed by Syveda, et al. (2011) where caregivers ranked financial difficulties as being the most stressful. One reason for this identified in the research is that there is a great cost associated with caring for a person with IDD (Murphy et al., 2006). Secondly, the caregiving responsibilities often prevent or create barriers to caregiver employment (Syveda, et al., 2011). This seems to be a common problem given that caregivers of people with IDD have been found to have lower socioeconomic status (Caldwell, 2008).

Participants ranked respite care (14.2%) as the second most needed service. Other studies also found caregivers placed importance on time away from caregiving to prevent burnout and reduce stress (Murphy et al., 2006). A need for information, on the other hand, was rated low by participants. This is surprising as caregivers of individuals with IDD often reported a high need for information, specifically about the individual's condition and treatment, and how to handle difficult situations (Douma, et al., 2006; James, 2013; Syveda, et al., 2011). Since the majority of the caregivers who participated in this study were family (67.1%), and lived with the individual (60.4%) there may be a lower need for information because they were already familiar with the care receiver's condition and other related information.

Access to services. Most (73.1%) of the participants indicated that they accessed formal support, or services from paid workers who were part of an organization. The most accessed formal support service was financial services (36%). Very few participants accessed respite despite expressing a need for this service. This may be due to the difficulties participants in other studies identified such as coordinating respite, and finding qualified respite providers that caregivers can trust (Murphy et al., 2006). Having to coordinate respite services might be overwhelming for caregivers, particularly if they are already stressed.

It was interesting to note that caregivers were almost equally as likely to receive support from neighbours as they were their own children. This may reflect what other studies have found about caregivers feeling guilty about asking their own children to assist in the caregiving role or reluctance to burden them with the responsibility (Griffiths, et al., 2002). Therefore, the caregivers in this study may have felt more comfortable asking neighbours to help. As well, it may also be due to proximity.

Neighbours may be closer compared to adult children or extended family that may live further away.

Barriers to accessing services. There were very few participants that expressed barriers to accessing services. This was surprising given that other research found caregivers reported significant barriers to accessing services (Chia & Lunsky, 2003). The reasons given by participants for not accessing the necessary services fell into three categories: professional help not available, financial reasons, and family reasons.

A lack of professional help was one barrier that has been extensively examined in previous research. It can be difficult to find professionals who are knowledgeable in the area of IDD to provide services to these individuals. For example, if individuals with IDD require mental health services there are few mental health professionals who have specialized training in this area (Sevin, Bowers-Stephenson & Crafton, 2003). Professionals' attitudes could also play a role in service provision and availability of professionals willing to provide effective services to people with IDD and their caregivers. It has been suggested that biases or attitudes towards people with IDD can partly explain healthcare inequalities (Lewis & Sternfert-Krose, 2010).

Financial reasons were another barrier identified by the caregivers who participated in this study. One reason for this may be that not all individuals with IDD can access services, in part due to eligibility criteria for certain programs. For example, in Newfoundland and Labrador the health authorities provide home supports and respite services to individuals with ID. But, individuals with ASD who do not have an ID may be in need of home supports or respite but they would not be able to avail of these services. Also, those who do qualify for home supports or respite may not receive a sufficient amount of respite, and it may be too costly to pay for an additional amount.

Family reasons given by participants included such responses as family was not available to help. Other studies found that caregivers of individuals with IDD expressed a need for support from family members. Support from family, along with other types of social support can act as a buffer for stress (Feldman et al., 2007). However, caregivers from other studies stated that they do not receive much support from family (Chia & Lunsky, 2003).

Need for support and self-reported stress. Research in this area found that unmet needs for services was related to caregiver stress and poor mental health (Caldwell, 2008; Williamson & Perkins, 2014). The results from the current study were consistent with previous research. As the caregivers, self-reported stress increased, so did their need for additional support.

A need for specific support services was not found to be related to caregiver stress. The formal supports used in the analysis were: home care, respite care, financial help, help from medical professionals, emotional support/counselling, and information or advice. Informal supports used in the analysis included voluntary and community supports. Other research found that participants reported a high need for informal support services (Douma, et al., 2006). However, previous research comparing informal social support was conflicted in this area. Some studies found that social support buffered stress and mental health concerns (Feldman, et al., 2007), while others found no connection between social support and caregiver stress (Plant & Saunders, 2007).

Formal Support. Receiving formal supports through paid workers or organizations was significantly related to self-reported caregiver stress. However, it was interesting to note the relationship between these two variables, individuals who reported they received formal support services reported more caregiver stress. This may be because of the challenges they faced when accessing services. Caregivers identified several issues with the structure of formal services such as difficulty finding services or service providers, long wait times for service, the need to continually advocate for services, and not feeling as though their concerns were adequately given attention by service providers (Chia & Lunsky, 2003; Faust & Scior, 2008; Murphy et al., 2006; Ward, Nicholas & Freedman, 2010; & Yoong & Koritas, 2012). All of these challenges can further increase stress for already stressed caregivers.

The only type of formal support that seemed to influence caregiver stress was receiving funding from government programs. What was interesting to note; however, is that individuals who did not receive funding from government programs were 2.67 more likely to report less stressed. It should also be noted that there was a trend towards significance in that caregivers who accessed informal financial support (received money from family or friends) were 2.54 times more likely to report higher levels of stress.

Other studies have found that financial difficulties were common among caregivers of individuals with IDD. This can be due to the cost of medical expenses for the individual (Murphy et al., 2006; Serrata, 2012), or because of difficulty maintaining full-time employment due to caregiving responsibilities (Chadwick et al., 2013; Syveda, et al., 2011). Seltzer et al. (2011) found in their research that caregivers who co-reside with the care receiver have lower socioeconomic status. It should be noted that, participants in this study, 37% had an average household income below $60 000.00, and 60.4% were co-residing with the care receiver. Perhaps the participants in this study were finding the financial demands of caring for their co-residing care receiver to be the most stressful aspect of providing care.

What was unexpected about these findings was caregivers who received financial support reported more stress with respect to their caregiving duties. There may be a few explanations for these findings. First of all, the funding provided was not sufficient to meet caregiver's needs. Second of all, low socioeconomic status among caregivers was often related to other factors such as marital status (being a single parent), and difficulty balancing employment with caregiving responsibilities (Gordon, Rosenman & Cuskelly, 2007; Syveda, et al., 2011). For example, a single parent who is unable to work because they need to provide care for their child with IDD may receive adequate funding to cover their income and the needs of their child; however, they may experience stress due to a desire to work.

Informal support. Having informal support was significantly related to self-reported caregiver stress. This was consistent with several other studies that found social support to be negatively correlated with stress in caregivers of individuals with IDD (Ben-Zur, et al., 2005; Hassell, et al., 2005; Hill & Rose, 2009). Informal support was found to moderate the relationship between depression and other factors such as child behaviour problems (Feldman et al., 2007). Also, caregivers who reported they have plenty of people to rely on when they had problems were less likely to report feeling stressed. Research into coping and stress in caregivers with adult children with IDD found that caregivers found informal support helped caregivers to effectively cope with stress (Lai & Oei, 2014; Murphy et al. 2006). While there was a correlation between informal support services and caregiver stress, there was no difference in the type of informal support. Informal support services received from family, extended family and friends did not significantly increase the odds of caregiver stress. This suggests that informal support is beneficial regardless of the type.

Other studies emphasized the importance of support from spiritual or religious sources to cope with and reduce stress (Lai & Oei, 2014). This study did not find that spiritual or religious support was a significant predictor of caregiver stress. Luther, et al. (2005) study found that while parents of children with Autism Spectrum Disorder (ASD) stated that religious or spiritual support was important to cope with stress, they were less likely to avail of this support compared to parents of typically developing children. The authors proposed that this may be because parents were unable to attend church or religious events while caring for an individual who needed constant supervision. This may also be the case for participants in this study.

The microsystem. The caregiver characteristics identified in this study based on previous research were: gender, level of education, income, and co-residence. None of the caregiver characteristics examined in this study had a significant impact on caregiver stress. Although, two of the factors had trends towards significance: co-residence of the care receiver and caregiver gender.

While co-residence was not a significant factor, there was a trend towards significance, indicating that caregivers who provided support to an individual with IDD who resided with them are more likely to report being stressed. This is consistent with research in this area (Seltzer et al., 2011; Williamson & Perkins, 2014). Co-residence with the care receiver was found to increase caregiver stress, especially when combined with caregiver age. Particularly, older caregivers reported increased stress when the care receiver is still residing with them (Seltzer et al., 2011). However, consistent with the research conducted by Seltzer et al. (2007), most (60.4%) caregivers were found to be co-residing with their care receiver. As mentioned previously, a common concern for caregivers of individuals with IDD was what will happen to their child when they are no longer able to care for them anymore (Caldwell, 2008; Murphy et al., 2006). Perhaps for some parents, continuing to have the care receiver reside with them reduces the stress and anxiety that caregivers often feel when thinking about having to place their son or daughter in the care of someone else.

Caregiver gender was not significant but was approaching significance, suggesting that female caregivers were more likely to report being stressed. Some of these findings may be due to the fact that female caregivers who participated in the Caregiving and Care Receiving Survey provided 20 hours or more of care per week (20% of females compared to 17% of males). Women and men also differed in the types of care they provide. Women were more likely to assist with hands-on tasks like personal care. In contrast

56% of men completed maintenance and outdoor work (Sinha, 2012). It is possible that tasks like personal care were more time consuming and stressful, which may account for the difference in self-reported stress between males and females. Lai and Oei (2014) found in their review of coping strategies of parents of children with ASD that fathers tended to use less effective coping strategies such as suppression or avoidance, compared to mothers. Therefore, this may mean that the fathers who participated in this research might not openly acknowledge that they find their caregiving responsibilities stressful.

The person. There are several care receiver characteristics that were found to influence caregiving. These included gender and severity of condition. None of these characteristics were found to have a significant impact on caregiver stress. Previous research indicated conflicting results on this topic. Some studies found that gender is related to caregiver stress (Lai & Oei, 2014), while others found no relationship (McStay et al., 2014). Other studies found that severity of condition, and other related factors such as functional behaviour of the individual and the presence of challenging behaviour and/or mental illness resulted in increased stress in caregivers (Chou et al., 2010; Plant and Saunders, 2007; Williamson & Perkins, 2014).

The chronosystem. Care receiver age was found to have a significant impact on stress for the caregivers in this study. Caregivers who provided care to individuals between the ages of 40 to 65 were more likely to report less stress compared to caregivers whose care receiver was 65 or older or between the ages of 20-39. Other findings in this area support that as care receiver age increases caregiver stress increases as well. Caregivers have to cope with declining health of the individual with IDD in addition to their other needs (Hayley & Perkins, 2004). Therefore it is not surprising those caregivers of individuals with IDD who are 65 or older are more likely to report experiencing stress in relation to their caregiving duties. What is surprising is that caregivers of individuals ages 20-39 are more likely to report stress. One of the overall themes expressed by caregivers interviewed in Chadwick et al. (2013) study was that that there were changes in stress throughout the lifespan and as the individual went through transitions. Many caregivers expressed increased stress in particular at the start of adulthood and when the individual was leaving school as caregivers had concerns about what the individual would do after finishing school. Perhaps the stress of the care receiver transitioning from adolescence to young adulthood explains the increased likelihood of caregiver stress for these participants.

As mentioned previously over half (54.2%) of caregivers in this study were parents caring for their own children. As a result, we would assume that caregiver age influenced stress as well. However, caregiver age did not have an impact on caregiver stress. Other studies found that older caregiver age was related to stress because of a combination of factors. One being that caregivers experience stress about the future for the care receiver with IDD. Specifically, they wonder what will happen to the care receiver when they die. Also, many caregivers of individuals with IDD have been providing care for the care receiver for many years and the cumulative stress of caregiving can impact them (Caldwell, 2008; Murphy et al., 2006).

Implications for Providing Support to Caregivers

The findings from this study can be used to inform supports provided to caregivers of individuals with IDD. There are several implications that can be used to help guide service provision. This study utilized Bronfenbrenner's Bioecological Model to explain caregiving. Eckenweiler (2007) stated using an ecological perspective to examine caregiving allowed for the consideration of the complexity of caregiving as a whole instead of a separate entity. This framework showed how decisions made even at the policy level have a profound impact on caregivers and care receivers (Eckenweiler, 2007). Williamson and Perkins (2014) recommended the use of an ecological assessment of caregiving. They stated that a better understanding of caregiver needs can occur through caregiver assessment that consider challenges, supports and resources unique to each caregiver (Williamson & Perkins, 2014). This type of assessment would be useful to support caregivers and reduce stress associated with caregiving.

Caregiving stress is complex and influenced by factors at the Person, Microsystem, Exosystem and Macrosystem levels. A Bioecological assessment can help to identify the factors at each level and identify the caregivers who are at risk for significant caregiver stress. This type of assessment should also identify supports or services in the caregiver's life that could act as a buffer to reduce or protect against stress. The value of this type of assessment was echoed in the research study conducted by Feldman et al., 2007. They suggested that early intervention programs should consider the following: child characteristics, caregiver resources, and parental mental health and mood when planning interventions for both the child and caregiver (Feldman et al., 2007).

Considering these factors will help to reduce caregiver stress, improve the effectiveness of other interventions and lengthen the caregiving relationship.

Caregiver self-reported stress. As is consistent with other studies, caregivers report that they are experiencing stress relating to their caregiving duties. The most reported sources of stress were: meeting the needs of the care receiver (29.3%) and balancing caregiving with other responsibilities (29.3%). This stress needs to be addressed as it can lead to negative consequences for both the caregiver and care receiver, such as poor physical and mental health (Chou, et al., 2010; Gallagher & Whiteley, 2012; McStay et al., 2014). When caregivers are stressed it can also lead to placement breakdown and increased hospitalizations for the care receiver (Murphy et al., 2006).

It should be noted that caregivers who participated in this research found managing the care receiver's mood resulted in a significant source of stress. When individuals with IDD have challenging behavior or comorbid mental illness, caregivers report a need for information regarding how to handle difficult situations with their care receiver (Syvedka, Weiss & Lunsky, 2011). In these situations, having that type of support available would help caregivers to better manage and cope with these types of situations.

The impact of financial support. Caregivers who participated in this study report a greater need for financial support compared to other services. Financial support was the only type of service received that was found to have a significant impact on caregiver stress. Before providing services to caregivers, financial needs must be considered and addressed.

The impact of respite support. Participants in this study also expressed a strong need for respite support. Caregivers in other studies have emphasized the importance of respite for their self-care (Murphy et al., 2006). However, respite is a service that caregivers find difficult to receive and those who do receive it often do not receive a sufficient amount (Chia & Lunsky, 2003). Also, the time it takes to coordinate or arrange respite and find qualified people causes additional stress for caregivers (Murphy et al., 2006).

Respite is very important to reduce caregiver stress and burnout. Respite services should be readily available to caregivers for this reason. The cost of caregiver stress is placement breakdown, and increased hospitalizations for the care receiver (Murphy et al., 2006). This costs the health and social services much more through hospital stays and placement often in 24 hour supported housing. Therefore, it would be more cost effective for respite services to be provided. It is likely that because caregivers of individuals with IDD already experience a significant amount of stress providing care to the individual, asking them to arrange their respite provides unnecessary additional stress. Caregivers may be more willing to avail of respite if they were provided with assistance in some of these areas.

Relationship between support and caregiver stress. The relationship between support and caregiver stress needs to be taken into consideration when providing interventions to caregivers and individuals with IDD. Both formal and informal supports have been found to be related to caregiver stress. One way to support caregivers and reduce stress is to identify supports that caregivers can avail of to reduce stress. Respite services are one type of formal support that has been identified in the literature to be important for caregiver self-care as well as to help families cope and reduce likelihood of crisis (Murphy et al., 2006; Syvedka, Weiss & Lunsky, 2011). While respite support was not found to have a significant impact on self-reported stress, caregivers who participated in this study did express a need for respite services.

Informal support. Informal support plays a significant role in caregiver stress and helps caregivers cope with stressors (Murphy et al., 2006; Wei & Oei, 2014). This was reflected in the findings from this study. What the research in this area indicated however, is that caregivers are often restricted in their ability to access social supports due to the demands of caregiving. Caregivers are often limited in their friendships to other caregivers (Yoong & Koritas, 2012). One way that caregiver stress could be reduced would be to provide services to caregivers that would allow them the opportunity to engage in social activities, such as respite.

Another way to encourage social support may be through support groups. Caregivers find that support groups help to promote resilience among caregivers (Murphy et al., 2006), and increase different types of social support among caregivers (Wei et al., 2012). Support groups may be an effective way to provide informal support to caregivers who may not otherwise receive this support through family, friends or community.

5.3 Strengths and Limitations

As discussed in chapter three, methodology, there are several benefits to using secondary data. The obvious would be the access to a large sample size of caregivers of individuals with IDD. Given the difficulties in recruiting caregivers of individuals with

IDD, because they are busy with the demands of caregiving (Crinland et al., 2014), having access to this secondary dataset allowed for a much larger sample size that would not have been obtained through primary data collection.

While there are benefits to using secondary data, there are also disadvantages. One being that secondary data does not always lead to meaningful comparisons because it was not designed for the specific research questions asked in the research study (Smith, 2008). While meaningful comparisons were able to be made, this researcher did not design this survey, so this limited the type of analysis that could be completed. For example, the only types of formal services that could be used for analysis were financial and respite services. There are others that play a role in caregiver stress such as, counselling, home supports, and medical services. If this study were to use primary data these other types of formal support could have been explored in more detail.

Another limitation was this survey used a cross sectional design. This means that data was only collected at one point in time (Cresswell, 2012). It might be that individuals were stressed or not stressed at the time of this study. As well, previous research indicates that caregivers stress may increase or decrease throughout their caregiving experience. For example, if an individual develops challenging behaviour or a secondary mental health diagnosis this may be temporarily stressful (Faust & Scior, 2008). Caregiver stress may decrease once the person is properly diagnosed and appropriate interventions are put in place. Another example is as caregivers' age they face transitions that can result in increased caregiver stress (Caldwell, 2008).

Finally, this study explored the types of formal and informal support that caregivers received. It did not measure satisfaction with services received. Findings from other studies indicate that caregivers have their needs met; however, many expressed dissatisfaction with the services they provided (Weiss & Lunsky, 2010). It should be noted that a large number of participants indicated that they received services, however satisfaction with services was not measured and therefore its impact on stress could not be explored. This may also shed some light on the correlation between formal support services and caregiver stress.

5.4 Future Research

While there has been a significant amount of research completed in this area of stress among caregivers of individuals with IDD, much remains to be discovered. There is potential for further analysis to be completed using the data from the Caregiving and Care Receiving survey. The Caregiving and Care Receiving survey collected data from caregivers who provide care to individuals for a variety of different reasons including age, illness, and disability due to accident. Comparisons could be made using this data between caregivers of individuals with IDD and caregivers of other groups of care receivers to determine if their needs are the same or different, if they vary in self-reported stress, support, and coping.

A second area of future research could explore the relationship between caregiver stress and financial support. This study, along with previous research, has found that financial services and a lack of financial support is a high rated need for caregivers and contributes to caregiving stress. It would be interesting to compare this to caregivers of other groups of care receivers. This would help determine if this is more prevalent among caregivers of individuals with IDD. It may be that as mentioned, the cost of care is more expensive for this population compared to others, or, caregivers of individuals with IDD often have difficulty seeking employment. The length of caregiving may contribute to financial difficulty as well. For example, a caregiver of a senior may only provide care for a few years, whereas, most individuals with IDD require support through their lifetime. Further research could be conducted to explore why these individuals who received financial support were more likely to report feeling stressed compared to those who didn't.

Third, there appears to be a correlation between formal support and self-reported stress. However, this relationship is correlational and therefore no conclusions can be made in regards to cause and effect. Future research could explore the potential reasons why this correlation exists and what specifically about support reduces caregiver stress.

A fourth area of future research is to examine the impact of care receiver age on caregiver self-reported stress. These findings are contradictory to other research in this area, typically as care receiver age increases so does stress (Hayley & Perkins, 2004). Also, caregiver age had no significant impact on age. Future research could further explore these questions in more detail.

Fifth, this study identified that caregivers who receive informal support are less likely to report stress related to caregiving. This was in combination with demographic factors and formal support. Future research can further investigate this relationship further in order to determine: What about informal social support helps to reduce caregiver stress? and How can we help caregivers develop informal social support?

Finally, as mentioned in the previous strengths and limitations section, this study was limited in the type of support and information about support and satisfaction with services was not explored in this study. Therefore, an area for future research may be to explore the perceived effectiveness of services and its impact on caregiver stress. Caregivers in previous studies report dissatisfaction with services received (Weiss & Lunsky, 2010). As a result, it would be important to understand why caregivers are dissatisfied and how it relates to caregiver stress.

5.5 Conclusion

The impact of long term stress on physical and psychological health is well documented (Lazerus & Folkman, 1984). Caregivers of individuals with IDD do report experiencing stress in relation to their caregiving duties. This stress has a negative impact on both the caregiver and the care receiver.

There were some key findings from this study that should be noted. First of all, there is a relationship between caregiver stress and several variables. As caregiver need for support increases, and formal support increases, so does caregiver stress. As informal support increases, caregiver support decreases. Second, caregivers who receive financial support or funding are more likely to report stress related to caregiving duties. This was the only type of formal or informal support that impacted caregiver stress.

Finally, caregivers who accessed informal support are 2.85 times less likely to report stress related to caregiving duties. There are many demographic risk factors which have been identified in previous research that increase or decrease the likelihood of caregiver stress. While these factors do help us identify caregivers at risk, we may not be able to improve or change these factors. However, informal support services can be changed to decrease caregiver stress and improve caregiver coping, if we can work with caregivers of individuals with IDD to help them build informal supports through the use of support groups or through other methods. Currently, caregivers of this population have access to a variety of formal support services. However, this study revealed that this may increase stress, suggesting that more effort should be placed in determining how caregivers can be supported to develop informal supports.

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Appendix A: List of Variables

Dependent Variable				
Variable name	Original Variable Name	Question	Coding	New Variable Coding**
Self-Reported Caregiver Stress	ICS_Q40	How stressful have your caregiving responsibilities been during the past 12 months?	1=Stressful 2=Very Stressful 3=Somewhat Stressful 4=Not at all Stressful 7=Not Asked* 8=Not Stated* 9=Don't Know*	1=Stressed 2=Not Stressed

*Dropped in Logistic Regression Analysis **Recoded only for logistic regression models

Independent Variables				
Variable Name	Original Variable Name	Survey Question	Coding	New Coding
Need for Additional Support	OAC_Q20	“Is there any other type of support that you would like to have, to help with your caregiving duties?”	1=yes 2=no 7=not asked 8=not stated 9=don’t know	Not Recoded
Formal Support	HPO_Q10	“During the past 12 months has your primary caregiver received help from professionals that are paid workers or part of organizations?”	1=yes 2=no 7=not asked 8=not stated 9=don’t know	Not Recoded
Informal Support	FLG_Q230	“Are there plenty of people you can rely on when you have problems?”	1=yes 2=more or less 3=no 7=not asked 8=not stated 9=don’t know	1 =yes 2=no
		“To accommodate your caregiving duties…”		
Help from Children	ACD_q20	“Have your children provided you with help?”	1=Yes 2=No 7=Not asked 8=Not stated 9=don’t know	Not recoded
Help from Family	ACD_q30	“Have your extended family members provided you with help?”	1=Yes 2=No 7=Not asked 8=Not stated 9=don’t know	Not Recoded

Help from Friends/Neighbours	ACD_q40	“Have your close friends or neighbours provided you with help?”	1=Yes 2=No 7=Not asked 8=Not stated 9=don’t know	Not Recoded
Help from Community	ACD_q50	“Have your community, spiritual, community or cultural or ethnic groups provided you with help?”	1=Yes 2=No 7=Not asked 8=Not stated 9=don’t know	Not Recoded
Respite	ACD_q60	“Have you had occasional relief or respite care?”	1=Yes 2=No 7=Not asked 8=Not stated 9=don’t know	Not Recoded
Informal Financial Support	ACD_q70	“Have your family or friends provided you with financial support?”	1=Yes 2=No 7=Not asked 8=Not stated 9=don’t know	Not Recoded
Funding	ACD_q70 ACD_q80	“Have you received money from government programs?” “Have you received any federal tax credits for which caregivers may be eligible?”	1=Yes 2=No 7=Not asked 8=Not stated 9=don’t know	Merged
Age of Caregiver	AGEGR5	“What is your age?”	1=15-17 2=18-19 3=20-24 4=25-29 5=30-34	1=15-19 2=20-39 3=40-64 4=65+

			6=35-39 7=40-44 8=45-49 9=50-54 10=55-59 11=60-64 12=65-69 13=70-74 14=75-79 15=80 and over	
Sex of Caregiver	SEX	“Are you male or female?”	1=male 2=female	Not recoded
Marital Status Caregiver	MARSTAT	“What is your marital status? Are you…”	1=married 2=common law 3=widowed 4=separated 5=divorced 6=single, never married 8=not stated 9=don’t know	1=Married/ Common-Law 2=Single
Caregiver Education	EOR_q04	“What is the highest level of education that you have completed?”	1=Less than high school diploma or equivalent 2=high school diploma/high school equivalent 3=trade certificate or diploma 4=college, CEGEP or other non-	1=High School or Less 2=Post-Secondary

			university certificate or diploma 5=University certificate/diploma below bachelor’s 6=Bachelor’s degree 7=University certificate/diploma or degree above bachelor’s 98=not stated 99=don’t know	
Age of Care Receiver	PRN_Q20GR5	“What is ____________ age?”	1=10 years or younger 2=11-14 3=15-19 4=20-24 5=25-29 6=30-34 7=35-39 8=40-44 9=45-49 10=50-54 11=55-59 12=60-64 13=65-69 14=70-74 15=75-79 16=80-84 17=85-89	1=under 19 2=20-39 3=40-64

			18=90-94 19=95-99 20=100 and over 95=deceased 97=not asked 98=not stated 99=don't know	
Sex of care receiver	CARE_RECIPIENT_SEX	"Is ____________ Male or Female?"	1=M 2=F 7=not asked 8=not stated 9=don't know	Not Recoded
RESIDENCE	PRD_Q10	"At the time you were providing help, how close did your primary care receiver live to you?"	1=In same household 2= In same building 3=Less than 10 minutes by car 4=10 minutes to less than 30 minutes by car 5=30 minutes to less than 1 hour by car 6=1 hour to less than 3 hours by car 7=3 hours or more by car 97=not asked 98=not stated 99=don't know	1=in same household 2=in different household

Severity of Condition	PRP_Q15	“Would you say that this main health condition or problem is mild, moderate, or severe?”	1=Mild 2=Moderate 3=Severe 7=not asked 8=not stated 9=don’t know	Not Recoded
Total Household Income	INCMHSD	“Can you estimate in which of the following groups your total household income falls for the year ending December 31st (of last year)? Was it…”	1=no income/loss 2=less than$5000 3=$5000-$9999 4=$10 000-$14 999 5=$15 000-19 999 6=20 000-29 999 7=30 000-39 000 8=40 000-49 999 9=50 000-59 999 10=60 000-79 999 11=80 000-99 999 12=100 000-149 999 13=$150 000 + 98= Not stated 99=Don’t know	1=under 39 000 2=40 000-79 999 3=over 80 000