

Mount Saint Vincent University  
Department of Family Studies and Gerontology

**Unpaid and Paid Supports in the Lives of Family Caregivers of Adults with  
Disabilities: Mapping Social Relations**

by

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A Thesis

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## Abstract

Caregiving for an adult family member with intellectual and developmental disabilities (IDD) is understood to have both positive and negative effects on a family member's quality of life. Little is known however, about how family caregivers experience social supports when supporting a family member with IDD. Social supports are comprised of both unpaid and paid supports; these function to strengthen, build capacities, address needs, and sustain the well-being of individuals, as well as their families. The research explored how unpaid and paid supports are socially organized within the everyday lives of family members supporting a family member with a disability. A critical-ecological framework served as the conceptual foundation for the study and was informed by the institutional ethnography (IE) methodology. Study participants were 5 family caregivers supporting a family member with IDD between the ages of 25-40 living in the family home or a community-based setting at the time of the research.

This study illustrates analyzing the immediate and broader environments in which family caregivers' lives are situated in are necessary to understand how unpaid and paid supports 'work' in family caregivers' everyday lives. Support networks were found to vary widely depending on family dynamics, abilities of their family member and considerations of changes over time and geographical distance. In a critical approach, this study exposed the social relations, structural power relations (ruling relations) and the line of fault present in family caregivers' lives. During interviews, the interdependent nature of unpaid and paid supports in family caregivers' lives became apparent. However, it was found unpaid and paid supports 'work' in different ways, through distinct

mechanisms in family caregivers' lives. To meet the needs of their family members, advocacy for paid supports was necessary by family caregivers. This involved family caregivers working within the system of paid support, governed by policies with institutional and ideological priorities that contrasted their own. Families prioritized support that upheld the rights of their family members through inclusive and accessible quality relationships, activities, and suitable provisions of paid support. Implications and recommendations for policy are articulated, supported by pre-existing findings in the Nova Scotia and broader disability support context. More research is needed with larger sample sizes to explore the topic further. Future directions for research regarding family caregivers accessing unpaid and paid support to live quality lives as they support family members with IDD are discussed.

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Unpaid and Paid Supports in the Lives of Family Caregivers of Adults with Disabilities:  
Mapping Social Relations

**Chapter I: Introduction**

For most children and adults with disabilities, particularly intellectual disability (ID) or intellectual and developmental disabilities (IDD) who require support, their parents and other family members will be their primary caregivers over the life course (Families Special Interest Research Group of IASSIDD, 2013). The stress placed upon families supporting a child below the age of majority with disabilities or an adult child with disabilities is often greater than that of families with children following a developmentally ‘typical’ track (Feldman et al., 2007; Plant & Sanders, 2007; Robinson et al., 2016).

Caregiving for an adult family member with IDD is understood to have both positive and negative effects on a family caregiver’s quality of life (Yoong & Koritsas, 2012). Positive effects of supporting an adult family member with IDD on a family caregiver’s quality of life include; the opportunity for friendships through meeting other caregivers; a sense of satisfaction with their life; and a more positive appraisal of one’s own life (Yoong & Koritsas, 2012). Negative effects are; a lack of time to spend with other family members; restricting friendships predominantly to others providing support for a family member; inflexibility of scheduling; restriction of employment and instability of finances; and fear, anxiety and worry over future support arrangements (Yoong & Koritsas, 2012).

Although adults with IDD may have caregivers whom occupy diverse roles within their lives, parents are most frequently the family caregivers in the lives of adults with disabilities, until they are unable to physically do so (Brennan, 2005; Hole et al., 2013). The parent-child relationship is characterized as being bi-directional as adult children with IDD receive support from their parents, and in turn, parents receive support for instrumental activities and psychological care (Bowey & McGlaughlin, 2007; MacLellan et al., 2002). As much as parents support their adult children with IDD, their children in many cases also support them (Bowey & McGlaughlin, 2007; MacLellan et al., 2002). As parents age, their adult child may provide companionship and comfort for instance (Yoong & Koritsas, 2012).

Research focusing on the network of social supports present in family caregivers' lives, particularly parents, has been a priority in other family contexts (Boehm & Carter, 2016); however, much remains uninvestigated regarding the everyday experiences of family members who support their adult family members with IDD (Families Special Interest Research Group of IASSIDD, 2013). Given that IDDs are lifelong, parents whom are primary caregivers supporting their child(ren) in a home environment will often do so until they are physically or mentally unable to support their child any longer (Crawford, 2011; Ouellette-Kuntz et al., 2014). Family members perceiving a variety of unpaid and paid supports prepared to support their adult family member report being able to provide primary support for longer in the home-based setting, as physically demanding support required by the family member with a disability can be transitioned to other paid supports, as health and life circumstances change (Baumbusch et al., 2017; Boehm & Carter, 2016). Little is known about how family caregivers experience unpaid and paid

supports when supporting a family member with IDD in the particulars of their everyday lives (Boehm & Carter, 2016).

My research focused upon unpaid and paid supports in the lives of family members supporting a family member with a disability (with a focus on ID) through making visible with a critical theoretical framework how the actions and everyday realities of family caregivers' lives are socially organized by discursive ideologies. Specifically, the research sought to draw out dominant ideologies that were embodied within family caregivers' everyday actions. Dominant ideologies are widely accepted beliefs and practices that shape how people make sense of their experiences, and conduct themselves in their everyday lives (Brookfield, 2005; Brookfield, 2009). The primary function of dominant ideologies is to convince people that society is optimally organized for the interests of people, whilst working effectively to ensure that oppression of persons, power imbalance and inequality are smoothly reproduced (Brookfield, 2005, 2009). Ideologies are analogous to air: omnipresent, there but unable to be captured and embraced as part of the everyday lives (Brookfield, 2005). In the research conducted, the dominant ideologies of neoliberalism, ableism, sexism (patriarchy) and familialism were brought to the forefront. The social organization of unpaid and paid supports in family caregivers' lives and corresponding ideologies were analyzed using the method of institutional ethnography (IE).

In using the method of institutional ethnography, I wish to be very clear as a researcher. It is important to note that although the base word is the same, "institution" and "institutional" have very different meaning. Institutions are recognized as by "any place in which people who have been labelled as having an intellectual disability are

isolated, segregated and/or congregated. An institution is any place in which people do not have or are not allowed to exercise control over their lives and day to day decisions” (PFC-CACL, 2010, p. 4). As a researcher I deeply condone the underlying ideas, treatment of persons with disabilities and continuation of institutions. I strongly support and advocate for inclusion of persons with disabilities through supported housing with appropriate services in community.

Institutional as referred to in institutional ethnography, IE, refers to social forces that exist and are exerting influence through all levels of a person’s environment (Smith, 1987). In the various interactions in people’s lives in a broad and intimate sense, it’s recognizing that larger scale social forces are responsible, perpetuating unconsciously accepted beliefs that benefit few, and oppress many groups within society (Brookfield, 2005). Although institutional forces such as ideologies, policy and state power exist at broad levels, they affect the social environment all the way down to the most intimate interactions in people’s lives (Brookfield, 2005). The choosing of institutional ethnography as the method for this research was deliberate to challenge dominant discourse that exists and bring family caregiver’s experiences and voices to be heard. In many ways, institutional ethnography is underpinned by opposite beliefs to institutions; IE serves to deconstruct taken for granted assumptions, challenge inequity, and promote social justice for persons who have historically been marginalized (Smith, 1987). A thorough discussion of critical theory, ideology and IE are discussed in subsequent chapters.

In the context of this research, unpaid and paid supports are defined using definitions broadly agreed-upon in relevant literature. One or both of the following types

of involvement constitute unpaid support: caring about people through concern or anxiety, and work that helps someone to take care of themselves (Bigby, 2004; Parker, 1981). As indicated by the term, unpaid supports are not compensated for their time or work (Duggan & Linehan, 2013; Lindblad et al., 2007). Unpaid support may be experienced through one or more of these sources: family, friends, other people in social or recreational organizations, other parents/families with an adult family member with a disability, parent and family member support groups (disability and non-disability specific) and neighbors (Boehm & Carter, 2016; Community of Practice for Supporting Families With Intellectual and Developmental Disabilities, 2014; Sanderson et al., 2017). Noting the bi-directional nature of the caregiving relationship for adult family members with disability, unpaid support in a family caregivers' life can be provided in part by the adult family member with IDD who is being supported (such as psychosocial support), depending on the dynamics of the relationship (Dillenburger & McKerr, 2009). In contrast to unpaid supports, paid supports are supplied by persons who are compensated for their time, typically through monetary means, such as service providers, non-profit organizations and professional staff in various fields (Boehm & Carter, 2016).

The 2017 Canadian Survey on Disability (CSD) “provides a range of data on 10 different disability types, focusing on activity limitations related to hearing, vision, mobility, flexibility, dexterity, pain, learning, mental health, memory and developmental disabilities” (Cloutier et al., 2018, para. 3). The most recent estimate of the rate of disability for persons over the age of 15 in Nova Scotia was 30.4%, compared to the national average of 22.3% (Statistics Canada [StatsCan], 2018). This represents 229,430 persons in Nova Scotia living with a disability, of the 6,246,640 persons in Canada who

are classified through the 2017 CSD as living with a disability (StatsCan, 2018).

Although the rate of disability from the previous 2012 CSD cannot be compared to rates collected in the 2017 CSD because of changes to the scope of the survey and questions asked, there is a consensus that rates of disability in Nova Scotia are increasing (Morris et al., 2018). It is worth noting that these estimates do not include persons housed in institutionalized care, Indigenous reserves or within “collective dwellings” (such as the Canadian Armed Forces bases; Cloutier et al., 2018, para. 5).

### **Researcher Positionality**

It is important to acknowledge my positionality within this research. As a researcher, I identify two factors as driving my interest in completing the inquiry that was conducted. First, I held a position as an adult outreach support worker in British Columbia providing paid supports to persons with disabilities, specifically persons with IDD. I worked with individuals who lived in independent or supported living arrangements within their communities. For the persons I supported, their families were pivotal in their everyday lives. Family relationships such as those with parents and siblings endure and are sustained with importance across the lifespan, for persons with disabilities the role of family, and specifically parents, has an even higher level of significance for the support they provide. This sentiment was and continues to be expressed in my volunteer work in organizations focusing on social inclusion.

The families I interacted with as an adult outreach support worker in British Columbia were primarily parents. Mothers took on the primary caregiving role when their adult child required a more sophisticated, higher level of support, such as assistance with the majority of activities of daily living (ADL) and instrumental activities of daily

living (IADL; Nova Scotia Department of Community Services [NS DCS], 2012). This parallels the past and present research on providing care to a family member with a disability and IDD specifically—that it is a predominantly female dominated role (Brennan, 2005). Given the lifelong nature of the strengths and areas of required support in their family member’s life whom has a disability, understanding how unpaid and paid supports work in the lives of family caregivers’ supporting their adult family member is crucial to person-directed planning (Jones & Gallus, 2016), that upholds the rights of persons with disabilities to choice, equity and inclusion within society.

There is a preference for the term person-directed planning as opposed to the commonly used term person-centred planning, as the term person-directed clarifies the person who is receiving supports is directing the process (Ministry of Community and Social Services Ontario, 2013). Person-directed planning is a set of approaches designed to assist someone independently, or with the decision-making support of others, to plan their life and supports (O’Brien & O’Brien, 2002). Person-directed planning has five key components: “the person is at the centre, family members and friends are partners in planning, the plan reflects what is important to the person, their capacities and what support they require, the plan results in actions that are about life, not just services, and reflect what is possible, not just what is available, the plan results in ongoing listening, learning, and further action” (Ministry of Community and Social Services Ontario, 2013, p. 10). In my work as a support worker, person-directed planning was crucial to carrying out paid support that was based on input, preferences and needs, of an individual and their family members.

Secondly, my interest in the experiences of family caregivers with unpaid and paid supports also stemmed from personal experience. In my own personal experiences, I recognized the salience of having a network of unpaid and paid supports experienced by myself and my primary support persons, my parents for my Type 1 Diabetes. As a complex, lifelong condition typically developed before the age of 18, the challenges to everyday life are those that can be ameliorated by accessing both unpaid and paid supports. At the time of my diagnosis as a child, continued to my present point in life as a young adult, I have experienced how unpaid and paid supports have broadened understanding and deepened both my own, and my family's capacity for balancing the family system following significant challenges that will be lifelong in nature.

At a structural, provincial level, disability policy addressing support and supported housing remains in a stage of *transformation* in Nova Scotia. This ongoing recognition and eventual envisioned transformation of disability program and policy in Nova Scotia is highlighted in the vital 2013 report, *Choice, Equality and Good Lives in Inclusive Communities: A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program*. The current state of paid supports in Nova Scotia for adults with IDD is regulated under the Nova Scotia Disability Support Program (DSP) Policies. The DSP policies govern access to and organize experiences of families regarding paid services. Ideally, decision making operates through a person-directed and/or family-centred way (The Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013). Family-centred services are based on the needs of an individual, and expressed in part by the individual and their family, collaboratively; services that are based upon an



individual's needs, as communicated and supported by their family (People First of Canada – Canadian Association for Community Living Joint Task Force on Deinstitutionalization [PFC-CACL], 2010).

Person-directed programming and planning must consider the everyday family context in order to meet the needs of the adults with IDD, and their families that support them (Jones & Gallus, 2016). Adults with IDD are more than twice as likely to still be living at home with one or more parents, than the general adult population (Crawford, 2011). The first-voice perspectives of family caregivers about how unpaid and paid supports function in their lives can provide insight for future development of policy and programs orchestrating paid support for adults with IDDs, and their families who provide indispensable support. A core component of advancing the disability movement is that “the the interests and wishes of this population group to be represented, whether it is done directly or through those people who live and work most closely with them” (Callus & Camilleri-Zahra, 2017, p. 21). In drafting The Convention of Rights for Persons with Disabilities (UNCRPD) the slogan ‘Nothing about us without us’ symbolized the position of the disability movement that any work about persons with disabilities should involve persons with disabilities (Callus & Camilleri-Zahra, 2017; Charlton, 1998). Until persons with disabilities are involved in decision-making processes, including formulating policy, their needs will remain unaddressed (Callus & Camilleri-Zahra, 2017). Family caregivers therefore provide a critical perspective to understand first voice experiences of caregivers of this population and persons with IDDs themselves.

Mapping unpaid and paid supports in the lives of family members supporting a family member with a disability holds promise for strengthening existing supports, and

alleviating gaps in support provided that necessitate unexpected changes to service provision, and even out of home placement for adults with IDD. In IE, mapping is a specific term referring to producing a working knowledge of forms of activities as they existed, based on people's accounts of their own lives (Campbell, 1990). As research is conducted using the method of IE, how things work is discovered and recorded, and this then can inform people how their lives are socially organized (Campbell & Gregor, 2002; Carroll, 2011).

### **Research Question**

The research sought to explicate, that is to discover 'how things work', rather than how they are actually put together (Dobson, 2001). To explicate, a researcher must become familiar with the everyday lives and experiences of the individuals using their voices as a starting point (Dobson, 2001). This research asked the following: how do unpaid and paid supports accessible to family caregivers supporting a family member with a disability operate within their everyday lives? The research questions were: (1) How are family caregivers of adult family members with disabilities (focusing on IDD) supported through networks of unpaid and paid supports? and (2) What dominant ideologies are embodied within the everyday lives of family caregivers supporting adult family members with disabilities (focusing on IDD) as they access unpaid and paid supports? To answer the questions posed above, the research was conducted as an in-depth exploration of the everyday functioning of unpaid and paid supports within the lives of family caregivers supporting adult family members with disabilities, focusing on IDDs.

## **Chapter II: Review of the Literature**

### **Introduction**

Social support refers to both unpaid and paid supports (Robinson et al., 2016), each provides different benefits; functions differently; and involves different activities (Boehm & Carter, 2016). Broadly, both unpaid and paid supports in family member's lives function to strengthen, build capacities, address needs, and sustain the well-being of individuals, and in this case their families (Boehm & Carter, 2016; Robinson et al., 2016).

It is important to resist oversimplifying the dimensions that unpaid and paid supports (Boehm & Carter, 2016). For example, who provides support and the types of supports provided must be understood in order to distinguish the similarities and differences in how unpaid and paid support work in the lives of family caregivers (Boehm & Carter, 2016). Ideally, unpaid and paid supports should be simultaneously present in family caregivers' lives (Robinson et al., 2016). Unpaid and paid supports frequently work interdependently to support the various needs of family caregivers supporting a family member with a disability (Boehm & Carter, 2016). Unpaid and paid supports also work separately to support aspects of a family caregiver's well-being when supporting a family member with a disability (Boehm & Carter, 2016).

### **Literature Review**

Studies conducted over the last 20 years (spanning 1999-2019) were reviewed and gaps in knowledge identified. Two or more of the following search terms guided the review: intellectual disability, developmental disability, social support, unpaid support, paid support, informal supports, formal supports, support, parents, family members,

caregivers, policy, programs and networks. The inclusion criteria guiding the selection of articles were; focused on the parents' or family's perspective, adults supported had ID or IDD and support was provided for adults over the age of majority. The exclusion criteria were the following: persons supported resided in out-of-home care, presented with physical disabilities but no other disabilities and persons supported were primarily youth, or not between the ages of 25-40. Searches were conducted using available databases: CINAHL Plus, SocINDEX (EBSCO), ERIC (EBSCO), PsycINFO (EBSCO), Academic Search Premier (EBSCO), Google Scholar, the Novanet Library Database and the Mount Saint Vincent University library. Additional materials of interest were located through handsearching the reference lists of articles that were identified through database searches.

In the review of the literature, three subject areas emerged from quantitative, qualitative, and mixed-methods studies. These are: (1) unpaid supports, (2) paid supports, (3) the dynamic nature of the parent-child relationship. These subject areas are interdependent and coexist in the quantitative and qualitative research carried out to understand the experiences of family caregivers.

### **Definitions: Intellectual Disability and Developmental Disabilities**

The definition for intellectual and developmental disabilities (IDD) used in this research follow those set out by the most recent 2018 Canadian consensus guidelines which are established and utilized by health professionals in Canada (Sullivan et al., 2018). In the guidelines, IDD “refers to various lifelong limitations in intellectual functioning and conceptual, social, or practical skills that emerge in persons before the age of 18 years” (Sullivan et al., 2018, p. 254). The exact nature of limitations differs

depending on severity, type and can be variable across a person's life course (Sullivan et al., 2018). The term IDD includes "intellectual disability, developmental disability, learning disability (as used in the United Kingdom), and autism spectrum disorder" (Sullivan et al., 2018, p. 254).

In developing and recently published research pertaining to the lives and experiences of individuals with IDD, there is an increased emphasis on the ability and self-determination of individuals (Shogren et al., 2006). Rather than seeing individuals as dependent, or having deficits, there is a drive to employ a strengths-based approach that recognizes the capacities, skills, and contributions of persons (Shogren et al., 2006). This applies to persons across the life course in both the personal and private spheres of life (Hole et al., 2013; Shogren et al., 2006).

A medicalized view of disability has limited viability, Oliver (1990) argues because it is pinpointing the issues of disability as individual level, as opposed to resulting from within society itself. Currently, the medical model continues to be the dominant discourse with social and critical models challenging medicalized notions of disability experience (Rioux & Samson, 2006; Oliver, 2004). The social model noted that it was not disability itself that was the primary barrier to social inclusion of persons with diverse abilities, but rather the way society responded and treated people with disabilities (Oliver, 2004; UPIAS, 1976). The ideas behind the social model of disability was first introduced through published work known as *The Fundamental Principles of Disability* by the Union of the Physically Impaired Against Segregation (UPIAS) in 1976 (Oliver, 2004). The social model of disability emphasizes a person's impairment are not the primary barrier for persons with disabilities, rather environments, barriers to participation

and broader culture must be examined (Oliver, 2004). The social model separates a person's impairment and disability; it views *disability* as a social construct and that a person becomes impaired by the ways in which society creates systematic barriers (physical, social, economic, political, etc.). Although the social model of disability focuses on broader understanding of disability, it does not mean individualized practices or treatments are not without their benefits or counter-productive to the recognition and subsequent challenging of societal barriers for inclusion within society (Oliver, 1996).

The social model is evident in work shaping discourse for disability rights, such as the UNCRPD. The UNCRPD outlines principles and rights to promote and protect people with disabilities inclusion and dignity; this human rights document was established in 2006 (United Nations, 2006). In 2010, Canada ratified the UNCRPD, a commitment to equity for persons with disabilities (PFC-CACL, 2010). This discourse is especially pertinent to Canada, where deinstitutionalization is occurring in all provinces and territories and remains a priority for those involved in advocacy, activism and human rights for individuals with disabilities (Rioux & Samson, 2006).

### **Family Members' Experiences**

The research focusing on family caregivers of individuals with IDD and their experiences using unpaid and paid supports predominantly addresses the period of time when the person with a disability is between the ages of 0-18 (Lee et al., 2019). This time period is critical for early intervention, skill development, and behaviour management. The experiences of family members' caring for a young child with IDD is distinctive and separate from experiences of family members' supporting an adult family member (Robinson et al., 2016). The transition from social supports provided to the family

caregiver of a younger child highlights the difference in the number, frequency and funding of services for adults with disabilities (Lee et al., 2019; Robinson et al., 2016). In Nova Scotia, adult paid supports begin at age 19 typically (NS DCS, 2012). Studies in Canada originate primarily from the provinces of British Columbia and Ontario. Limited research existed within Nova Scotia, apart from a thesis by Brennan (2005) and report by MacLellan et al. (2002). Provision of paid supports for persons with disabilities and their families is provincially regulated, therefore studies of paid supports conducted in other Canadian provinces, have generalizability only to those provinces with the specific disability programs and policies (Baumbusch et al., 2017).

### **Unpaid Supports**

Unpaid supports are referred to as ‘informal’ or ‘natural’ supports in the disability literature (e.g. Boehm & Carter, 2016; Sanderson et al., 2019). In the context of this research, the term unpaid supports will exclusively be used, which reflects the preferred language choices of caregivers and support advocates (e.g. Caregivers Nova Scotia, 2020; Stall et al., 2019). Unpaid support may be experienced through sources such as the following: family, friends, other people in spiritual, social or recreational organizations (Sanderson et al., 2017), other parents/families with an adult family member with a disability, parent and family member support groups (disability and disability non-specific) and neighbors (Boehm & Carter, 2016; Community of Practice, 2016; Robinson et al., 2016). Unpaid supports are not compensated for their time or work (Duggan & Linehan, 2013; Lindblad et al., 2007). Unpaid supports may be provided by persons who have a relationship with a family caregiver that is characterized as a friendship, affiliations are also a source of support (Boehm & Carter, 2016). However, the examples

of potential sources of unpaid supports does not encompass an exhaustive list, the very definition of what and whom an unpaid support is depends upon the family caregivers' interpretation and experiences.

Unpaid supports are undoubtedly important for family members' supporting an adult family member with a disability (Boehm & Carter, 2016). Parents who are a caregiver for their adult child with IDD who perceive a higher level of unpaid supports assess their caregiving responsibilities as less stressful and taxing (Boehm & Carter, 2016; Robinson et al., 2016). This is true, regardless of the actual level of unpaid supports present in their lives (Robinson et al., 2016). In looking at family caregivers who were parents to the family member they supported, emotional support was the most commonly reported type of unpaid support provided in their everyday lives (Boehm & Carter, 2016).

Parents in midlife (average age 36) supporting young adult children with disabilities experience about the same number of unpaid supports as do their counterparts who are supporting adult children without disabilities (Boehm & Carter, 2016; Seltzer et al., 2001; Seltzer et al., 2011). Parents in midlife supporting an adult child with IDD have the same number of affiliations with social organizations, frequency of visits with friends and family members and a close friend with whom they could confide with, compared to same age parents who are not supporting an adult child with IDD (Seltzer et al., 2001; Seltzer et al., 2011). Friend is a general term that in the context of this research will refer to someone with whom there is a social bond, who is outside of the family system and is not paid to have connection or interaction (Boehm & Carter, 2016). Parents supporting their adult child with a disability in midlife reported one to four friends in their lives



(Boehm & Carter, 2016). This parallels closely with other work that finds in individual interviews parents supporting their adult child with ID report having 2.66 unpaid supports (Iacono et al., 2016). Comparatively, in focus group sessions parents supporting an adult child with ID report 3.76 unpaid supports, on average (Iacono et al., 2016).

The frequency of visits with unpaid others was different for parents supporting an adult child with IDD as they aged (average age 53) compared to their similar age peers not supporting adult children with IDD (Seltzer et al., 2011). For parents supporting an adult child, visits with friends and relatives decreased significantly more than their peers (Seltzer et al., 2011). Mothers in their sixties supporting an adult child with IDD reported over the course of four weeks an average of 3.4 visits by unpaid supports, whereas their same-age peers not supporting an adult child reported 5.7 visits during the same time period (Seltzer et al., 2011).

**Other parents/families supporting an adult family member.** Interpersonal relationships made through connections within the disability community were described as different from other unpaid supports received (Boehm & Carter, 2016). The support provided by disability-affiliated others are unique in their benefits to family caregivers (Boehm & Carter, 2016). Parent support groups, for instance, provide opportunities for parents to discuss and reflect upon subjects pertinent to their adult child's well-being and quality of life (Shogren et al., 2013). Meeting parents in similar support roles who can relate to the circumstances of parents' lives becomes increasingly more difficult as children become adults with fewer paid support program opportunities (Shogren et al., 2013). Opportunities for interaction with other parents providing support to adult children

with IDD become increasingly rare as organized educational and recreational activities diminish (Shogren et al., 2013).

### ***Family Support Relationships***

The unpaid supports provided by other family members remain constant while other sources of unpaid supports fluctuate (Boehm & Carter, 2016). In other words, the number of family support relationships cannot be as easily expanded or contracted as other sources of unpaid support (Boehm & Carter, 2016). For parent caregivers, parents remain divided on the role of family members, specifically their children not living with IDD, as supporters to their adult children with IDDs (Brennan, 2005; Hole et al., 2013).

Descriptions of parent caregiver's relationships with non-disabled children vary within the literature, reflective of the complexity of familial systems. The maintenance of unpaid relationships between parent caregivers and their children without IDDs positively influence the lives of parents providing care and their adult children with IDDs (Baumbusch et al., 2017). Unpaid support provided by other family members is acknowledged as essential to an adult family member with a disability continuing to live in community as the parent caregiver ages.

**Aging.** As parent caregivers of adult children with IDDs age, the unpaid support system present in their lives lessens regarding the number of times it is accessed and the number of different kinds of supports (Hole et al., 2013). Persons providing unpaid supports may pass away, move, or find that "life takes them elsewhere" (Hole et al., 2013, p. 580). Aging may diminish the number of opportunities for unpaid supports, as proximal relationships with other parents or family members also supporting an adult family member with IDD become distant, as a result of a decrease in social inclusion and

recreational activities offered to aging persons with IDD (Dillenburger & McKerr, 2009). As family members not living with IDs age, life milestones of careers, family and geographical distance effect the availability and proximity of the relationship with the caregiver. The nature of family relations varies widely, depending on the family cohesion, abilities of the adult family member with IDD and their corresponding needs (Dillenburger & McKerr, 2009). First voice experiences by family caregivers has the potential to add detail to understanding the landscape of family relations when supporting an adult family member with IDD.

In some cases where an aging parent is the primary caregiver to their adult child with a disability, siblings not living with IDs are expected to become the primary support person(s) for their sibling with IDD due to the familial bond that ties them to their sibling (Dillenburger & McKerr, 2009). In these instances, the female sibling is expected to take on the primary support role, taking their adult sibling with IDD into their family home (Dillenburger & McKerr, 2009; Hole et al., 2013). Female siblings are often the unconscious choice for parents whom are no longer able to be a primary caregiver (Hole et al., 2013), reflecting the traditional gendered nature of providing support and care. As one mother expressed, "I think maybe because they're girls that they would probably take care of him best" (Hole et al., 2013, p. 581).

Other parents planning for the futures of their adult children with IDD are reluctant to ask or expect for greater support to be provided by the sibling(s) not living with IDs to the adult family member needing support (Brennan, 2005; Hole et al., 2013). In some cases, the need for future planning following the deaths of parent caregivers was prepared for by creating a "microboard" to oversee the adult child's care

when parents were no longer able to (Hole et al., 2013). Microboards are formal, multi-member committees of persons delegated to manage funding, benefits, trusts and other financial concerns for an individual deemed as needing guidance and/or representation (Hole et al., 2013). In other cases, unpaid supporters agree to remain connected to the person with IDD and provide for their psychosocial needs upon the deaths of the parents (Dillenburger & McKerr, 2009). One mother referred to this arrangement of family members and friends as a ‘circle of support’ (Dillenburger & McKerr, 2009).

For some parent caregivers, the parent-child relationship between parent(s) and siblings not living with IDDs is negatively impacted by the imperative to support the adult child with IDD (Iacono et al., 2016). In some cases, parents report that children not living with IDDs perceive differential attention paid to the child with IDD during childhood and, in some cases, through to adulthood (Iacono et al., 2016). In cases of the non-disabled sibling having resentment towards the parents over attention differentials between siblings, this led to parents feeling unable to talk with their child not living with IDD about concerns and tensions in their lives with providing support to the adult family member with IDD (Iacono et al., 2016). Alternately, the differential attention was accepted by the adult child who does not have a disability, as understood and adequate under the circumstances (Iacono et al., 2016).

### **Paid Supports**

Whereas, unpaid supports are not compensated for their time or work, paid supports are carried out by persons compensated for their work (Hole, Stainton, & Wilson, 2013). In the literature paid support is often referred to by the term ‘formal’ support (e.g. Boehm & Carter, 2016; Sanderson et al., 2019). In the context of this

research, the term paid supports will exclusively be used, which reflects the preferred language choice of caregivers and support advocates (e.g. Caregivers Nova Scotia, 2020; Stall et al., 2019). In Canada, provincial governments provide funding for paid supports, according to the provisions of provincial disability program policy. Examples of paid supports are the following services provided by professionals: personal care, support (social inclusion, life skills, etc.), respite, day programs, sheltered workshops, vocational training, specialized health services and case management (Boehm & Carter, 2016; Llewellyn et al., 2004). This is a list of paid supports, although not exhaustive based upon the diversity of needs of families, and therefore a variety of supports that may be accessed. In Nova Scotia, provisions for paid supports are overseen by the Nova Scotia Department of Community Services (NS DCS). The exact nature of funding for paid supports depends on the assessed level of support required by the person. Under the Nova Scotia Disability Support program policies, a person can be assessed at a level from one to five, ranging from minimal support to intensive (NS DCS, 2012).

Paid support is provided in a system, one that is often characterized by academics, community providers, staff, families and individuals with disabilities alike as being fragmented and disconnected (Baumbusch et al., 2017; Hole et al., 2013; McKenzie et al., 2018). The funding allotted for paid supports, healthcare and the basic living allowance was variable in the literature, due to policies being individualized to each province in Canada, or structurally different in other countries (Hole et al., 2013). Based on the assessed needs of each adult with a disability, the extent of funding for paid support hours are different. In Nova Scotia and most provinces across Canada, navigating the paid service system is challenging (Baumbusch et al., 2017; Hole et al., 2013). For

parents who have poor experiences with the paid service support system (for a spectrum of reasons), relations with paid support providers are tense in many cases (Iacono et al., 2016).

Family members' experiences with paid support services left them feeling like they were competing for access to services for their adult family member with a disability (Dillenburger & McKerr, 2009) and fighting higher-level power structures (government agencies, service providers) for control, choice and person/family-directed services (McKenzie et al., 2018; Shogren et al., 2013). Family members also acknowledge the strains placed on staff working within the system, such as managing expectations, and paid service regulations (McKenzie et al., 2018). Given this, there is an evident need to hear first voices of family caregivers, to understand the priorities of families, persons working in the paid support system, and how such standpoints may work together.

### ***Respite***

Family caregivers report that respite is a significant paid support resource that contributes to their capacity to support their family member with a disability (Dillenburger & McKerr, 2009). Respite also was seen as a paid support that could be used effectively to transition unpaid and paid supports their family member with a disability received as they aged (Dillenburger & McKerr, 2009). However, family members experienced serious concern with consistency of respite, staffing and availability in emergency circumstances (e.g. Dillenburger & McKerr, 2009). Family members reported turning to unpaid supports for respite care because of the lack of suitable paid respite options available (Dillenburger & McKerr, 2009). For high level

support needs, overnight respite may be forced to take place in a hospital, or institutional facility (Dillenburger & McKerr 2009; McKenzie et al., 2018).

### *Availability of Supports and Services for Future Planning*

The issue of future planning brings into view the interdependence between unpaid and paid supports. In the event of no longer being able to provide support, parent caregivers were more likely to feel an urgency to secure paid support for their children if they had fewer unpaid supports present in their everyday lives (Garnham et al., 2017). However, parents were more likely to conduct planning if paid resources were in place to assist (Baumbusch et al., 2017). Future planning took place in an unofficial, and official sense depending on families, and the area of future planning (financial, housing, recreation, social connections etc.; e.g. Baumbusch et al., 2017; Garnham et al., 2017; Hole et al., 2013; Iacono et al., 2016).

Future planning for support arrangements for a family member with a disability following a primary caregiver's inability to provide ongoing support is a prominent theme that was identified as a gap for family members (Hole et al., 2013). Paid supports to aging parent caregivers for adult children with disabilities were either absent, deemed inaccessible or assessed to be inadequate (e.g. Baumbusch et al., 2017; Dillenburger & McKerr, 2009; Hole et al., 2013). Navigating a system of paid supports that offered reduced services and programs as their adult family member with IDD aged was a barrier family caregivers expressed (Baumbusch et al., 2017; Dillenburger & McKerr, 2009; Hole et al., 2013). Aging parent caregivers report shifting the support they provide as they age, from day-to-day physical demands of personal care, to support concerned with psychosocial well-being (Baumbusch et al., 2017; Dillenburger & McKerr, 2009).

Personal care for example, became increasingly difficult for parent caregivers as physical changes associated with aging occurred (Hole et al., 2013). The need for others to take over support occurred because physical care became increasingly strenuous as parent caregivers aged, prompting the need or consideration for future planning (Hole et al., 2013).

### **The Dynamic Parent-Child Relationship**

The relationship between parent caregivers and their adult children with IDD is unique, compared to parent-child relationships for children with disabilities, and also parent-child relationships for persons without IDDs (Hole et al., 2013). In the parent-child relationship of a parent caregiver supporting an adult child, advocacy was identified as a core tenet of the relationship (Grossman & Magaña, 2016; Hole et al., 2013). The bond between a parent caregiver-adult child with IDD is based upon a relationship spanning decades and is described by parents to be an expression of caring and comfort for their children (Brolan et al., 2012). Ideally, adult family members with disabilities would serve as self-advocates, and family caregivers would support their family member through supportive advocacy (Grossman & Magaña, 2016; Llewelyn & Northway, 2008). In the various supports present in their children's lives, parent caregivers spoke of their readiness to ensure the rights of their adult child as a person with IDD was upheld (Brolan et al., 2012). Advocacy to ensure high-quality health care, wider psychosocial needs connected to paid services, programs and policies was cited as a top priority of parent caregivers (Llewelyn & Northway, 2008). As parent caregivers aged, advocacy lessened and the provisions of paid supports faced fewer criticisms by parents (Baumbusch et al., 2017).



### *The Reciprocal Nature of Caregiving*

The relationship of parent caregiver(s) supporting an adult child is different from other familial caregiving relationships. Prior research notes the *burden of care* that parents sustain as a result of supporting their adult child at home; dominant discourse in parent caregiver-adult child literature of the support relationship no longer accepts the notion of a burden of care as encompassing the complexity of the relationship (e.g. Dillenburg & McKerr, 2009). The *invisible care* often carried out by the adult children, such as practical tasks and emotional support can make the caregiving relationship reciprocal, rather than unidirectional (Robinson et al., 2016). This is true regardless of the severity of disability of the adult (Dillenburg & McKerr, 2009).

As parent caregivers face challenges relating to aging, their adult children may be able to provide support to parents in managing their activities of daily living (Dillenburg & McKerr, 2009). Family caregivers (primarily parents) frequently described the care relationship as interdependent, rather than their adult child being dependent on them (Dillenburg & McKerr, 2009; Robinson et al., 2016). Examples of emotional and psychological care provided by the adult child were to comfort the family member in events such as bereavement, for practical tasks involving other family members requiring support, or when they were in ill health (Dillenburg & McKerr, 2009; Weeks et al., 2008). The exact nature of the practical tasks that adults with IDD are able to assist their aging parent caregivers with depends on the abilities of each person (Hole et al., 2013; Robinson et al., 2016).

## **Gaps and Limitations**

This review brought to light the current state of knowledge regarding the experiences of family caregivers, primarily parents, who are accessing unpaid and paid supports while supporting adult family members with IDD. In much of the research highlighted in this review, mothers were the primary supporters of adult family members with IDD. This confirms and strengthens the previously stated findings of the traditional gendered nature of support and caregiving. In some research, the perspectives of both parents and/or other family members were collected and presented.

The review of the literature highlights a gap in knowledge about family caregivers' experiences with unpaid and paid supports, in terms of quality and perceived ability to support the needs of their adult family member with a disability. It is notable that for some parent caregivers, the adult child had been in a residential housing option or outside of home placement within supported housing, and the family had removed them from such services. Removal from a higher level of outside the family home services reflected the dissatisfaction with the quality and consistency of support being provided (e.g Dillenburger & McKerr, 2009; Iacono et al., 2016; McKenzie et al., 2017).

The participant sampling techniques utilized (primarily self-selected, snowball sampling or convenience sampling) limit the generalizability of conclusions, even in cases of quantitative research. Since gatekeepers' organizations were used as the first point of contact with potential participants, sample groups of participants were more likely to have distinctive, polarized experiences with unpaid and paid supports. Further, caregivers with greater access and connection to multiple unpaid and paid supports would be in a position more conducive to participate within research. While it is difficult to

eliminate these limitations of previous research in the relevant areas, it is critical to acknowledge the understanding and potential implications of their existence.

This review of the literature provides an overview of the context of known research focusing on the experiences of family caregivers who are accessing unpaid and paid supports while supporting adult family members with IDD. There is growing recognition in the last 20 years of the complexity of the dynamic nature of the care relationship between family caregivers and adult family members with IDD. As provinces in Canada continue to move towards more inclusive societies, understanding the social supports of family caregivers' supporting an adult family member with IDD becomes more evident for future policy and programming. Chapter III positions this research as critical qualitative inquiry under the chosen theoretical framework of the critical-ecological paradigm (Norris et al., 2013). A deeper exploration of family caregivers' experiences of unpaid and paid supports in the lives of supporting an adult family member with IDD are explored through the model.

### **Chapter III: Theoretical Framework**

Critical qualitative inquiry is distinct from other forms of qualitative research for a number of reasons. Amongst these differences, is the emphasis of research as a means to promote justice, diversity, ethical responsibility and equity (Denzin et al., 2017). The aim of critical qualitative inquiry is the “*critique and transformation of the social, political, cultural, economic, ethnic and gender structures that constrain and exploit humankind*” (Guba & Lincoln, 1994, p. 113).

#### **Critical Theory**

Critical theory has an ontological position of historical realism. This means research in the critical paradigm assumes that reality is molded and affected by the “social, political, cultural, economic, ethnic, and gender factors” (Guba & Lincoln, 1994, p. 110). These factors are falsely accepted as structures that construct a reality of social life that is seen to be natural and unchangeable (Guba & Lincoln, 1994). The structures are in a sense real, because they shape the historical and social circumstances of persons’ lives by existing accepted by the dominant culture, and remaining relatively unchallenged (Guba & Lincoln, 1994). It is not whether they are real or not, as long as they are perceived to be real and affecting the lives of persons (Guba & Lincoln, 1994). A critical qualitative approach seeks to identify and deconstruct power relations that marginalize or oppress groups of people based on their historical realities and/or social status (Brookfield, 2005). Researchers who seek to conduct critical research recognize social stratification as implicit and explicit in society (Kincheloe et al., 2011).

### ***Subjectivity***

Epistemologically, critical theory is transactional and subjectivist (Guba & Lincoln, 1994). The researcher, and participants are assumed to be linked through bi-directional interactions (Guba & Lincoln, 1994). The values of the researcher are inexplicably intertwined with the inquiry (Guba & Lincoln, 1994). For this reason, recognizing the positionality of oneself as a researcher is crucial for critical qualitative inquiry (Guba & Lincoln, 1994).

### ***Relationship Between the Researcher and the Researched***

The methodology of the critical theory paradigm is dialogic and dialectical (Guba & Lincoln, 1994). Dialogic work constantly engages with and is informed by other voices besides the researcher's, it is concerned with utterances made by participants in their daily lives that a researcher can be privy to, to understand the lived social realities of participants (Freire, 1970; Smith & Turner, 2014). To do research that is critical, dialogue must take place between researcher and participants (Guba & Lincoln, 1994). In order to construct accurate understandings of the realities of participant's experiences and lives, researcher and participants must collaborate for the coproduction of knowledge (Guba & Lincoln, 1994; Karnieli-Miller et al., 2009; Smith & Turner, 2014).

### ***Bifurcation of Consciousness and Lines of Fault***

Exploring the everyday lives of family caregivers' supporting adult family members with IDD is particularly relevant to a critical qualitative approach, as the disconnect between dominant discourse and the routine of everyday practices as a family caregiver is of interest. The concept of bifurcated consciousness (Smith, 1987) refers to the disconnect between the everyday world of persons who experience it, and the

objective and disconnected analyses and explanations that come to characterize it ideologically (Spence, 2002). The bifurcated consciousness is especially relevant to the experiences of women, persons who have been marginalized (whether women or not) and persons whose voices are absent from spaces where discourse is created (Spence, 2002). The voices of family caregivers supporting their adult family member with disabilities remains arguably hidden in the line of fault, the space of disconnect between discourse and people's reality (e.g. Smith, 1987).

### *Ideologies*

Dominant discourse embodies ideologies that are pervasive. In case of this research, the dominant ideologies of neoliberalism, ableism, sexism (patriarchy) and familialism were found to be pertinent. I understand ideologies are historically rooted, sustained by actions, and complex. By stating their definitions my intent is not to oversimplify the impact and ways that these dominant ideologies inform and impact individual experience, but rather make this more accessible to readers. Although a simple explanation for these ideologies would be ideal, their complex and evolving nature is central to their continuance and inability to be extricated from the everyday practices of society (Friedman & Owen, 2017). Ideologies are widely accepted beliefs and practices that shape how people understand their experiences and live their everyday lives (Brookfield, 2005). Neoliberalism strives towards a system of individualization; the central belief is individuals have the same opportunities and options possible to them (Treanor, 2003). Ableism is discrimination towards persons with disabilities, valuing of ideals and attributes that serve the interests of the ruling elite of society (Friedman & Owen, 2017; Wolbring, 2008). Familialism is the ideals that family life is private, cannot

be violated or harmful to individual's family life is not to be interfered with by others outside the family, even in the occurrence of potential need (Norris et al., 2013).

Familialism is the ideology responsible for the widely held belief that family is always a safe haven (Norris et al., 2013).

### **Critical-Ecological Framework**

The critical-ecological framework combines the ecological model (Bronfenbrenner, 1979) and principles of critical theory. Visually, the critical-ecological framework is represented through a nested layer of circles, starting with the microsystem circle, and increasing in size to include the systems below until the macrosystem circle encloses all of the subsequent levels (Norris et al., 2013). The different levels of the system are considered bidirectional and interconnected to one another (Norris et al., 2013). The nature of the systems as nested within each other means that changes within one environment are not isolated to that context; the systems are responsive to changes in factors residing at other levels (Norris et al., 2013).

This research sought to understand the social relations of family caregivers' lives through consideration of micro, meso, exo and macro level analysis, using the critical-ecological framework. Microsystems refers to the setting in which individuals are immediately situated in and participate directly (Bronfenbrenner, 1979). Examples of microsystem level factors are family members, friends, unpaid and paid support providers (Norris et al., 2013). Unpaid supports in the context of this research are at the microsystem level for family caregivers', and also could exist in the mesosystem. The mesosystem refers to interactions between two or more microsystems. Often the mesosystem comprises connections between family and friends, and family and

community. For family caregivers' supporting an adult family member with IDD, a peer support group may be part of their mesosystem. The exosystem can be seen as a further extension of the mesosystem, at a more formal level (Norris et al., 2013). Agencies, policies and governmental entities that are responsible for the upholding of social order and functioning are part of this level (Norris et al., 2013). For family caregivers, the DSP could be considered part of their exosystem, as provision of disability services and supports are dictated by the program, and corresponding program policies. The macrosystem consists of ideologies and cultural values that affect all other levels of the system. Critical theory paradigm is arguably most concerned with the macrosystem, and the interrelationships that exist with other levels of the ecological system in relation to omnipresent ideologies. Utilizing a critical-ecological framework in this research made visible how ideologies are embraced, practiced and accepted as the norm in the everyday lives of parents (e.g. Norris et al., 2013).

A critical qualitative approach contends that hegemony and control of individuals operates most fluidly in the lives of individuals when they accept their positions socially, as natural and unavoidable (Norris et al., 2013). In their everyday practices, persons carry out actions that oppress them and embody large scale ideologies, unknowingly and unquestionably, this is hegemony (Brookfield, 2005). The potential for emancipation of family caregivers' through explication of the various systems of the critical-ecological framework present in their lives highlights possibility for disrupting the embodiment of relations of ruling evident in everyday actions (Norris et al., 2013). The critical-ecological framework informed the progress of the research through providing a lens that disentangled the multiple levels of interaction that comprise the realities of family



caregivers' everyday lives. The critical ecological framework works towards the "first step in transformation [which] is the critique of the social, political, cultural, economic, ethnic, and gender structures that constrain and exploit" (Norris et al., 2013, p. 51) family caregivers supporting an adult family member with IDD.

## Chapter IV: Method

IE as a method is compatible with the guiding methodology of critical theory for the emphasis the methodology and method place on socially and historically mediated contexts in order to understand the circumstances of people's lives (Brookfield, 2005; Smith, 1987). In the use of language, IE is purposeful, direct and distinct through the terminology that characterizes the methodology. To understand IE as a methodology, the following terms are essential to know additionally for the research: social, social relations, ruling relations, dominant culture. The social refers to the continuous coordination of a person's activities (Smith, 1987). Social relations are organized, planned sequences or paths of social action that implicate "more than one individual whose participants are not necessarily present or known to one another" (Smith, 1987, p. 155). Ruling relations are text-based environments wherein power begins to be exercised and activated across multiple sites (Wright, 2003). Examples of ruling relations are "legislation, governing boards, program planners, management and administration" (Wright, 2003, p. 244). Dominant culture serves the interests of ruling relations and refers to the discourse which is widely accepted unquestionably as knowledge (Wright, 2003). What dominant culture perpetuates becomes the reality of people, as culture pervades their everyday lives (Wright, 2003).

Critical theory and IE aim to challenge dominant discourse through bringing people's voices up out of the fault line to be heard (Smith, 1987). Power is recognized as interspersed in the relations of people's everyday lives and exercised through action (Brookfield, 2005). Dominant discourse is recognized to be problematic in critical theory and IE, for the experiences of people who are marginalized and oppressed by ruling

relations are not represented (Brookfield, 2005; Smith, 1987). Unlike other research approaches, the institutional ethnographer enters the research through investigating the “social in people’s experiences to discover its presence and organization in their lives” (Smith, 2005, p. 11). The purpose of an IE is to investigate how everyday experiences of people are socially organized and how various structures, agencies and relations in peoples’ lives intersect (Wright, 2003). An IE typically involves the collection and analysis of three levels of data: a) first-voice accounts of experiences of the problematic, b) interviews with service providers and c) policy analyses (Campbell & Gregor, 2002; Smith, 1999). Given the scope and limitations of a master’s thesis, a modified IE was carried out. The modified IE conducted used two of the three data sources traditionally found in an IE; data collected were first-voice experiences and policy analyses. For this modified IE research, interviews with service providers were omitted.

### **Procedure**

Prior to recruitment or data collection, approval to undertake the research was obtained from the University Research Ethics Board (UREB) at Mount Saint Vincent University. Ethical approval was obtained in February of 2020. The research was conducted with human subjects; therefore, the research adhered to the Tri-Council Policy Statement on Ethical Research Involving Humans.

The recruitment of participants for this research relied on gatekeepers. An introduction letter to gatekeeper organizations, community members and stakeholders was created, in order to inform gatekeepers of the goals of the research; inclusion and exclusion criteria of potential participants; and researcher contact information (Appendix A). The age of family caregivers was variable, however for inclusion in the study, the

adult family members with disabilities family caregivers support were required to be between the ages of 25-40. The criteria for age of the adult family member with a disability was for having a focused sampling frame for the study, necessary based on the limitations of the research as a master's thesis. To understand how unpaid and paid supports have changed over the life course as family caregivers and their family members with a disability have aged, this was inquired about in the interview. For gatekeepers to recruit participants, a recruitment poster was created to be printed out and posted at the gatekeeper organization, and/or sent to potential participants electronically (Appendix B). For potential participants, a preliminary letter for the research was written up for viewing (Appendix C). The letter to potential participants (Appendix C), participant consent form (Appendix D) and consent for audio recording form (Appendix E) were distributed together by gatekeepers to participants. The participant consent form provided a more in-depth description of the research to be conducted. A consent form (Appendix D) and consent for audio recording form (Appendix E) were distributed to potential participants by gatekeepers for review and signature, if family caregivers chose to voluntarily participate in the research. Researcher contact information was provided in Appendices A, B, C and D.

### ***Recruitment***

Gatekeepers were contacted within community organizations in order to obtain participants. Gatekeepers included management within the Dartmouth Adult Service Centre (DASC), and physicians involved with the Dalhousie Family Medicine Adult Developmental Clinic. In the recruitment of participants, gatekeeper organizations were clear to potential participants that participation in the research was voluntary and would

not affect their services or supports in any way, regardless of whether they choose to participate or not. Criterion and snowball sampling techniques were implemented.

Criterion sampling involved recruiting participants who meet the eligibility criteria and represented a diverse sample of the population, as determined by gatekeepers.

Participants were recruited through paper flyers placed on bulletin boards at gatekeeper organizations, presentations at board meetings of gatekeeper organizations and word of mouth, through gatekeepers to potential participants. Snowball sampling involved initial participants making contact and potentially recruiting further participants for the study through word of mouth communication.

Gatekeepers made initial contact with potential participants. Sampling took place within the Halifax Regional Municipality (HRM), located in the province of Nova Scotia, Canada. The HRM encompasses the communities of Dartmouth, Halifax, the former Halifax County and Bedford areas (HRM, 2018). Prior to being interviewed, participants will be required to have read a letter to potential participants by the researcher (Appendix C), and then signed a participant consent form (Appendix D) and consent for audio recording form (Appendix E). Signing a consent form confirmed they were voluntarily consenting to participate in the research, understand what the research was regarding, and understood their rights as a participant. Participants signing the consent for audio recording form confirmed they were knowingly and voluntarily consenting to be audio recorded during the interview, and that they understood the recording would be transcribed to be used for data analysis.

### ***Data Collection***

Institutional ethnographers seek to explore the established problematic of their research through explicating what happens in a setting wherein people live their everyday lives-the local (Campbell & Gregor, 2002). The problematic refers to the social organization of the everyday world, it is not the same as problem (Smith, 1987). In IE, the problematic is beyond the level of experience and action, it exists at the level of concept or theory (Smith, 1987). As previously discussed, explicating is discovering ‘how things work’, how they are put together (Smith, 1987).

### ***Interviews***

To do this modified IE, I began in the everyday world, collecting data through interviews with family caregivers and then explicated the problematic by going further beyond what was known in the local setting, to the extra-local. In IE, the extra-local is organizational settings that are responsible for texts that organize and exert influence on the way people carry out their everyday lives (Campbell, 1998).

In the original study design, interviews were to be conducted in person, with one caregiver who provides support to their adult family member with a disability. However, in mid-March of 2020 when recruitment was underway, the COVID-19 pandemic was active globally, and within Canada. Public health measures put in place included social distancing of a minimum of six feet distance from others. Given the impact of this, a modification/change of protocol request was sent to the UREB to allow for interviews to be conducted via telephone. This request was approved, and the data collection proceeded through telephone interviews with participants.

Interviews were semi-structured, sample interview questions can be found in Appendix F. In length, interviews were anticipated to take one to two hours to complete. In actuality, interviews took approximately forty-five minutes to complete. The time difference is attributed in part to the shift from the expected in-person interviews, to telephone interviewing. The guiding methodology, IE, looks specifically at the everyday experiences of family caregivers' in order to map the social relations present. The interview guide reflects the inquiry pertaining to understanding 'how things work' in family caregivers' lives (Appendix F; Smith, 1987). To understand the lives of family caregivers', the interviews took an in-depth dialectical and dialogical exploration through interviews to record the first-person voices. Interviews are necessary for IE is a method of inquiry for the people, as opposed to being conducted detached from people the research is concerned with (Smith, 2005).

An estimated 8-10 participants were desired for data collection. However, in total five participants were interviewed. Participant recruitment and interviewing was hindered in part by the circumstances of COVID-19. The process of interviewing participants took place over several weeks. Interviews were audio recorded with participants' consent, and then transcribed. Participants were reminded at the beginning of interviews that as a participant they had the right to refuse to answer specific questions, have the tape recorder stopped at any point or withdraw completely from the data collection process (Appendix D). Ethics of data collection and analysis were carefully reflected upon and documented.

### ***Policy Analysis***

In interviews, the language of text-mediated relations was expected to be used by family caregivers (e.g. Campbell & Gregor, 2002). This proved to be true. The text-mediated relations appear within people's descriptions of the reality of their lives, because they are embedded in what people do and know (Campbell & Gregor, 2002). IE uses texts as a second level of data beyond individual's personal accounts of their lives, to understand linkages between factors at different levels (Campbell & Gregor, 2002). Texts that were collected for analysis were publicly available (Campbell & Gregor, 2002), such as the DSP Program Policies. Collecting of relevant texts was contingent upon data obtained in interviews with family caregivers. The data collection process in IE is recursive, going back and forth between the local site in which family caregivers are situated, and ruling relations that are textually mediated (Campbell & Gregor, 2002).

### ***Alignment with Critical Research***

The social organization of peoples' everyday experiences were investigated in order to understand power relations, social forces and ideologies embodied within participants' lives and map them so how things work can be understood (Smith, 1999; Wright, 2003). In order to understand the social reality of family caregivers' lives, it was paramount that conflicting interpretations of people's own lives be heard, and respected (Spence, 2002). Meaningful social change is not connected to the social, rather it begins there (Spence, 2002). This premise of IE echoes critical theory, wherein meaningful social change has to ripple outwards, to levels extended beyond just the individual. The theoretical framework used, the critical-ecological framework, aligned with the intentions of IE research to uncover 'how things work' in the everyday lives of people (Norris et al.,



2013; Smith, 1987). Understanding and disentangling power relations are critical to the overarching methodology of critical theory, the critical-ecological model and IE (Campbell & Gregor, 2002; Norris et al., 2013). Moreover, the interactions between ruling relations and people are complex, operating at multiple levels of an individual's environment and affecting other systems in response to changes (Norris et al., 2013).

### ***Addressing Research Questions***

IE helped to address the two research questions that had been posed prior to beginning the research: (1) How are family caregivers of adult family members with disabilities (focusing on IDD) supported through networks of unpaid and paid supports? and (2) What dominant ideologies are embodied within the everyday lives of family caregivers supporting adult family members with disabilities (focusing on IDD) as they access unpaid and paid supports?. The research questions were explored through the method of IE, which allowed the research to explicate how “our world is continually being brought into being as it is and as it is becoming, in the daily practices of actual individuals” (Smith, 1987, p. 125). By conducting a modified IE, the first-person voices of family caregivers and text-mediated relations were delved into to explicate and then map how the social realities of family caregivers supporting an adult family member with IDD are constructed, constantly re-negotiated and continue to exist as they do.

### ***Reflexive Journaling/Observation/Fieldnotes***

The subjective nature of researcher as intimately positioned within the process of the research, being privy to the personal experiences of participants necessitated the need for reflexive journaling, observation and fieldnotes. Research and power are interdependent and cannot be disentangled (Guba & Lincoln, 1994). Power is inevitable

in research, and critical theory seeks to deconstruct historically constituted power structures through liberation and emancipation of persons who have been oppressed (Campbell & Gregor, 2002; Guba & Lincoln, 1994; Smith, 1987). In conducting research with persons who have been unheard in contexts that privileges knowledge production that serves ruling relations and is not reflective of the experiences of persons, it was important to recognize my inherent privileged position as a researcher (e.g. Smith, 1987).

**Member checking.** Member checking entails once transcription of interviews is complete, sending the full transcript back to the participant for viewing, and feedback (e.g. Tracy, 2010). Member checking was conducted to ensure the power and control of participants in their research participation. Data collected from participant interviews was used for analysis, and ultimately study findings. Therefore, it was important to the researcher that the information shared in interviews was consistent with the realities of their everyday lives that participants wish to share. The member checking process was intended to verify the words participants expressed during interviews had been accurately captured in transcriptions.

### ***Ethical Considerations***

Conducting research requires ethics be at the forefront of researcher's conduct, as evidenced through reflecting upon historical and social positioning of the researcher and participants (Guba & Lincoln, 1994). Families supporting adults with disabilities have been marginalized, therefore including family caregivers' as informed, included and respected collaborators to the critical qualitative research was a noted concern for the research when considering ethics (Brennan, 2005). This study posed minimal-low risks to

participants. Due to the nature of this study, there was no risk for physical harm, but the possibility of mental and social harm was acknowledged.

**Procedural ethics.** Total anonymity was not possible, as the identities of participants were known to the researcher during the research/interviewing process. To ensure confidentiality, participants were assigned pseudonyms, and potentially identifying details were removed from transcripts. As a researcher and transcriber, I was bound by the limits of confidentiality. All electronic data was password protected and kept on the researcher's personal laptop. All raw paper data (field notes, consent forms, transcripts) were kept stored in a secure, locked filing cabinet within my home. As the researcher, I was the only person who had access to the filing cabinet key. All data collected will be kept for five years, then destroyed, as per regulations set out by the Tri-Policy Council. Raw paper data will be destroyed through shredding completed by myself as the researcher. Electronic data will be transferred to a USB stick, then submerged in water and hammered to ensure data is irretrievable.

**Situational and relational ethics.** Emotional risks were anticipated, based on the potential everyday experience's participants shared. Participants did share disempowering experiences, such as a lack of perceived support (e.g. Boehm & Carter, 2016; Brennan, 2005). However, through sharing their experiences empowerment was aimed to be gained through the research collected being shared to participants, community service organizations and the broader institutional and academic community. Participants were supplied with a list of appropriate resources after their interview,

should they wish for emotional support (Appendix G). As well, participants were invited to contact the researcher at any point before or after the interviews took place.

Throughout the research process, conduct of the researcher was mindful of relational ethics, which intersects with the ethics of care (Vandekinderen et al., 2014). Relational ethics addresses human, respectful and morally acceptable conduct towards research participants, whilst being a researcher (Guillemin & Gillman, 2004). In critical qualitative inquiry, relational ethics necessitates considering the sociopolitical context within which the research, participants and area of interest is historically, socially and politically positioned at various points in time (Vandekinderen et al., 2014). As a researcher, one cannot conduct research without exercising power; where research is being conducted, power is involved (Vandekinderen et al., 2014).

Institutional ethnographers seek to do research that is for the people (Smith, 1987). The final research write-up was presented in the form of this master's thesis to my supervisor and committee. Additionally, I wrote a report of findings that was disseminated to participants, community members and interested stakeholders (Appendix H). The language of academia is not widely accessible, therefore I sought to empower participants with the knowledge they had graciously supplied. The summary of findings was a report designed to be accessible for those in society generally, as opposed to purely academia. However, the report also introduced language of discourse that may have utility for family caregivers' as they navigate the paid support system.

### **Analysis**

In entry-level and secondary-level data collection, far more data was collected than necessary for analyses (Rankin, 2017b). The research problematic identified in

preliminary IE data collection was used to guide and support analysis (Campbell & Gregor, 2002; Rankin, 2017a). I established a standpoint of family caregivers' experiences of unpaid and paid supports, through which small problematics were exposed, and tugged at to understand the comprehensive problematic (e.g. Campbell & Gregor, 2002; DeVault & McCoy, 2002). Analysis sought to identify disjunctures, which are tensions wherein the language and realities of person's lives do not align with ruling relations that perpetuate the ideologies embedded in people's everyday lives (Campbell & Gregor, 2002).

Analysis of entry-level interview data was an ongoing process during data collection. The process of coding began at open coding, then proceeded to axial coding and finally selective coding (Kendall, 1999; Strauss & Corbin, 1990). Strauss and Corbin (1990) establish open coding as "the process of breaking down, examining, comparing, conceptualizing, and categorizing data" (p. 61). Following this, axial coding took place wherein the data was put back together in new ways, by making connections between categories and subcategories (Kendall, 1999; Strauss & Corbin, 1990). Lastly, selective coding took place, where the data was systematically related from the core category to other sub-categories, and combined and refined, to create theoretical concepts (Kendall, 1999).

To conduct this analysis, the qualitative software program MAXQDA was utilized. The research sought to map the social relations of unpaid and paid supports in the lives of family caregivers supporting an adult family member with IDD. IE, the critical-ecological framework, and critical theory were used to analyse the linkages and explicate at the micro, meso, exo and macro level of a family caregivers' experiences. By

creating a map, the analysis orientated how the relations are put together, how things are existing (Rankin, 2017b).

### **Participant Descriptions**

Each of the five participants met the eligibility criteria for participation in the study. Each resides within the HRM; has an adult family member requiring daily support; is the primary caregiver of the adult with IDD requiring support; and resides either with the family member with IDD or supports them as they live in a community-based setting. Names used for participants are pseudonyms. Potentially identifying details have been omitted from individual descriptions to protect the identity of participants and their family members. A summary of characteristics of participants follows individual participant descriptions.

Robin is a family caregiver in her early sixties. She identifies as the primary caregiver to her male family member who is in his mid-twenties and who lives in the family home with her. She has been the primary caregiver for her family member his whole life. Robin described her family member as needing support 24-hours a day for his IDD-related co-occurring health needs. He communicates primarily non-verbally.

Monica is a family caregiver in her early sixties. She describes herself as the primary caregiver to her male family member who is in his late twenties and who lives in the community in supported housing. For the first 19 years of his life, he lived in the family home with her. While he does not live with her, she remains involved in his caregiving and daily life. Monica described her family member as able to complete some life skills in a limited capacity. For most daily activities, he requires support through direction or physical assistance. He communicates primarily non-verbally and has

challenges with processing communication from others. She described him as enjoying being around other people, especially when doing physical activities (i.e. walking or swimming).

Nicole is a family caregiver in her early sixties. She identifies as the primary caregiver to her female family member in her mid-twenties. Her family member lives in Nicole's family home. Although Nicole has not been the primary caregiver for her family member for most of the family member's life, she has been the primary caregiver to her family member for two years, beginning when the family member moved into her home. While her family member is largely independent, communicates verbally, and has strong social skills, Nicole provides prompts for personal care and daily activities.

Kim is a family caregiver in her mid-thirties. She identifies as one of two primary caregivers to her male family member who is in his early thirties and who lives in the family home. For the past ten years, she has shared the primary caregiving role with her partner. Kim describes her family member as needing support in most aspects of his daily life, requiring 24 hours a day care for IDD related needs, and co-occurring health conditions. He communicates non-verbally. One of his noted strengths is his mobility.

Brenda is a family caregiver in her early sixties. She supports a male family member in his early thirties who lives in the family home. She has been his primary caregiver for his whole life. Brenda describes her family member as needing limited support in specific areas of his life including transportation, cooking, and time management. He communicates verbally. Social abilities are a noted strength.

All five of the participants identified as female, ranging in age from 36-63 years old. Their family members range in age from 25-34 years old. Four participants support a

male-identified family member, while one participant supports a female-identifying family member. Participants reported their family members had a diverse array of abilities, and correspondingly differing levels of support needs. Three participants described their family member's communication as primarily or exclusively non-verbal. Two caregivers reported that their family members communicated verbally.

Primary caregiving responsibilities ranged from support required by the family member 24 hours a day, seven days a week in all aspects of daily life, to their family member being able to support themselves in most aspects besides cooking and transportation. All participants identified as their family member's primary caregiver as per the inclusion criteria for the study. One participant described the role of primary caregiver as a shared role between herself and her spouse. Four participants lived with their family member; one participant's family member lived in a supported housing arrangement in the HRM community. Three participants identified their role as 'mother', one participant as 'stepmother', and another as 'aunt'.



## Chapter V: Findings

Hearing the experiences of family caregivers allowed me to understand how unpaid and paid supports operated in their local, everyday lives. This provided a starting point for connection to the extra-local which is the broader setting in which their experiences were organized. While all participants noted some level of unpaid and paid supports in their lives, it is important to note that each of the networks of unpaid and paid supports in the family caregivers' lives were different. This created a complex, rich puzzle that was analyzed to understand their experiences.

Coding of the data revealed three primary themes, under which sub-themes are evident. First, inclusive and accessible networks function to support family caregivers of family members with IDD. Their belief systems and availability of networks is tied to the support received. Second, unpaid and paid support provide family caregivers and their family members with opportunities for meaningful engagement with persons in their immediate and broader environments. This included social interaction in settings such as family gatherings, organized sport activities, advocacy with community organizations, and recreational activities for persons with IDD. Finally, there is a disjuncture (line of fault) between institutional priorities and the everyday experiences of family caregivers as they access unpaid and paid supports. This can be seen through policy analysis, using the DSP Policies which dictate disability support in Nova Scotia. Family caregivers respond to the line of fault through advocacy and utilization of available resources to best meet their needs. Family caregivers were cognizant of the line of fault in some instances. These themes will be discussed through first-person experiences described in this chapter.

## **Inclusive and Accessible Networks of Unpaid and Paid Support**

The interviews with family caregivers' reveal inclusive and accessible networks that function to support them in their role. Networks of support involving unpaid individuals included family members, friends, and disability-affiliated friends.

### ***Unpaid Supports***

Family members providing unpaid support included current or former partners, adult children, and other family members. Family caregivers provided physical support (i.e. unpaid respite) in short- or long-term increments depending on health needs and abilities of the family members requiring support as well as the extent to which their behaviours were challenging. Behaviours that challenge are a way persons with IDD may communicate unmet needs (Green et al., 2018; Sullivan et al., 2018). Behaviours that challenge is the preferred language choice according to the 2018 Canadian consensus guidelines (Green et al., 2018; Sullivan et al., 2018), however the term *challenging behaviours* is still frequently used within the disability support community. Some behaviours that challenge, such as aggressive behaviour or unpredictability, limited options for seeking and receiving unpaid respite for family caregivers. This was exacerbated when the communication of family members was primarily non-verbal.

Monica identified her family member's behaviours that challenge as significantly impacting the amount of physical support she was able to receive from family and friends while the family member was living in the family home. Instead, she relied on paid respite workers to provide physical support to her family member when she was not present. The aggressive behavior of her family member prompted her to seek alternate housing for him within the community.

Robin's experience is similar to Monica's. Paid respite workers were relied on for physical support primarily. She describes the need for more than one person to provide support in outdoor settings in the following quote.

*I have to get two people usually when he goes for his walks. I have to get two people to walk with him because he is a big guy and uh you know, if something happens, ah, keep him in line kind of thing [i: Mmhm]. For example, like uh he goes for a walk, so they take him for a walk to go to the park and play basketball with him but you know, like ever once and a while he'll decide he's going to run into the traffic or something like that. So it takes two people to hold him back kinda thing.*

[Robin, line 42]

Her former spouse was the only family able to offer physical support as needed because of her family member's behaviours that challenge. As an example, she stated that because of her family member's behaviours that challenge, her former spouse was helpful to her when participating in outdoor activities with their son. Other participants reported support from their current or former partners also.

**Current or former partners.** Four participants receive support from a current or former partner. Nicole reported being widowed and having no partner at the time of the research. Monica reported both her current and former partners being essential in how her daily life operated. Former partners who were fathers of the family member remained involved, providing varying levels and kinds of support. Monica noted that caregiving decisions and responsibilities were left to her with her former partner involved as a supporter, providing financial support and spending quality time with their son. Indeed, she described her former partner's role as one involving meaningful and regular social activities with their son.

*He certainly goes to visit [family member]. [Family member] lives fairly close to him now, and [family member's dad] is able to take him out on a regular basis, well every Sunday they go out, they go bowling.*

[Monica, line 36]

Monica's quote demonstrates the consistent social activities her former partner and son participate in that add quality to her son's life. Robin's former partner provided physical care for their son every second weekend, offering emotional and physical respite. The son also benefitted from the opportunity to engage in activities otherwise not available to him, enhancing his well-being. This is evident when Robin described her son's weekends with her former partner.

*They do different things cause his dad has a car, I can't afford a car so I don't have a car. So his dad takes him for drives. His dad also takes him swimming, because his dad can handle him pretty much. So ah he'll take him swimming to like the community pool. He'll take him somewhere where you know it's not very busy [i: Right]. They have their own little, you know thing.*

[Robin, line 48]

Her son was no longer in school and unable to attend a vocational centre, based on his abilities and behaviours that challenge. The care her former partner provided allowed her son to be included in a variety of activities and settings. This added value to both her and her son's life.

**Adult children.** The adult children of family caregivers may also be involved in the provision of physical and emotional support to their family member with IDD. Support to family members with IDs offered by adult children is unique because of its duration and emotional significance. Nicole referred to this while noting that her adult children fulfill a primary role in supporting both her and their family member with IDD.

*They've all been involved in [family member's] life since they were little. Since she was born. She kind of grew up with them. So they look out for, her rights and her welfare.*

[Nicole, line 56]

Similarly, Kim described family dinners and monthly visits by adult children noting that they are integral to the family system and reliable.

*His brothers for example would be uh right up there with people we can rely on, although they may not be prepared to manage his medications, they generally can troubleshoot his [medical apparatus] if something is going wrong or um-, um getting him to the bathroom and then helping him.*

[Kim, line 34]

Sometimes the focus of the involvement of adult children is specific. Nicole shared that increasing opportunities for physical activity for the family member with IDD was a goal initially pursued by herself as their family caregiver but subsequently taken on by her daughters as well.

*They're good at ah-, you know, we were trying to get [family member] to walk and to exercise and that's really been a struggle. [Daughter] made an exercise routine for her, which [family member] really wanted [i: Mmm.] And they really encouraged her, and still do. They encourage her to do her exercises, and you know, really make a big deal of her doing them. My daughter who's house she goes to after work, she would do the exercises with her when she comes home from work. So they've always been good at encouraging her.*

[Nicole, line 52]

In addition, one of the daughters in this family, an employee working in a disability-related agency, facilitated access to community activities for the family member with IDD, enhancing well-being through inclusion for this individual.

In this study, greater flexibility in daily scheduling and new opportunities resulted from the support provided by the adult children of family caregivers. For example, Nicole reported that her adult daughter's accessibility and willingness to support her family member made it possible for her to work full-time. In this instance, the adult child spent time with the family member with IDD in the interval between the end of her scheduled activities and the parent's return from work. Paid respite was not accessed or believed to

be available to this family for this period of time during weekdays. Without this support, Nicole reported that she would not be able to work in her current full-time position. Her family member spending time with her daughter also created the opportunity for emotional support to be provided to the family member.

Monica noted that the emotional support provided by adult children had changed over time, as they themselves became adults. She actively worked to ensure continuity of quality support, both unpaid and paid, for her family member in the future. Part of this planning involved discussion of future planning, particularly the caregiving needs of the family member with IDD and contingencies required when the primary caregiver, the parent, was no longer able to assume this role. In this instance, the parent was not intent on her other adult children filling in her place, but, rather, to continue to visit the family member in his supported housing.

*My other two kids are now [adults] and-, I can let them know I'm upset about something now that I would've been when they were younger, obviously I tried to protect them from a lot of the emotional angst (sighs) when they were younger, but um if I was really upset about something I'll just tell them you know what's going on with [family member] so they have an idea because they will be his support people when I'm gone, and his dad's gone so-, but what I've tried to do is set up [family member] so that, and I keep-. this is one of the reasons I keep saying to people, until I know that [family member] has a life that will continue after I'm gone (emphasis) [i: Mmhm] and his siblings won't have to be worrying all the time about what is happening to him, that their role will be just to go visit him.*

[Monica, line 52]

For Monica's family, future planning focused on minimizing her adult children's responsibility for her family member's care. This intent was the impetus for placing the family member in supported housing in the community, a proactive strategy implemented to secure a quality living situation so that when life circumstances changed, such as the

death of the parent, it would be less chaotic for her family member and adult children, as alternate housing would already be in place. The objective here was to minimize burden for the adult children by limiting their responsibilities for financial management, bureaucratic oversight, and visits with the family member.

*I want them to know their responsibility is to manage maybe the financial resources that are going to be available to [family member] and that they can go and visit him without feeling like they're going to be on the hook for doing something. Because that makes it less likely that you enjoy it, you know. They love their brother, they want to do what they can for him but I don't want them to feel like it's going to be a burden for them, so. I have lived that burden, I'm still living that burden so (laughs) I'm trying to avoid it for them at all costs.*

[Monica, line 54]

Monica was motivated to develop this proactive plan for the future because she, herself, cared for a sibling with substance abuse and mental illness, a situation she described as a *caregiving burden*, one that she did not want her children to experience. She was not wish for her children to compromise their own well-being in caring for their brother.

Some adult children of participants in this study who were geographically distant (i.e. more than two hours away) and/or considered to be busy with work and their own family obligations were still involved in offering support, even if accessibility was limited. Emotional support was provided through phone calls; however, the frequency of contact was less than what it had been prior to the change of circumstances.

**Other family.** Unpaid support provided by siblings and parents of family caregivers was noted by two participants. This involved physical support and/or emotional support. Kim notes that her unpaid physical support she could access for caregiving included not only adult children or her partner, but also other family.

*He's got a few aunts that uh we would be comfortable with leaving him with for an extended period of time.*

[Kim, line 54]

In most cases, siblings and parents were more involved in providing one-to-one support when their family member and other children were younger. Changes in capacity to provide support were attributed to aging and/or the death of the person within the family who provided the support. This happened in Kim's family.

*He had an uncle who was excellent for him who passed away last year who was one of our main-, you know would do sleepovers and they were very very close.*

[Kim, line 54]

The support this uncle provided was unlike that of other family, Kim reflected. Similarly, Monica noted changes within her family support system, also attributed to death.

*I had a brother-in-law who quite often would take the kids, I have three children, so, he would quite often take them out because he was very good with [family member] and could manage him quite well. And my dad, but my parents have been gone for a long time [i: Mm right. I'm sorry to hear]. Yeah, well that's been a while now so it's fine.*

[Monica, line 50]

She noted the passage of time as lessening the impact of losing her parents and the support they offered.

Monica elaborated that the absence of her parents in her life was felt in multiple ways. This included providing physical support through spending time with her family member, and also encompassed emotional support through listening, and empathizing.

*They were certainly-, they always provided if not support for [family member] support to me [i: Right] so, you know, emotional support which isn't necessarily direct caregiving, but knowing that there is someone you can go to and talk to, or just tell them how shitty it is (laughs). If things aren't going so well, I mean you know you're not expecting them to come and do anything because you know they can't but at least they understand.*

[Monica, line 50]



When prompted about who provided emotional support to her presently, she reported that her current partner, friends (general and disability-affiliated), former partner, and now adult children did so.

In times of need, family members could be relied upon to step in to provide physical support. This applied to both special event and crisis situations. For example, Nicole noted that other family were able to accommodate her family member in their home for two nights, so she could attend a wedding by herself. This provided a break from caregiving for her and was also a welcome change of routine for her family member for a weekend. Kim noted that when her family member required hospitalization, other family members were able to provide physical support. She explains that while these individuals need to be well-known to him in order to provide effective support, the circle of support expanded as needed.

*He needs to have someone in the hospital with him 24/7 who's not just his nurse or a sitter. It needs to be someone who knows him. So in those cases I would say that circle expands because (...) um you know we just-, it's a little bit more tricky to balance and so we've got lots of family members who have gone and be with him, so that's uh, that's not uncommon.*

[Kim, line 50]

Large family settings were also instrumental in providing accessible and inclusive support. Brenda spoke about the valued involvement of her large, extended family in the following quotation. She noted how interactions between her family member and others in the family network were inclusive.

*We as our own family have a lot of parties, we're big party people. (...) So like you know, I may have a party for my birthday and rent a hall and DJ, and he'd be there, any family functions he's there. Like my whole family, everybody in our family is (...) very supportive of him and very um, good with him. You know like, including him in the discussions when we are out and about and stuff like that.*

[Brenda, line 42]

Kim echoed a sentiment similar to Brenda's. She reported that large family gatherings took place with regularity in their lives. These entailed gatherings of 10 to 25 people, usually for a meal, and provided valuable opportunities for socialization. Even activities where her family member could not actively participate because of medical considerations, he was included and welcomed by her family. Participating in meals, for example, was about socialization rather than eating.

**Friends.** Kim reflected upon her friends being there for both physical support and emotional support in her life. When asked who she reached out to with regularity, she reported her friends as emotional supports.

*I would say friends. You know I've got a close group of friends who-, who are great and we share all of those things um. That would be the main. We've got a pretty-, we are very lucky that we have a very extensive um, yes close knit support group both for you know the actual hands on stuff and the emotional, the telephone calls kind of support.*

[Kim, line 36]

Kim noted that her friend network was significant to her feeling connected and supported in various aspects of her life.

Nicole noted that her friends had stayed the same since becoming a family caregiver. Moreover, they welcomed her family member to join in their activities. She explains what spending time with her friends entails.

*I have a group of friends and we get together and go out for dinner for each other's birthday's and they've really ah (...) you know, she really enjoys going out with my friends, so, where I go [family member] goes pretty much.*

[Nicole, line 40]

Nicole voiced that activities she previously had done by herself such as seeing friends, were now activities done with her family member included. This was both positive and negative from her standpoint. She was aware of the social engagement and enjoyment her

family member got from spending time with her friends. She wished for separation of their lives at times, such as in the context of her friends. Putting the needs of her family above her individual needs is demonstrated here. The emotional support provided by friends was viewed as lessened because her family member was still there.

**Disability-affiliated friends.** Three participants had connections with disability-affiliated friends and acquaintances. They had been introduced through recreation activities that their family member attended previously and/or currently and through involvement in advocacy activities on behalf of their family members. In some cases, participants were involved with multiple disability organizations and knew these friends from more than one organization. Brenda explained her experiences with developing friendships within these organizations. She mentioned that she was friends with other family caregivers (specifically parents in this case), but also that her family member was friends with their adult family members.

*We have um there's probably 5 of us [disability organization] parents that met through [disability organization] and we've become really good friends. And our kids are good friends too, like you know like [family member] would have the circle of friend's parents that we have too would be our friends right.*

[Brenda, line 74]

Brenda experienced these friendships beyond the settings in which they originated. Her family member, for instance, enjoyed birthday parties attended by friends met through these recreational activities.

### ***Paid Supports***

The three participants with family members in vocational centres, described the paid supports of vocational centres as inclusive and accessible. Nicole discussed her experiences with her family member's vocational centre in this passage.

*They're [vocational centre] great to deal with. We have a yearly review and they're always very encouraging, and help [family member] set goals and just the way they interact with her. You know, they treat their clients with respect and (...) if it wasn't for [vocational centre] I wouldn't be able to continue to work.*  
[Nicole, line 62]

Family members attending vocational centres did so during the daytime four or five days a week. This depended, in part, on the vocational centre, program attended, the abilities of the family member, and whether employment was also being carried out at another site by the family member.

Brenda's family member worked at a vocational centre and at a second position within the HRM community. Both the vocational centre position and the job in the community were well suited to the abilities of her son. She described the overall work environment as inclusive and accessible, giving a specific example that demonstrated the underlying beliefs of the work environment.

*It's a great place, it's a really good place for him to work. Very good place for him to work. They're very supportive of him. Like they had an issue one time, somebody, I don't know, they said something to him and it wasn't-, it was kind of rude and he went and spoke up about it because he's been taught to speak up to people, you know, you don't have to let people do that to you right [i: Right] anyway so he told the supervisor, and they nipped it in the bud and they supported him. Because they knew the other person was in the wrong right.*  
[Brenda, line 56]

In this workplace, the supervisor took action against ableism, an act of support extended to the family caregiver's son. By addressing the incident, the supervisor recognized the value of the family member and sought to mitigate ableist attitudes in the workplace.

Even Robin, whose family member was not eligible to work in a vocational centre or in another work setting expressed a desire for such an opportunity for her family

member. She voiced her desire for an environment equivalent to a vocational centre in inclusive beliefs and practices to be available to her family member.

*Wouldn't it be great if my son had a place to go everyday [i: Mm] like either a school or a learning centre and feel like he's a-, you know like make him feel good, make him feel important.*  
[Robin, line 79]

Robin's family member was ineligible to work in a vocational centre. She attributed this to her son's abilities and the behaviours that challenge he exhibited. Since aging out of the education system, she desired more than at-home respite care for her son, which was provided for 45 hours a week when she worked. She did not feel she was alone in desiring additional opportunities for meaningful engagement for her son in inclusive and accessible environments.

*I think it's not as much as being in-, you know it's not as much as the respite part, you know [i: Mmhm]. Anybody can look after him but he needs a place to go, when he needs a place to go. And he's not the only one, like I have friends or acquaintances with, uh you know I call them kids, but you know, well you'll always be my kid. My other 30 year old son [i: laughs] is my kid. But uh, ah they-, they're too disabled to got to either [sheltered workshop] or uh [sheltered workshop]. But they do-, there's a lot there inside of them and I'm sure it's very frustrating to have to sit home day after day after day. It just has to be terribly frustrating. Like I couldn't do it.*  
[Robin, line 81]

She noted the disparity between perceptions of acceptable care and care that upholds the interests and needs for social engagement. Robin carefully considered the conditions of her son's daily activities and concluded the level of engagement was below reasonable expectation for care standards. She concluded that able-bodied persons such as herself would not be able to have the limited opportunities for engagement that her son had. Without access to suitable programming, the family member was not able to participate in meaningful social activities. She reported that this service gap had existed since the

time her son left school. This situation highlights a gap between programs available to children and those available to adults within networks of paid support services.

In some cases, paid supports provided by respite workers or placement students were also described as being inclusive and accessible. Brenda, for example, hired a respite worker for her son who was employed with a vocational centre. Therefore, the respite worker was well-versed in supporting individuals with disabilities. She also had an established relationship with the family member as a result.

Another participant, Kim, notes that her partner and she were deliberate in their hiring of paid support persons, selecting individuals with similar belief systems. This ensured a continuation of support that upheld the rights of her family member and was consistent with care that herself and other family members provided.

*For the most part um we have um, really uh made a conscious effort to ensure that the people who are looking after, you know we kind of frame it as a relationship more than anything [i: Mmhm] um having a relationship with [family member] that they see his inherent value and they don't see it as a one-way kind of relationship. So it- it's people who understand, or who have an appreciation for what they can also get from that relationship. Um, so I don't know that there is a particular belief system or uh value system, but it's just-, they're valuing him for who he is and uh and appreciating what he has to give back (...) um is what we look for in people and we've been really lucky in that-, that uh-, for the vast majority of people that we've hired there's been this belief or value system.  
[Kim, line 52]*

Kim expressed that having control over who provided paid support allowed for inclusive and accessible supports in her life. She was responsible for hiring, managing, and paying respite workers. However, paid support varied widely in how it worked in family caregivers' lives.

Accessibility and inclusivity are valued by family caregivers accessing paid and unpaid supports. These networks function interdependently, as noted in a description of a

typical day provided by Nicole. She referred to both unpaid and paid support as necessary and noted that each allowed for the other to function and to meet the needs of family caregivers.

*We have breakfast together, and [transportation service] comes and picks her up about (...) between 8 and 8:15 and we both go off to work. She gets off at 2:30 and [transportation service] drops her off at my daughter and son-in-law's house. And she stays there until I-, I come home from work around 5 and I pick her up there.*

[Nicole, line 38]

In the example provided by Nicole, the transportation service, the workplace for her family member, and the support provided by family enabled the arrangement to work. Without even one components of her support system in place, opportunities for her family member could not be realized.

Without the work in each of the networks, family caregivers reported they would be unable to function as the primary caregiver to their family member. However, the networks supported the family caregiver in different ways. Emotional support, for example, was rarely accessible through paid supports. However, physical support was frequently reported as accessible through paid supports.

As discussed, inclusive and accessible unpaid and paid supports function in family caregivers' lives to provide physical, emotional and informational assistance. Supports also create and sustain opportunities for meaningful engagement with persons in the immediate and broader context of their ecological systems. However, the everyday experiences of participants and the ideologies evident in practice and policies did not align in many cases. The policies and how family caregivers navigated the gaps in support are explored.

## Exploring the Problematic

Participants voiced concerns that historical practices of institutionalization and discrimination against persons with disability contributed unconsciously to how persons in general society treated their family members. Nicole explained her experiences with having her family member included in public spaces.

*There are people who are just not comfortable. Mind you, it's not nearly as bad as it used to be [i: Right] um, years ago people with Down Syndrome were just put in institutions and not out in the community at all. But there-, there are people who are uncomfortable around people with intellectual difficulties and they just don't wanna-, want them to be in their sight.*

[Nicole, line 111]

She was aware of a division of how her family member was viewed by persons with historically grounded views of persons with disabilities.

Monica shared a similar view, drawing in how from a programming and policy perspective she felt this also rang true.

*I think part of the problem is for a very long time, for many many years, all of our people with these kind of challenges were kept in institutions and you know they were never seen out in community and people just are still lagging very far behind in what needs to be put into place and how that needs to be modified for each individual [i: Mmhm, mmhm] so that's something that we work on all the time [i: Right]. And when I say that, I don't just work on that for [family member], I'm working on that for a more broader community.*

[Monica, line 72]

Her account highlights how she uses advocacy to bridge the divide between her experiences as a family caregiver and institutional priorities.

This modified IE involved analysis of both first-person experiences and relevant policies. The selection of polices was based on the analysis of first-voice accounts (Campbell & Gregor, 2002; Smith, 1999). The DSP Policies were identified as the textual documents organizing social relations embodied within the everyday lives of family



caregivers of persons with IDD. The policies serve persons who qualify for assistance, under the *Social Assistance Act* (NS DCS, 2012). The DSP Policies statement includes the following explanation, to promote “participant’s independence, self-reliance, security, and social inclusion. The goal of the DSP is to support participants at various stages of their development and independence through a range of programs” (NS DCS, 2012, p. 11). Institutional or service agencies disability-support policies are derived based on the DSP Policies.

A disjuncture exists between institutional priorities and the everyday experiences of family caregivers of family members with IDD accessing unpaid and paid supports. This is evidenced through the first-person experiences of participants navigating through systems of paid supports. Monica reflected on the gap between practice and policy in action and the needs for her family member in the following quote.

*Unfortunately you know it-, they continue with this one-size fits all sort of mentality and-, (exclaims) and they've trying to change it, it it's slow. I mean I've been at this for a long time so I have [i: Mmhm] seen changes it's just-, you'd like it to be faster (laughs). We always feel that.*  
[Monica, line 74]

She recognized the difference in priorities between the broader policy, those implementing it, and herself as a family caregiver. Although she recognized that the policies had been changed to better reflect the needs of persons with disabilities and their families is evident, a significant gap existed between priorities of herself as a family caregiver and policy priorities. In critical theory and IE work, the disjuncture is known as the line of fault.

### *The Line of Fault*

The disjuncture is created and sustained through institutional priorities, which claim to centre around priorities of families, but ideologically centre around priorities of neoliberalism, and capitalism. Namely, the quality of care of persons with disabilities is prioritized after economic concerns. This is supported by policies that are aimed to address needs broadly, rather than individually. Monica explained her experiences with obtaining paid support for her family member.

*It's still very much driven towards what is better for-, you know, here is a policy that dictates that so therefore we cannot do that. That policy might work for the whole organization, but it's not working in [family member's] circumstance, so you-, you need to modify it a bit. And they're not (...) because they want to keep everything the same, then they're not necessarily modifying for the individual, as much as they probably could or should [i: Right] it's easier just to do it as a-, a broad format [i: Mmhm, mmhm] because once you change something then it's a precedent, and someone else can use that. Right? [i: Absolutely, yeah] you set precedent and then people go uh-oh (laughs). So you try not-, so people try not to. But by having precedent's set over the time I've been doing this, um I know it can be done. You just hav-, but they make you, they really make you work for it. [Monica, line 34]*

Family caregivers' interests do not appear to be served by this disjuncture, quite the opposite. In Monica's case, she was aware of the line of fault as demonstrated in this quote.

Family caregivers who understood the hierarchy of the paid support system and processes were able to have gaps in services addressed in some cases. Monica noted persistence was required to obtain what she felt her family member needed for support. Despite policies claiming to be aimed towards the people they served, her experiences highlighted the line of fault present.

*By having precedent's set over the time I've been doing this, um I know it can be done. You just hav-, but they make you, they really make you work for it. So, I used to say to [family member's] dad, you know I've had to beg and grovel and*

*humiliate myself in oh so many ways to get what [family member] needs, but he's gotten it. Because I don't give up until I get what I want. Or what I think he needs [i: Right] so, but that-, (...) takes an incredible amount of stamina (laughs) and reserve, emotional reserve sometimes [i: Mmhm, mmhm] so sometimes you back away [sic] and take some time to kind of regroup, and then you go at it again. But, I mean, I've had people at DCS say to me, the Department of Community Services say to me, you know, like okay yeah you know you're going to have to write another letter but you know that you're probably going to get it. And I said I know, but I'm probably going to have to jump through some more hoops. And they'll just say yeah you do but we know that you're not going to give up so-, (sighs) you know these are people I've known for a very long time so they kind of (laughs) we both know what's going to happen, it's just they make it as difficult as possible, even though they're saying you know, it's all about the family, it's all about the person. It-, it's really not.*

[Monica, line 34]

As noted by Monica, advocacy by family caregivers can be instrumental in navigating through administrative networks governing access to paid supports. A bifurcation of consciousness is seen, how she splits between her everyday role as a mother, a caregiver and an advocate working to create change within the system of paid support. The disjuncture between family caregiver's needs and institutional priorities led to irreconcilable differences in perceptions of an optimal standard of care. For instance, funding for summer day programs (both day programs and overnight stays) was considered as an unnecessary expense by some case workers, while family caregivers viewed this as programming that was greatly beneficial to the social and emotional well-being of their family member. These camps also provided paid respite, considered to be of high quality when tailored to the individual needs of their family members.

Family caregivers of family members with IDD responded to the disjuncture through advocacy and utilizing unpaid supports to reconcile their needs with the paid support system. In Kim's case, her family paid out-of-pocket for additional respite hours.

She recognized funding through the DSP Policies met the majority of her family's needs for paid support, but not completely.

*His paid workers, the majority of that comes from um DCS and then because we require more hours than are available, so that-, we pay a little bit out of pocket for that. Um, so that's-, you know we are in a pretty-, we're in a-, again we're fortunate to have the support through the government for that type of care because we require that and [family member] I believe is at kind of that (...) highest end of needs and supports that they uh-, that they provide.*  
[Kim, line 41]

She noted that fortunately her family was financially able to fill this gap in paid support that was unaddressed by policy provisions.

In each of the interviews with family caregivers, the participants and/or another person in their unpaid support system were able to liaise with paid supports. Nicole recalls how employment at the vocational centre was secured for her family member through her sister, who is a social worker, and who had previously provided paid support to her family member.

*My sister did, we knew about [vocational centre] (...) um and it may have been through the school. [i: Oh okay.] She went to [school name] high school. And it may have been through the social worker at the school.*  
[Nicole, line 52]

She also recognized her adult daughter working providing paid support for persons with disabilities allowed for opportunities for her family member to be connected with.

*One of my daughter's is a social worker so she has, kind of a finger on activities and such [family member] can get involved in.*  
[Nicole, line 52]

She felt this contributed greatly to her family member's social engagement. Through these connections to the broader disability community, she and her family member felt supported.

Despite having a case worker for her family member, Nicole reported that accessing opportunities for her family member was primarily her responsibility. She credited the vocational centre her family member worked at for connecting her to opportunities for her family member.

*I think that-, that there are lots of opportunities now for people with disabilities. There's ah, a choir that meets at [name] church for people that like to sing [i: Mmm] um, there's opportunities in the community. But, there are so many people that don't know about the opportunities (...long pause...) oh and unless someone works at [vocational centre] or has a connection with a group home, often people don't know about the things that are available [i: Right] so that's kind of a (...) you-, you know, sometimes you really have to look for things.  
[Nicole, line 118]*

Nicole claimed that other family caregivers may not be in a position to access supports because of smaller networks.

Monica provides insight regarding gaining access to services and specific support to address her family member's needs in the following quotation. She describes her role as a 'case manager', which is language that closely mirrors that which is in the DSP Policies.

*I kind of am a case manager if you will. I just make sure that everything is in place as much as possible that I can do from a distance or in terms of what the policy is for the organization that is providing his care.  
[Monica, line 16]*

Monica's quote illustrates her understanding of both broader disability policy organizing her everyday activities regarding caring for her family member and also organization-specific policies. In Canada, disability support is primarily a provincial jurisdiction. Therefore, no federal policy exists that is relevant to the research at hand. The DSP Policies works and coordinates people's lives at DCS sites, which are provincial level. These policies are unique to Nova Scotia.

The DSP Policies work as ruling relations, coordinating the everyday work of DCS staff and the lives of persons with disabilities and correspondingly, their family caregivers. Those with disabilities deemed eligible and ineligible for support are affected by what is written in the DSP Policies in both visible and unseen ways. What is written translates into work carried out by DCS staff, which organizes the lives of family caregivers of family members with IDD in interconnected ways, from multiple sites. This constitutes disability support discourse prominent in Nova Scotia. Written within the ruling relation of the policies is the quintessential terms “care coordinator”, “case management” and “casework supervisor” (NS DCS, 2012, pp. 99-100). Although her family member had an assigned care coordinator and casework supervisor for case management, Monica emphasized that to meet the basic needs and to ensure her family member was well cared for, she had to advocate for his needs according to how the system was designed. This was echoed by the first-hand experiences of other participants. Monica advocated by working within the case management system. According to the DSP Policies (2012) case management is defined as the following.

A participant focused process that includes assessment, case planning, care coordination, and monitoring and evaluation of the DSP participant’s case plan. It is a continuous and collaborative process where the participant and their family/personal support, as appropriate, works in tandem with the service provider to meet the participant’s identified goals and outcomes. Case management addresses the well-being of the DSP participant, while promoting quality of care and support, as well as ensuring and managing cost effective outcomes. (p. 99)

When Monica refers to “what the policy is for the organization that is providing his care” she reveals another site that is being activated at the organizational level that is working to organize the supports and everyday life of her family member, and her as his primary caregiver and advocate. These organization-specific policies are beyond the scope of this research and not publicly available for viewing. Furthermore, identification of the specific organization has the potential to compromise the identity of one or more participants and therefore will not be disclosed. However, regarding organizational level policies she notes the following regarding person-centered care her family member does and does not receive.

*I think lots of people think the way, I do, it's just how-, how do we get other (...) (sighs) it's very hard to change the policies within organizations to think individually, and that's, you know, it's hard. You get x number of homes and how do you follow through? And I always used to think if [family member] was in a smaller home with you know, limited number of staff it would be easy to train them. But what I have found is when you have, let's just say an executive director and then a senior supervisor and an intermediate supervisor, then a supervisor and then the frontline staff, by the time all of it crawls through, what gets down to the frontline staff is not what needs to get there. So, part of my problem right now is having to work through a system that's really, it's structured from an insurance or liability perspective for the-, to make sure that there's no liability.*  
[Monica, line 79]

Prior to living in supported housing in the community, her family member lived in a Regional Rehabilitation Centre (RRC) which employed more than 100 employees. She notes that although the current smaller housing arrangement her family member lives in is much preferable to a larger facility, the case management principles written in the DSP policies still compromise the person-centered quality of care and support her family member receives. The case management principles from the DSP Policies directly and indirectly affect her and her family member’s everyday lives. The organizational policies derive from the DSP Policies and therefore are implicated as textually mediating Monica

and her family member's lives. The power exercised by ruling relations of administrative staff carrying out policies was evident in all of the family caregiver's lives for the paid supports received.

### **Conclusion**

This chapter exposed the social relations, ruling relations, and line of fault present in family caregivers' lives. During interviews, the interdependent nature of unpaid and paid supports in family caregivers' lives became apparent. However, unpaid and paid supports 'work' in different ways, through distinct mechanisms in family caregivers' lives. To meet the needs of their family members, advocacy for paid supports was necessary by family caregivers. This involved family caregivers working within the system of paid support, governed by policies with institutional and ideological priorities that contrasted their own. The disjuncture between the standpoints is the line of fault discussed. To explicate these relations as was done in this chapter creates the groundwork to discuss how these findings relate and expand on current literature regarding unpaid and paid supports in family caregivers' lives when supporting a family member with IDD.



## Chapter VI: Discussion

Institutional ethnography was purposefully chosen for this research with the understanding that unpaid and paid supports in the everyday lives of family caregivers are socially organized. Ruling relations are implicit within networks of paid supports and embody ideological (institutional) priorities. In conducting this modified IE by starting with first-person experiences of family caregivers, I was able to understand participants' everyday lives. This laid the groundwork for the second aspect of this modified IE: analysis of related policies. Interviews with service providers are included in a traditional IE as well. Due to this study being done in the scope of a master's thesis, this was beyond the realistic constraints of this research and therefore omitted.

In this final chapter, I will discuss summative themes emerging from analysis of the everyday lives of participants and compare to the literature previously reviewed in this thesis. Moreover, a critical-ecological analysis of larger scale ideologies embodied in practice will be incorporated. Implications and recommendations for policy are explored. I then describe limitations of the study. Finally, directions for future research are discussed.

The methodology of a modified IE was selected to represent the voices of the people, rather than the institutions through which their lives are coordinated (Campbell & Gregor, 2002). First-person experiences provided by participants helped me map their everyday experiences, which is where I began my analysis. The experiences of family caregivers interviewed were distinct from one another, yet intersections with unpaid and paid supports in their lives were evident.

The ideologies shaping the supports in participants' lives reveal patterns of social relations consistent through multiple contexts. The main ideologies that will be discussed, as they appear relevant to the contexts of everyday lives of family caregivers, are neoliberalism, ableism, sexism (patriarchy) and familialism. When ideologies are discussed, they are placed in the macrolevel of the critical ecological framework. However, as will be evident, they pervasively influence all the levels of the ecosystem below them. One must consider that, at all times, the different levels of the ecological system are constantly interacting and being influenced by each other.

When first-person experiences and policies were analyzed, three themes were evident. These were described using participant quotes in the previous chapter. First, inclusive and accessible networks function to support family caregivers of family members with IDD. Second, unpaid and paid supports provide family caregivers and their family members with opportunities for meaningful engagement with persons in their immediate and broader environments. Finally, there is a disjuncture (line of fault) between institutional priorities and the everyday experiences of family caregivers as they access unpaid and paid supports.

### **Inclusive and Accessible Networks**

Family caregivers in this study accessed a variety of inclusive and accessible unpaid supports in their lives. The number of supports were variable. One participant had an unpaid support network characterized by only two family members. Four family caregivers discussed a variety of unpaid supports operating in their everyday lives. These supports included family, friends and disability-affiliated friends. Unpaid support relationships provided physical, emotional, and informational support.

For participants in this research, current or former partners remained involved in their everyday lives through providing physical care and/or emotional support. Only one participant shared the family caregiver role with her current partner, the other four female participants were sole primary caregivers. This is in line with caregiving research broadly, and specifically for persons with IDD, that the majority of primary caregivers are female (e.g. Boehm & Carter, 2016; Brennan, 2005; Iacono et al., 2016; Llewellyn et al., 2004; Sanderson et al., 2017; Werner & Shulman, 2013). From a critical standpoint, historical and structural considerations oppress women into primary caregiving roles. It is both unconscious and conscious for women to take on the caregiving role. For the women in this study, their current and/or former partners participated in the decision-making about the care of the person with IDD.

The nature of the role of current and former partners in family caregiver's lives was influenced by the historical relationship with the partner, geographical proximity, and abilities of the family member. The sample of participants represented in this research comprise women who were able to achieve relative balance between the institutions of work and home life. However, indirect expressions of the strain of competing demands of work and caregiving responsibilities were evident. Former and current partners of the participants helped to balance the competing demands through the physical and emotional support provided.

All participants in the study reported having at least one other adult child. The number of adult children ranged from one to three. Adult children worked in family caregivers' lives to provide physical support, and emotional support. Family caregivers with more than one adult child cited stronger unpaid family support that could be

accessed. Isolation was experienced by the participant with only one adult child. Relationships with adult children contributed to the quality of life experienced by the family caregiver and the family member. To a decreased extent, this was true even for adult children who were unavailable due to distance and provided infrequent emotional support. Not only was the provision of support important to how participants conceptualized their support, but also just their perceived potential support. For some participants, it was enough just to know that the support was potentially available even if not readily accessible. This was found true whether or not the actual support was or was not there (e.g. Boehm & Carter, 2016).

Support from family besides current or former partners and adult children took place in larger social contexts. In all cases, the family caregivers and their family members reported being included. This included gatherings such as birthday parties, potluck dinners, and visits with grandchildren. The impact of aging on social support provided was most felt regarding the accessibility of family supports. This included siblings and grandparents of the family caregiver who had been actively involved in providing support during the childhood years of the family member's life but who were no longer present. Other family members were reported to have aged, physically and/or cognitively unable to provide accessible support, or, had passed away since their family member entered adulthood.

Two participants in the study had not been family caregivers for their family member's whole life. In these cases, they indicate that since taking on the role of primary caregiver, the number of friends in their unpaid network did not change. Their friends

were reportedly supportive and inclusive of their family member. This included providing emotional support to them.

Four family caregivers had disability-affiliated friends or acquaintances they connected with. Commonly, disability-affiliated persons were met when one's family member was much younger. Recreational programming for persons with IDD is more common in childhood and early adulthood (Shogren et al., 2013). In some cases, the family member was also friends with disability-affiliated others and their family members. Participants had contact with the disability-affiliated friends through one or more organizations. Overlap of persons in the settings reflects the close-knit nature of the disability community in the HRM. These friends had been met through recreation activities for their family member or advocacy in community organizations, both aimed towards persons with IDDs.

Disability-affiliated friends/acquaintances exchanged informational and emotional support with family caregivers. Potential opportunities for family members were communicated through informational support supplied to family caregivers. Emotional support was also provided through in-person exchanges and telephone/texting communication. The first-person experiences of family caregivers suggested these relationships with disability-affiliated others were different from other unpaid supports, such as family or friends; this is in line with existing research (e.g. Boehm & Carter, 2016; Shogren et al., 2013).

In ways unseen to participants, family caregivers' unpaid supports and paid supports coalesced to form an interdependent network. Gaps in services and support in family caregivers' lives were addressed because of the intersection of paid and unpaid

supports. Microsystem and macrosystem supports (i.e vocational centres, recreational programming) worked together in family caregivers' lives for continuity of support and service. For the three family caregivers who accessed respite, services were controlled by themselves. Who, when, and what was provided in respite care was primarily under the discretion of family caregivers. However, the number of funded respite hours was dictated by DSP Policies. The funding support through the NS DCS was strongly valued, although not enough to fully meet the needs of family caregivers. Two participants did not have respite as a paid support in their lives. One family caregiver did not access respite, another family caregiver had their family member in supported housing.

Being able to choose who to employ for respite services enabled compatibility with family beliefs. What this means, therefore, is that ableism in respite support provision was largely felt to be absent in the first-person experiences of parents because they had choice in the selection of respite workers. However, participants served as employers to their respite workers. This allowed for more equal power relations between themselves as family caregiver, their family member with IDD, and the respite worker. In some cases acting as an employer created a barrier to accessing appropriate paid respite workers and services. Participants noted difficulties securing respite workers, particularly those who were suitably trained and had flexibility in scheduling. For persons who family caregivers deemed had commonality of values and belief system to their family, they would train them for the position even in absence of past experiences, or any relevant qualifications.

In one case, a family caregiver did not access paid respite for her family member. Instead, her adult children and another relative were able to provide unpaid respite in

short increments of time (i.e. one to three hours) for her family member. Overnight unpaid respite was rarely provided. As Dillenburg & McKerr (2009) note, if support from a family caregiver is provided at no financial cost, this lessens the likelihood of access to paid caregivers. Therefore, if family caregivers do not seek out, or follow through with such opportunities for paid support they may be more difficult to access in the future. Inclusive and accessible unpaid respite by family paradoxically could negatively impact future paid supports for family caregivers to access as they supported their family member with IDD.

Vocational centres were described as providing not only physical support through provision of employment, but also informational support. As one participant noted, a result of their family member being involved in the vocational centre, she received information regarding potential programming and events in the broader disability support community.

### **Opportunity for Meaningful Engagement**

Unpaid supports facilitated meaningful social engagement for family caregivers with their immediate and broader environments. This involved interactions within a family caregivers' microsystem and mesosystem. Inclusive and accessible family supports meant family caregivers felt welcomed. It was important for family caregivers that persons they engaged with socially shared similar beliefs. In most contexts, their family member actively participated in social interactions with them.

Recreation activities were focused on inclusion in community through structured and unstructured social activities and sports/physical activity. Community organizations were committed to supporting persons with disabilities to live as included, active

members of the community. In some instances, advocacy was actively pursued by the organizations. One participant was invested in community organizations that supported persons with IDD and family caregivers by advocating for services focusing on quality of life for the entire family. Participants with family members in vocational centres had met disability-affiliated friends through work in advocacy organizations and from prior or current involvement in activities for their family member.

Vocational centres provided meaningful employment for family members during the weekdays. These centres acknowledge that attitudes and structuring of society create barriers to employment of persons with IDD and aim to eliminate the barriers through yearly reviews, and person-centred practices. Vocational centres created meaningful engagement through employment with staff and other employees for family members. The employment of family members created the opportunity for family caregivers to pursue their own employment.

Participants found that disability-specific organizations provided informational support and engagement with staff and other family caregivers. This informational support connected family caregivers to future recreational programming and events in the HRM community. These events were primarily aimed towards persons with disabilities. In some cases, family caregivers connected with other caregivers. Relationships were forged as either acquaintances or friends, wherein emotional support could be accessed. Disability-specific organizations were inclusive and accessible in participants' experiences.



## **Institutional Priorities and The Everyday Experiences of Family Caregivers**

Unlike unpaid support, paid support is structured as a hierarchical system wherein power is exercised constantly. Participant's local experiences were shaped through extralocal contexts, the exo and macro levels of their ecological system. Family caregivers' experiences with paid supports reveal a disjuncture between their beliefs and priorities and the extralocal context. The DSP Policies are relevant policies to understand participant's experiences. These policies describe DSP options for eligible persons. DSP options are the following: "1) a Community Based Option (unlicensed); 2) a Community Home (licensed); 3) Residential Care Facility; and 4) Adult Residential/Regional Rehabilitation Centre (licensed)" (NS DCS, 2012, p. 15).

Four participants in the study had family members in the community based option. The DSP community based options are comprised of the Flex Individualized Funding Program (Flex); Independent Living Support (ILS) Program; and Alternate Family Support (AFS) Program. The Flex Program is the only program in the community based option that participants used. The Flex Program has three funding streams: Foundational Allowance, Intermediate Funding and Enhanced Funding (NS DCS, 2012). The Flex program has two options: Flex Living with Family or Flex Independent. Four participants had their family member in Flex Living with Family Program.

One participant had a family member in a community home (licensed). Residential home support is provided by staff in the Small Option Home (SOH) for up to four participants with disabilities. These homes are funded by the NS DCS, and privately run by organizations. Living in a SOH is in high demand for persons with IDD in NS; this is evidenced by waitlists (Autism NS, 2019a; Autism NS, 2019b; The Nova Scotia

Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013).

Family caregivers are responsible for organizing and maintaining paid respite supports (Nova Scotia Respite Partnership, 2019). Experiences of family caregivers revealed that responsibility for overseeing paid respite support was a barrier to accessing suitably experienced, available persons to provide support for their family member. Alignment of paid respite support needs of family caregivers was not met by appropriate available supports. The available supply of suitably trained respite workers with flexible schedules was inadequate for the needs of family caregivers. This led to family caregivers feeling their support needs were unrecognized in policy governing the organization of paid support in their lives.

DCS policy identifies seven competencies required in the provision of supported housing. Training competencies were not specific to diagnoses or abilities. Rather, they focused on “CPR/First Aid, non-violent crisis intervention, non-aversive behaviour management, medication awareness, fire and life safety, individual program planning, and basic principles and practices of personal care” (Hampton, 2015, p. 3). While these core competencies are undeniably foundational to working with persons with disabilities, they are not specific to the actual abilities and needs of the population. What this means is that persons working primarily with individuals with, for example, autism, had little to no training related to the needs of persons living with autism. Whether additional training is provided is up to the discretion of family caregivers and individual organizations. Respite and workers in supported housing without adequate training is concerning (e.g. Autism NS, 2019a, Autism NS, 2019b). A lack of awareness of abilities of individuals

may perpetuate ableist beliefs. Service providers and community stakeholders have voiced concern over lack of policy oversight mandating training for frontline workers in care contexts (e.g. Autism NS, 2019a; Autism NS, 2019b; The Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013).

Employees of the DCS are responsible for the administration and implementation of the DSP Policies. Participants recognized that provisions for paid support were dependent on assessments conducted by their family member's "Care Coordinator" (NS DCS, 2012, p. 28). Four participants reported infrequent contact with their family member's care coordinator. Reviews of support needs are conducted quarterly, annually, or every two years, depending on whether changes to service are requested, needs have changed, or there are no reported changes. At case reviews for their family member's care, family caregivers reported that paid support provisions changed very little, if ever. Few participants were able to describe the policies dictating their family member's paid support or how such decisions were made. This is in spite of being part of the case management process previously discussed.

The NS DCS discourse regarding disability support versus everyday lives of family caregivers as shared in this study highlights the line of fault that exists. Family caregivers are claimed to be important in the case management process, as described by DSP policies. However, participants indicated a lack of understanding of the policies governing their family member's paid support. Family caregivers cannot be viewed as an informed part of a process, if they do not understand what the process is. Family caregivers who were able to liaise with their care coordinator or have an unpaid support

person assist them with navigating the paid disability support system were advantaged over those who lacked the background to have the same opportunities.

### **Implications and Recommendations for Policy**

The current study and existing research lead to multiple implications and recommendations for policy pertaining to disability support in NS. The line of fault between NS DCS priorities and the everyday realities of family caregivers is broad. As a consequence, family caregivers have challenges/barriers to navigate accessing and advocating for paid supports to meet the needs of their family members. Implications and recommendations for policy are drawn from the findings of this study and the broader Nova Scotia disability support research and reports. I recognize due to the small data sample size of my study limits the applicability for policy recommendations. More research is needed, as evidenced by the findings of my study and similar work conducted within Nova Scotia.

#### ***Recommendation One***

The first recommendation is to publish a plain text version of the DSP Policies and establish support navigators. This is in line with recommendations made by Autism NS (2019a, 2019b). By creating a plain text version of pertinent policies and establishing system navigators, family caregivers are in positions to effectively exercise power regarding support decisions and resist oppression that compromises quality of life for themselves and their family members.

#### ***Recommendation Two***

The absence of first-person experiences and voices of persons with IDD and their family caregivers is evident in disability support structuring in a paid capacity. As a

result, options that are organizational centred, as opposed to person-centred. The second recommendation is for conscious steps taken by those exercising power to engage in relations wherein the voices of community organizations, other stakeholders', persons with disabilities and their families are heard. This is a well-documented need in the Nova Scotian disability support context (i.e. Autism NS, 2019; Community Homes Action Group [CHAG], 2020; Community Homes Action Group [CHAG] & Nova Scotia Association for Community Living [NSACL], 2014; Nova Scotia Department of Community Services-Services for Persons with Disabilities [NS DCS SPD], 2008; The Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013). This is specifically in relation to supported housing and provisions for paid support that allow for persons with IDD to live in the family home in community successfully.

### ***Recommendation Three***

Vocational centres meet an established need of persons with IDD in Nova Scotia and their caregivers. However, a gap for meaningful social engagement appears to be present for these between the ages of 18-21 and also persons with IDD with complex behaviours that challenge. A 2008 summary report on vocational and day service for adults with disabilities available through the NS DCS acknowledges the gap of services for such individuals. For individual's ineligible for these programs, respite appears to be the only option. This was cited by participants to lead to regression of social abilities of family members and contributing to behavioural challenges through a lack of meaningful social activity. It is recommended that social engagement opportunities be created for

persons who are unable to attend vocational centres. This would uphold the rights of persons with disabilities, according to the UNCRPD.

### **Limitations**

A limitation of this study was because of the scope of the master's thesis, a modified IE was done. Therefore, although service providers and the corresponding texts they work with are central to this thesis, it does not have perspectives from this group. Persons from the NS DCS's voices were accordingly absent from this study. This means I did not have any first-person accounts of administration and implementation of policies reflecting unpaid and paid support operating in the lives of family caregivers. I do not as a result have an understanding of the perspectives of persons administering support, and how they perceive the administration and implementation of policies to affect the populations aimed towards.

Interviews with participants were originally designed to be carried out in-person, unless geographical distance prohibited this possibility. At the time of recruitment and subsequent interviewing in mid-March to May, social distancing measures were in place due to the COVID-19 pandemic. All interviews were shifted to telephone interviews out of public safety necessity. This meant the micro-expressions of in-person interviews were not captured in my notes as a researcher.

To have research completed within a reasonable timeframe, participants were recruited through two main gatekeepers, located at the Dartmouth Adult Service Centre (DASC), and the Dalhousie Family Medicine Adult Developmental Clinic. Despite every effort to achieve a diverse sample of family caregivers within this population, the nature of how recruitment was conducted through gatekeepers undoubtedly contributed to the

sample of participants interviewed. Family caregivers accessing resources specifically aimed towards persons with disabilities are likely advantaged in terms of informational support, compared to other family caregivers. Furthermore, potential participants who reported higher levels of unpaid and paid supports faced fewer barriers to participation in the research.

### **Recommendations for Future Research**

The findings from my study confirm and expand upon current research regarding how unpaid and paid supports function in family caregivers' lives. The critical nature of this research along with the modified IE approach bring to the forefront how support is socially coordinated in family caregivers' lives. This is true for both unpaid and paid support. Unpaid support is coordinated through access and lack of access to appropriate paid supports. Paid supports is more explicitly coordinated through text, such as the DSP Policies, and communication between persons working in organizations with a hierarchical structure of command (i.e. supported housing options). Future research could explore unpaid and paid supports of family caregivers living in rural areas, and with family members who remain largely isolated from disability-specific supports.

Future research that brings together various stakeholders in unpaid and paid disability supports to have conversations is a current gap. Documents by community stakeholders over the last 15 years (i.e. Autism NS, 2019a; Autism NS, 2019b; CHAG, 2020; CHAG & NSACL, 2014; NS DCS SPD, 2008; The Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013) continually highlight the need for changes to service provisions that better meets the needs of the people it serves. Supported housing in

community is perhaps the most underserved gap in service delivery that is evident in NS (e.g. Autism NS, 2019a; Autism NS, 2019b; The Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013).

The lack of available supported housing results in placement of persons with IDD and other disabilities in facilities designed for crisis-stabilization, or short-term placement. As persons with disabilities live longer lives, the need for appropriate supports becomes increasingly pressing as they outlive their primary family caregivers. In many cases, one or both parents with function as the primary caregiver. However, unpaid and paid supports in family caregivers' lives reflect a lack of future planning. Conditions supporting future planning include family members having abilities requiring higher levels of support with daily activities and a lack of suitable family to potentially take over as the primary caregiver (e.g. Brennan, 2005; Burke et al., 2018).

## **Conclusion**

As this study illustrates, unpaid and paid support networks in family caregivers' lives are complex. The immediate and broader environments in which family caregivers' lives are situated in are necessary to understand how supports 'work' in their everyday lives. Support networks vary widely depending on family dynamics, abilities of their family member and considerations of changes over time and geographical distance. In a critical approach, this study exposed the social relations, ruling relations and the line of fault present in family caregivers' lives. During interviews, the interdependent nature of unpaid and paid supports in family caregivers' lives became apparent. However, unpaid and paid supports 'work' in different ways, through distinct mechanisms in family



caregivers' lives. To meet the needs of their family members, advocacy for paid supports was necessary by family caregivers. This involved family caregivers working within the system of paid support, governed by policies with institutional and ideological priorities that contrasted their own. The disjuncture between the standpoints is the line of fault was discussed. Implications and recommendations for policy were articulated, supported by pre-existing findings in the Nova Scotia and broader disability support context. Future directions for research regarding family caregivers accessing unpaid and paid support to live quality lives as they support family members with IDD are discussed.

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## Appendix A

## Introduction Letter to Gatekeeper Organizations, Community Members and Stakeholders



*Department of Family  
Studies and Gerontology*

**Title of Study:** *Unpaid and Paid Supports in the Lives of Family Caregivers of Adults with Disabilities: Mapping Social Relations*

To Whom it May Concern:

My name is Madison Brooks. I am completing a Master of Arts in Family Studies and Gerontology at Mount Saint Vincent University. I am currently seeking participants to take part in Master's thesis research being conducted by me in partial fulfillment of the requirements of my degree program. My research focuses on understanding how unpaid and paid supports function within the lives of family caregivers supporting an adult family member with a disability, focusing on intellectual and developmental disabilities (IDD).

The exact nature of unpaid and paid supports varies depending on families. Unpaid support can refer to, but is not limited to, persons, such as family, friends and acquaintances, who are not funded or paid for their support. Paid support can refer to, but is not limited to, paid persons, often professionals providing support. This study will address the following research questions:

- (1) How are family caregivers of adult family members with disabilities (focusing on IDD) supported through unpaid and paid support networks?
- (2) What values/perspectives are evident within the everyday lives of family caregivers supporting adult family members with disabilities (focusing on IDD) as they access unpaid and paid supports?

This research project will involve interviews with 8-10 family caregivers providing primary support to a family member with IDD. In order to be eligible to participate in this study, prospective participants must:

- Reside within Halifax Regional Municipality
- Have an adult family member who is between the ages of 25-40 who requires daily support
- Be the primary family caregiver of the adult with IDD who requires support
- Reside with the family member with IDD or support them while they live in a community-based setting



Interviews will be approximately 90 minutes in length. During the interview I will be asking questions such as “What unpaid supports do you access? Who/what are they?”; “In meeting expectations for your role in your family member’s life, what are your everyday activities?”; and “Are the supports in your life now different from past years of supporting your family member? If yes, how so?”.

At any given time, a participant may choose not to answer any question, without penalty. Participants will also be given the opportunity to offer opinions and information on issues or subjects not directly asked by me but which they think are related to my research. With their permission the interview will be audio taped and later transcribed verbatim.

There is no expectation that any distress will be experienced by participants or others as a result of these interviews. It should be noted, however, that the personal nature of the questions may lead to unanticipated emotional recollections. Given this, participants will be advised that they may stop the interview at any time if the process creates any discomfort. If they experience significant emotional or psychological discomfort, contact information will be provided for resources within the community that will be able to support them.

Participation or non-participation by family caregivers in this study will not influence any services or programs they or their family members are accessing or wish to access in the future.

Personal information about participants will only be known by myself as the researcher. Names of participants and other identifying information (e.g. the names of their family members, support agencies, neighborhoods, workplaces) will be changed as required. Identifying information will also be removed from the transcript of each interview. All written material, such as the informed consent letters, transcripts, and notes, will be kept in a locked filing cabinet. Access to the original data will be limited to myself, and my research supervisor, Dr. Deborah Norris. All electronic records of transcripts will be stored on a computer that is password protected. As noted, interviews may be audio-recorded, with participants’ consent. Voice files will also be stored on a password-protected computer. The recording device may be switched off at any time, if participants so choose.

Following the completion of the research, audio recordings will be destroyed. Other materials (transcripts, notes, informed consent letters) will be retained for five years as per guidelines on ethical research involving humans.

Any information participants share in their interviews may be used in future publications, presented at conferences and shared within the wider disability support community. A summary of the findings will be provided to participants for the purposes of knowledge translation. Their names and their family member’s names will not appear in any publications, papers, or presentations resulting from this research.

Should any questions or concerns arise regarding this research, I can be reached at [madison.brooks@msvu.ca](mailto:madison.brooks@msvu.ca) or at [REDACTED]. I am also available and would be happy to meet in person to discuss this study in greater detail.

Further questions regarding this study can additionally be directed to my thesis supervisor, Dr. Deborah Norris at [deborah.norris@msvu.ca](mailto:deborah.norris@msvu.ca). If there are any questions about how this study will be conducted, the Chair of the University Research Ethics Board (UREB) c/o the Mount Saint Vincent University Research and International Office, who is not directly affiliated or involved with this study at 457-6350 or via email at [research@msvu.ca](mailto:research@msvu.ca).

Thank you in advance for taking the time to read this and consider assisting through participant recruitment towards the completion of my thesis research.

Sincerely,

Madison Brooks

M.A. Candidate, Department of Family Studies and Gerontology

Mount Saint Vincent University

Appendix B  
Recruitment Poster



Interested in sharing your experiences being a caregiver for an adult family member with a disability?

I am seeking family caregivers who support an adult family member (ages 25-40) with intellectual and developmental disabilities (IDD) to take part in a study focusing on unpaid and paid supports.

I am interested in learning about your everyday lives, specifically about the people in your life who help you to care for your family member in an unpaid or paid capacity. This information has the potential to support future community programs and services at the for families.

If you would like to share your experiences, you will be asked to take part in an interview lasting approximately one to two hours in length.

If you are interested in participating in this study or would like to receive more information, please contact:

Madison Brooks  
M.A. Candidate, Department of Family Studies and Gerontology  
Mount Saint Vincent University  
Email: [madison.brooks@msvu.ca](mailto:madison.brooks@msvu.ca)

Appendix C  
Letter to Potential Participants



*Department of Family  
Studies and Gerontology*

**Title of Study:** *Unpaid and Paid Supports in the Lives of Family Caregivers of Adults with Disabilities: Mapping Social Relations*

My name is Madison Brooks. I am completing a Master of Arts in Family Studies and Gerontology at Mount Saint Vincent University. I am currently seeking participants to take part in Master's thesis research being conducted by me in partial fulfillment of the requirements of my degree program. My research focuses on understanding how unpaid and paid supports function within the lives of family caregivers supporting an adult family member with a disability, focusing on intellectual and developmental disabilities (IDD).

The exact nature of unpaid and paid supports varies depending on families. Unpaid support can refer to, but is not limited to, persons, such as family, friends and acquaintances, who are not funded or paid for their support. Paid support can refer to, but is not limited to, paid persons, often professionals providing support. This study will address the following research questions:

- (1) How are family caregivers of adult family members with disabilities (focusing on IDD) supported through unpaid and paid support networks?
- (2) What values/perspectives are evident within the everyday lives of family caregivers supporting adult family members with disabilities (focusing on IDD) as they access unpaid and paid supports?

This research project will involve interviews with 8-10 family caregivers providing primary support to a family member with IDD. In order to be eligible to participate in this study, you must:

- Reside within Halifax Regional Municipality
- Have an adult family member who is between the ages of 25-40 who requires daily support
- Be the primary family caregiver of the adult with IDD who requires support
- Reside with the family member with IDD or support them while they live in a community-based setting

Interviews will be approximately 90 minutes in length. During the interview I will be asking questions such as “What unpaid supports do you access? Who/what are they?”; “In meeting expectations for your role in your family member’s life, what are your everyday activities?”; and “Are the supports in your life now different from past years of supporting your family member? If yes, how so?”.

At any given time, you may choose not to answer any question, without penalty. You will also be given the opportunity to offer opinions and information on issues or subjects not directly asked by me but which you think are related to my research. With your permission the interview will be audio taped and later transcribed verbatim (in exactly the same words as used originally).

There is no expectation that any distress will be experienced by yourself or others as a result of these interviews. It should be noted, however, that the personal nature of the questions may lead to unanticipated emotional recollections. Given this, you are advised that you may stop the interview at any time if the process creates any discomfort. If you experience significant emotional or psychological discomfort, contact information will be provided for resources within the community that will be able to support you.

Participation or non-participation by yourself in this study will not influence any services or programs you or your family members are accessing or wish to access in the future.

Personal information about participants will only be known by myself as the researcher. Names of participants and other identifying information (e.g. the names of their family members, support agencies, neighborhoods, workplaces) will be changed as required. Identifying information will also be removed from the transcript of each interview. All written material, such as the informed consent letters, transcripts, and notes, will be kept in a locked filing cabinet. Access to the original data will be limited to myself, and my research supervisor, Dr. Deborah Norris. All electronic records of transcripts will be stored on a computer that is password protected. As noted, interviews may be audio-recorded, with participants’ consent. Voice files will also be stored on a password-protected computer. The recording device may be switched off at any time, if you so choose.

Following the completion of the research, audio recordings will be destroyed. Other materials (transcripts, notes, informed consent letters) will be retained for five years as per guidelines on ethical research involving humans.

Any information you share in your interview may be used in future publications, presented at conferences and shared within the wider disability support community. A summary of the findings will be provided to you for the purposes of knowledge translation. Your names and your family member’s names will not appear in any publications, papers, or presentations resulting from this research.

Should any questions or concerns arise regarding this research, I can be reached at [madison.brooks@msvu.ca](mailto:madison.brooks@msvu.ca) or at [REDACTED]. I am also available and would be happy to meet in person to discuss this study in greater detail.

Further questions regarding this study can additionally be directed to my thesis supervisor, Dr. Deborah Norris at [deborah.norris@msvu.ca](mailto:deborah.norris@msvu.ca). If there are any questions about how this study will be conducted, the Chair of the University Research Ethics Board (UREB) c/o the Mount Saint Vincent University Research and International Office, who is not directly affiliated or involved with this study can be reached at (902) 457-6350 or via email at [research@msvu.ca](mailto:research@msvu.ca).

Thank you in advance for taking the time to read this and consider participating in my thesis research.

Sincerely,

Madison Brooks

Halifax Nova Scotia B3M 2J6 Canada

Tel 902-457-6321 • Fax 902-457-6134

[www.msvu.ca](http://www.msvu.ca)

Appendix D  
Informed Participant Consent Form



*Department of Family Studies and  
Gerontology*

**Title of Study:** *Unpaid and Paid Supports in the Lives of Family Caregivers of Adults with Disabilities: Mapping Social Relations*

My name is Madison Brooks. I am completing a Master of Arts in Family Studies and Gerontology at Mount Saint Vincent University. I am currently seeking participants to take part in Master's thesis research being conducted by me in partial fulfillment of the requirements of my degree program. My research focuses on understanding how unpaid and paid supports function within the lives of family caregivers supporting an adult family member with a disability, focusing on intellectual and developmental disabilities (IDD).

The exact nature of unpaid and paid supports varies depending on families. Unpaid support can refer to, but is not limited to, persons, such as family, friends and acquaintances, who are not funded or paid for their support. Paid support can refer to, but is not limited to, paid persons, often professionals providing support. This study will address the following research questions:

- (1) How are family caregivers of adult family members with disabilities (focusing on IDD) supported through unpaid and paid support networks?
- (2) What values/perspectives are evident within the everyday lives of family caregivers supporting adult family members with disabilities (focusing on IDD) as they access unpaid and paid supports?

This research project will involve interviews with 8-10 family caregivers providing primary support to a family member with IDD. In order to be eligible to participate in this study, you must:

- Reside within Halifax Regional Municipality
- Have an adult family member who is between the ages of 25-40 who requires daily support
- Be the primary family caregiver of the adult with IDD who requires support
- Reside with the family member with IDD or support them while they live in a community-based setting

Interviews will be approximately 90 minutes in length. During the interview I will be asking questions such as “What unpaid supports do you access? Who/what are they?”; “In meeting expectations for your role in your family member’s life, what are your everyday activities?”; and “Are the supports in your life now different from past years of supporting your family member? If yes, how so?”.

At any given time, you may choose not to answer any question, without penalty. You will also be given the opportunity to offer opinions and information on issues or subjects not directly asked by me but which you think are related to my research. With your permission the interview will be audio taped and later transcribed verbatim.

There is no expectation that any distress will be experienced by yourself or others as a result of these interviews. It should be noted, however, that the personal nature of the questions may lead to unanticipated emotional recollections. Given this, you are advised that you may stop the interview at any time if the process creates any discomfort. If you experience significant emotional or psychological discomfort, contact information will be provided for resources within the community that will be able to support you.

Participation or non-participation by yourself in this study will not influence any services or programs you or your family members are accessing or wish to access in the future.

Personal information about participants will only be known by myself as the researcher. Names of participants and other identifying information (e.g. the names of their family members, support agencies, neighborhoods, workplaces) will be changed as required. Identifying information will also be removed from the transcript of each interview. All written material, such as the informed consent letters, transcripts, and notes, will be kept in a locked filing cabinet. Access to the original data will be limited to myself, and my research supervisor, Dr. Deborah Norris. All electronic records of transcripts will be stored on a computer that is password protected. As noted, interviews may be audio-recorded, with participants’ consent. Voice files will also be stored on a password-protected computer. The recording device may be switched off at any time, if you so choose.

Following the completion of the research, audio recordings will be destroyed. Other materials (transcripts, notes, informed consent letters) will be retained for five years as per guidelines on ethical research involving humans.

Any information you share in your interview may be used in future publications, presented at conferences and shared within the wider disability support community. A summary of the findings will be provided to you for the purposes of knowledge translation. Your names and your family member’s names will not appear in any publications, papers, or presentations resulting from this research.

If you have any questions presently or following the interview, I can be contacted through the information provided below:

Madison Brooks  
M.A. Candidate, Department of Family Studies and Gerontology



Mount Saint Vincent University  
Telephone: [REDACTED]  
Email: [madison.brooks@msvu.ca](mailto:madison.brooks@msvu.ca)

You additionally or alternately may contact my thesis supervisor:

Dr. Deborah Norris  
Professor, Department of Family Studies and Gerontology  
Mount Saint Vincent University  
Email: [deborah.norris@msvu.ca](mailto:deborah.norris@msvu.ca)

If there are any questions about how this study will be conducted, the Chair of the University Research Ethics Board (UREB) c/o the Mount Saint Vincent University Research and International Office, who is not directly affiliated or involved with this study can be reached at (902) 457-6350 or via email at [research@msvu.ca](mailto:research@msvu.ca).

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**Consent to Participate in Research Study**

**Title of Study:** *Unpaid and Paid Supports in the Lives of Family Caregivers of Adults with Disabilities: Mapping Social Relations*

I have read the information provided with this consent form and understand the purpose of this research. I have been provided the opportunity to discuss this research and my questions have been answered to my satisfaction.

I understand that this study in which I have agreed to participate, will involve the audiotaping of confidential interviews involving my everyday experiences with unpaid and paid supports as a family caregiver to an adult family member with a disability. I understand that my participation in this study is voluntary and that I may withdraw at any time and for any reason without penalty. I understand that there is no obligation to answer any question or participate in any aspect of this project that I find invasive. I understand that all personal data will be kept strictly confidential and that information will be stored securely so that only the researcher and her supervisor will have access to the data.

\_\_\_\_\_  
Name of Participant (Please print)

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Researcher/Witness

## Appendix E



## Consent for Audio Recording

Participant Name (please print)	
Research Study Title	
Researchers	

As a participant in this research study, I agree to be audio recorded for the purpose of facilitating data collection and analysis in this study. I am aware that I am able to withdraw this consent at any time without penalty or consequence, at which time the recordings will be completely erased and destroyed.

I understand that the recordings will be kept confidential and that no information about me, including these recordings, will be given to anyone.

I consent to excerpts of these recordings, or descriptions of them, being used by the researcher for the purpose of research or the presentation of research. I understand that the researcher will edit out from these recordings, or from descriptions of the recordings, any information that may identify me.

I understand that I will be offered the opportunity to review the transcript of the recording and that I may withdraw or alter part or all of the transcript.

I understand that I will be given the opportunity to provide or withdraw my permission for the use of the recordings for purposes other than what was stated in the original consent form prior to their use.

I understand that if I have any comments or concerns resulting from my participation in this study that I can contact the Research Ethics Coordinator, Office of Research Ethics, at 902-457-6350 or [research@msvu.ca](mailto:research@msvu.ca).

### Signatures

Participant	
Date	
Researcher	
Date	

## Appendix F Sample Interview Guide

Thank you for agreeing to participate in this study. Sharing your experiences with supports is important to increasing our understanding of how they work in the lives of caregivers of adult family members with intellectual disabilities.

Just as a reminder, I am interested in addressing the following questions:

(1) How are family caregivers of adult family members with disabilities (focusing on IDD) supported through networks of unpaid and paid supports?

(2) What barriers and ideas about caregiving and disability are present within the everyday lives of family caregivers supporting adult family members with disabilities (focusing on IDD) as they access unpaid and paid supports?

-Before we begin, do you have any questions about the introduction or consent form you signed?

- Can we also confirm that you consent to this interview being recorded?

- You can choose not to respond to any question or stop the interview at any time for any reason.

### **Demographic questions:**

- What year were you born?
- With what gender identity do you identify? (Probe: please specify your gender, for example: female, male etc.)
- What year was your family member born?
- With what gender identity does your family member identify? Probe: please specify your family member's gender, for example: female, male etc.)
- How would you describe or identify your family member's disability?
- How would you describe your role in their life?
  - What level and kind of support do you provide to them?
  - How long have you been in this role?

**General interview questions:**

- Describe a day in your life for me. How do you begin your day?
- What are the day-to-day activities you do?
- What is your understanding of unpaid support? (Probes: sources of unpaid support are people you reach out to who are not paid for their involvement or support. Examples may be family, friends, people you know through organizations, etc.)
- What is your understanding of paid support? (Probes: sources of paid support are persons who are funded to provide services, professionals who are involved in some capacity in your family member's life, and therefore yours. Examples: support workers, care coordinators, employment support, speech-language pathologists, occupational therapists, persons in non-profit organizations, etc.)
- What is your understanding of the difference between unpaid and paid support?
- What unpaid supports do you access? Who/what are they?
  - Who provides these supports?
  - How do you access these supports?
  - What do these supports do with you and your family member?
  - Why do you access these supports?
  - How would you describe your experiences with these supports?
- What paid supports do you access? Who are they?
  - Who provides these supports?
  - How do you access these supports?
  - What do these supports do with you and your family member?
  - Why do you access these supports?
  - How would you describe your experiences with these supports?
- Are the supports you access now different from those you accessed in the past? If yes, how has access changed? And to which supports? What prompted these changes?

- Do persons providing supports hold certain beliefs about caregiving or persons with disabilities? If yes, how would you describe these beliefs?
- What policies or programs shape the supports your family member does or does not receive?
- Please complete the following prompt: Wouldn't it be great if...?

Appendix G  
Resource List for Participants

Nova Scotia Association for Community Living

Phone: 1-844-469-1174

Email: [inform@nsacl.ca](mailto:inform@nsacl.ca)

Caregivers Nova Scotia

Phone: 902-421-7390

Toll-free: 1-877-488-7390

Email: [Info@CaregiversNS.org](mailto:Info@CaregiversNS.org)

Family Service Association

Phone: 902-420-1980

Toll Free: 1-888-886-5552

Email: [admin@fshalifax.com](mailto:admin@fshalifax.com)

## Appendix H

### Summary of Findings

#### **Unpaid and Paid Supports in the Lives of Family Caregivers of Adults with Disabilities: Mapping Social Relations**

**Authors note:** Thank you to the five participants who volunteered their time and energy to share their experiences. The research discussed in this summary was conducted by Madison Brooks (Graduate student, Department of Family Studies and Gerontology, Mount Saint Vincent University). The purpose of the research was to partially fulfill the requirements of a master's thesis. For more information regarding the study, please contact [madison.brooks@msvu.ca](mailto:madison.brooks@msvu.ca). The research was supervised by Dr. Deborah Norris, and supported by committee members Dr. Karen McNeil, Dr. Sarah Reddington and Cathy Deagle Gammon.

For most children and adults with disabilities, particularly intellectual disability (ID) or intellectual and developmental disabilities (IDD) who require support, their parents and other family members will be their primary caregivers over the life course (Families Special Interest Research Group of IASSIDD, 2013). Caregiving for an adult family member with intellectual and developmental disabilities (IDD) is understood to have both positive and negative effects on a family member's quality of life. Little is known however, about how family caregivers experience social supports when supporting a family member with IDD. Social supports are comprised of both unpaid and paid supports; these function to strengthen, build capacities, address needs, and sustain the well-being of individuals, as well as their families. The exact nature of unpaid and paid supports varies depending on families. Unpaid support can refer to, but is not limited



to, persons, such as family, friends and acquaintances, who are not funded or paid for their support. Paid support can refer to, but is not limited to, paid persons, often professionals providing support.

This research asked the following: how do unpaid and paid supports accessible to family caregivers supporting a family member with a disability operate within their everyday lives? The research questions were: (1) How are family caregivers of adult family members with disabilities (focusing on IDD) supported through networks of unpaid and paid supports? and (2) What dominant ideologies (beliefs and values) are embodied within the everyday lives of family caregivers supporting adult family members with disabilities (focusing on IDD) as they access unpaid and paid supports? A critical-ecological framework served as the conceptual foundation for the study and was informed by the institutional ethnography (IE) methodology. Study participants were 5 family caregivers supporting a family member with IDD between the ages of 25-40 living in the family home or a community-based setting at the time of the research.

Three primary themes were revealed through analyzing the data from participant interviews. First, inclusive and accessible networks function to support family caregivers of family members with IDD. The belief systems and availability of networks is tied to the support received. Second, unpaid and paid support provide family caregivers and their family members with opportunity for meaningful engagement with persons in their immediate and broader environment. This included social interaction in settings such as family gatherings, organized sport activities, advocacy with community organizations, and recreational activities for persons with IDD. Finally, there is a gap (line of fault) between institutional priorities (larger government agencies such as the Department of

Community Services) and the everyday experiences of family caregivers as they access unpaid and paid supports. This can be seen through policy analysis using the Disability Support Program (DSP) Policies which dictate disability support in Nova Scotia (Nova Scotia Department of Community Services, 2012). Family caregivers respond to the line of fault, the difference between priorities, through advocacy and utilization of available resources to best meet their needs.

A notable difference between the Nova Scotia Department of Community Services (NS DCS) priorities and the everyday realities of family caregivers was found. The implication is that family caregivers are unable to navigate accessing and advocating for paid supports to meet the needs of their family members, based on their understanding of the NS DCS practices and policies. The first recommendation is to publish a plain text version of the DSP Policies, and establish support navigators. This is in line with recommendations made by Autism NS (2019a, 2019b).

Second, the absence of first-person experiences and voices of persons with IDD and their family caregivers is evident in the structuring of disability support in a paid capacity. The implication is that support options are organization-centred, as opposed to person-centred. The second recommendation is for conscious steps to be taken by those exercising power to engage in relations wherein the voices of community organizations, other stakeholders, persons with disabilities and their families are heard. This is a well-documented need in the Nova Scotian disability support context (i.e. Autism NS, 2019; Community Homes Action Group, 2020; Community Homes Action Group & Nova Scotia Association for Community Living, 2014; Nova Scotia Department of Community Services-Services for Persons with Disabilities [NS DCS SPD], 2008; The Nova Scotia

Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013).

Third, vocational centres meet an established need of persons with IDD in Nova Scotia, and their caregivers. However, a gap for meaningful social engagement appears to be present for those between the ages of 18-21, and also persons with IDD with complex challenging behavioral needs. For persons ineligible for these programs, respite appears to be the only option. It is recommended that equivalent options for social engagement for persons outside the scope of vocational centres are created. This would uphold the rights of persons with disabilities, according to The Convention of Rights for Persons with Disabilities (CRPD).

Future research directions could explore unpaid and paid supports of family caregivers living in rural areas and family members who remain largely isolated from disability-specific supports. Research that brings together various stakeholders (people who are impacted by such supports, such as persons with disabilities, their families, and community organizations) to have conversations about unpaid and paid disability supports is a current gap. Documents by community stakeholders over the last 15 years (i.e. Autism NS, 2019a; Autism NS, 2019b; Community Homes Action Group, 2020; Community Homes Action Group & Nova Scotia Association for Community Living, 2014; NS DCS SPD, 2008; The Nova Scotia Joint Community-Government Advisory Committee on Transforming the Services to Persons with Disabilities (SPD) Program, 2013) continually highlight the need for changes to service provisions that better meets the needs of the people it serves. Unpaid and paid supports in family caregivers' lives reflect a lack of future planning. Conditions supporting future planning include family

members having abilities requiring higher levels of support with daily activities and a lack of suitable family to potentially take over as the primary caregiver (e.g. Brennan, 2005; Burke et al., 2018).

This study illustrated that the immediate and broader environments in which family caregivers' lives are situated are necessary to understand how unpaid and paid supports 'work' in family caregivers' everyday lives. Support networks were found to vary widely depending on family dynamics, abilities of their family member, and considerations of changes over time and geographical distance. During interviews, the interdependent nature of unpaid and paid supports in family caregivers' lives became apparent. However, it was found unpaid and paid supports 'work' in different ways, through distinct mechanisms in family caregivers' lives. To meet the needs of their family members, advocacy by family caregivers for paid supports was necessary. This involved family caregivers working within the system of paid support, governed by policies with institutional and ideological priorities that contrasted their own. The research articulates implications and recommendations for policy, supported by pre-existing findings in the Nova Scotia and broader disability support context.

## References

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