SOCIAL WORK KNOWLEDGE, VALUES, AND SKILLS: IMPROVING SERVICES TO PARENTAL CAREGIVERS OF PERSONS WITH DEVELOPMENTAL DISABILITIES

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SOCIAL WORK KNOWLEDGE, VALUES, AND SKILLS: IMPROVING SERVICES TO PARENTAL CAREGIVERS OF PERSONS WITH DEVELOPMENTAL DISABILITIES

by

Karen Pollett ©

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ABSTRACT

Social workers can play an important role in the lives of parental caregivers and their children who have developmental disabilities. However, these individuals often do not experience meaningful social work services. This qualitative study focused on meaningful social work services that can assist in the provision of parental care and caregiving to persons with developmental disabilities. The question under review was: “From the perspective of caregivers, what knowledge, values, and skills are necessary for social workers to provide meaningful services to them in caring for their daughters and sons who have developmental disabilities?” A fundamental assumption of the study was the recognition of caregivers as the experts with respect to their needs. A purposive, convenience sample of 15 caregivers was developed in St. John’s, NL., where they each participated in nonscheduled, standardized interviews. Interviews involved an open-ended interviewing technique that emphasized personal experiences and participants’ viewpoints using probes to ensure in-depth coverage of broad topic areas. The study’s findings were obtained through a synthesis of the audio tape-recorded interviews, documented through written summaries, and approved by the respective study participants. A feminist theoretical lens was used to interpret the findings and enhance the discussion. The findings lent support to a number of significant contentions. First, parental caregiving of persons with developmental disabilities is a women’s issue. Second, this caregiving often results in oppressive life circumstances for caregivers. Third, caregiving, while typically viewed as a private issue, is intricately linked to public structural issues and social policy. Fourth, social workers who use a feminist practice lens have an ability to provide life enhancing service to caregivers. Fifth, caregivers are the experts in their lives. They provided valuable information pertaining to the appropriate combination of knowledge, values, and skills that social workers need to best serve them. The study's results are discussed in consideration of social work practice, social work education, and social service agency opportunities to make a positive difference in eradicating oppression for caregivers by addressing their needs as defined by them.

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Mostly, I acknowledge my parents. My Dad who shared my dream and my Mom whose support in every way kept me going through the difficult times and cheered me on to the finish. They have been my champions through my life and this dissertation is dedicated to them.

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CHAPTER ONE:

INTRODUCTION

Study Purpose and Rationale

This study began as an exploration of social work intervention with individuals who have developmental disabilities. However, as this study unfolded, findings, based on the initial data analysis, highlighted developmental disabilities as an issue of caring and a women's issue in this study. These findings led to a change in direction to explore parental caregiving of persons with developmental disabilities. Hence, the purpose of this study is to enhance knowledge, values, and skills important to social work interventions with parental caregivers of individuals with developmental disabilities. The setting is the city of St. John's, the capital of Newfoundland and Labrador, Canada. Caregivers' contact with social workers in this city has primarily involved securing support services to assist with caregiving and help to obtain services on behalf of their children.

Parent caregivers recognize the important role social workers can play in their lives. However, my experience has witnessed their expressed dissatisfaction with social work services. To provide effective intervention, social workers must be knowledgeable about and understand this specific field of practice. Understanding effective social work practice with parental caregivers of persons with developmental disabilities can be enhanced by identifying the necessary knowledge, values, and skills needed to provide meaningful services in this area.

I have had the privilege of knowing and working with primary caregivers, their daughters and sons with developmental disabilities, and other family members, since the mid 1970s. My professional social work practice began in institutional settings. It has crossed the spectrum from institutional care to community living and community-based practice. Through these experiences I have come to realize that parent caregivers and their children often reside on the margins of society. The following two vignettes give some insight into the nature of life as a caregiver.

> Paula[1] is a single parent with a middle-aged son, John. She has always been her son's primary caregiver. After John finished school he attended a program to learn employment skills. He was not able to travel in the community independently so Paula accompanied him everyday. For Paula, this meant getting both of them ready for the day, leaving her home early in the morning, taking a bus downtown, transferring to another bus and accompanying her son into the school.
> School was a long way from home. There wasn't a lot of time for Paula to return home and travel back to school in the afternoon. So Paula took another bus to a shopping mall where she would wait for several hours. As a single mom, money was tight. She could not afford to spend and so she just hung out at the mall waiting everyday. Paula waited and watched others, who were able to purchase items and come and go when they wanted, until the time came to get a bus back to the school. She would meet her son and then take two more buses to get home just in time to prepare dinner. She traveled through all kinds of weather conditions and went on days when she really did not feel like going. Paula did this because it was

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[1] Vignettes use pseudonyms.

important to her that John be able to avail of every opportunity to further his development.

John is much older now and has acquired significant physical disabilities. Paula continues to be his primary caregiver in spite of having developed significant health problems due to lifting him and providing personal care. She will not consider John living apart from her even though she cannot get the support services at home that would reduce undue hardship.

Then there is Martha:

Martha has two children whose names are Jane and Jack. They both have a developmental disability. They have always lived at home. She is a single mom, who had to stay at home to care for her children. When her children were small her only source of income was welfare. In addition to caring for her own children, Martha provided day care for other children in her home to help pay her bills. Jack had to be assigned to a special class because Martha was too tired to assist him at home. She literally would fall asleep at the kitchen table while trying to help her son complete tasks assigned from school. There was no support available to her.

Today, Martha's children are both adults and they still live with her. Martha is employed outside her home now. She travels to work by bus where she spends eight hours a day caring for others. She then comes home and cares for her two adult children. She has been advocating for an independent living situation on her son's behalf but she has not been able to talk to a social worker for a month.

Paula's and Martha's stories represent the sacrifices and extraordinary lengths mothers, as caregivers, go to in providing care for their children with developmental disabilities. Appropriate knowledge, values, and skills are critical dimensions of effective social work intervention with these caregivers. Caregivers' perspectives, in this field of practice, can enhance our knowledge and understanding of how social work services can be made more relevant and effective in these situations. They can assist in identifying and expanding on these three dimensions relevant to social work practice (Dominelli, 1996, 2002).

I have witnessed the life defining effects for parents who provide care for their children with developmental disabilities. I have seen the positive effects of an inclusive life that provides dignity and respect to parents and their children. I have also seen the negative effects where they live isolated lives, are not valued or respected, and have come to not value themselves. The latter is disturbing.

Social work has a critical role to play in the lives of families where a family member has a developmental disability. However, my experiences suggest this role has neither been given much attention in social work practice nor has it been placed at the forefront of social work research, education, or practice (Begab, 1970; Burge, Druick, Caron, & Oulette-Kuntz, 1999; Cole, Pearl, & Welsch, 1989; Deweaver & Kropf, 1992; Dunn, Hanes, Hardie, & MacDonald, 2006).

In Newfoundland and Labrador, public social work involvement with families began primarily with a policy of deinstitutionalization initiated during the 1980s and continues to the present. Social workers have worked with caregivers, individuals with developmental disabilities, and other family members providing such services as counseling, assisting with obtaining supportive services, and advocacy. However, developmental disabilities, including support for parent caregivers, have only recently emerged as an area requiring more attention and in-depth preparation of social workers (Chappell, 2006; Dinitto & McNeece, 1997; Kirst-Ashman, 2003; Morales & Sheafor, 2004).

The purpose of the current study is to enhance our understanding and knowledge of what is necessary and important to those involved in caregiving activities for their children with developmental disabilities, and thus contribute to social work research, education, and practice. It is a study exploring, with parental caregivers of persons with developmental disabilities, their perspectives on what constitutes the essential components of knowledge, values, and skills for meaningful and effective social work intervention in their lives.

This current study is timely because it is conducted in Canada, and addresses the need for more in-depth social work knowledge and understanding with respect to women's care and caregiving of their children with developmental disabilities. Implications for social work practice and education with respect to caregivers, persons with developmental disabilities, and other family members are addressed. These caregivers, all mothers except one, tell their stories about how social work intervention has affected their individual lives. From the lens of their experiences, we can learn about the knowledge, values, and skills sets important and necessary for effective social work service. The advantage of engaging with caregivers in this way merits explanation.

In Canada, evidence of the importance of this field of practice, particularly in relation to professional education is seen in the formation of the Persons with Disabilities Caucus in 1993 within the Canadian Association of Schools of Social Work (renamed the Canadian Association for Social Work Education – CASWE). The Persons with Disabilities Caucus mandate includes developing accreditation standards that are inclusive of and promote the inclusion of disability related courses within the social work curriculum. The caucus published the results of a survey of schools of social work in Canada that addressed how they attend to disability issues (Dunn et al., 2006). It created an educational video for Schools of Social Work, held a Best Practices Conference in Winnipeg in 2004, and has recently completed an article related to best practices (Dunn, Hanes, Hardie, Leslie, & MacDonald, in press), (J. MacDonald, Chairperson, Persons with Disabilities Caucus, CASWE, personal communication, January 17, 2008).

Contemporary social work theory and practice give recognition to the important contribution to be made by those who receive services and how they can inform social work knowledge, values, and skills. Alternative theories and intervention approaches juxtaposed to traditional theories and intervention modes consider the person, who seeks social work services, to be the expert in her/his life situation (Dominelli, 1996, 2002; Nes & Iadicola, 1989). The current study takes the position that persons, who seek social work services, are the most informed about their own lives, and therefore, are in the best position to articulate their needs and define how these needs can be most effectively met. The social worker works in partnership with parental caregivers to help them meet their needs (Baines, Evans, & Neysmith, 1991, 1998; Baldwin & Walker, 2005; Chappell, 2006; Dominelli, 2002; Hanes, 2006; hooks, 2000; Salleebey, 1996). This 'person as expert' perspective is incorporated into the study's methodology and is profiled in the question being explored in this study: *From the perspective of caregivers, what knowledge, values, and skills are necessary for social workers to provide meaningful services to them in caring for their daughters and sons who have developmental disabilities?*

This is a phenomenological qualitative study resulting in the collection of data from in-depth one-on-one interviews with caregivers. These interviews give individual caregivers an opportunity to tell their stories that can elicit a wide range of emotions from sadness, pain, and discomfort, to joy and satisfaction. This storytelling experience, revealing the pain and hardship that many caregivers, care recipients, and other family members endured, further sparked my interest and motivation for the study.

The study question contains two fundamental concepts: a) care and caregiving, and, b) the constellation of knowledge, values, and skills intrinsic to social work practice. Roeher (2000) identifies women's caring issues pertaining to mothers who have children with developmental disabilities. The mothers in Roeher's study shouldered the responsibility of caregiving for their children. The availability of support services to help fulfill this responsibility was reported to be minimal. The current study explores caregiving as a women's issue, female parental caregiving of individuals with developmental disabilities, and the role of social work services to this vulnerable population.

Conceptual and Theoretical Framework

In considering the question being addressed, the fundamental concepts of care and caregiving, together with social work knowledge, values, and skills underpin the exploration of how social workers can provide meaningful social work services to caregivers. Further, considering these particular concepts from the perspective of the caregivers is consistent with feminist social work theory. For the purpose of this study, *caregivers are defined as parents who take a lead role in providing care, negotiating services, and advocating on behalf of their daughters and sons with developmental disabilities.* Feminist social work theory provides the guiding framework for the study and is used as the lens from which to view care and caregiving, and social work knowledge, values, and skills. Feminist social work theory guides the study's methodology and provides the framework for interpreting the findings.

Care and Caregiving

According to Baines et al. (1998), "caring refers to the physical, mental and emotional activities and effort involved in looking after, responding to, and supporting others" (p.3). They further delineate caregiving as a form of paid or unpaid work that takes place in one's home, in another person's home, or in the workplace. The most prevalent aspect of caregiving they note is the societal assumption that caregiving is women's responsibility. Thus, caregiving can be seen as a gender issue.

Traditionally, women have been seen as caring and nurturing. In fact, these characteristics were linked to their identity as women. Caregiving has been defined not only as woman's work, but also as part of a woman's nature (Baines et al. 1998; Traustadottir, 2000). For some women, caregiving is problematic because it is not a matter of choice. It is not a negotiated position, but happens by default. The result is many caregivers experience care as a burden (Baines et al. 1991, 1998).

Mothers who provide care to individuals with developmental disabilities face unique challenges. These mothers, in contrast to paid primary caregivers, experience caregiving as an all-encompassing activity with little time to pursue other activities or interests. According to Traustadottir (2000),

> "caring, which appears to be something women do for themselves to achieve their femininity, is better understood as something women do for others to keep them alive. Care is more than feelings women have; it is a specific kind of labor women perform that requires that women constantly organize and rearrange their lives to meet the needs of others" (p.269).

Being the parental caregiver of a person with a developmental disability, where supports and services are minimal, and educational, employment, social, recreational and spiritual opportunities are scarce, can mean carrying a heavy burden (Baines et al., 1998; Neysmith, 2000; Roeher, 2000; Traustadottir, 2000).

In the recent past, government measures to control budgetary deficits have resulted in a significant rollback of social and health services to vulnerable populations in Canada (Baines et al., 1991, 1998). There continues to be significant devolution of services from government to community agencies, without concomitant resources to support such services (Neysmith, 2000). These cost control initiatives have increased the responsibilities and work of caregivers. For many, the burden is overwhelming creating hardships for the caregivers and those receiving care (Baines et al., 1998; Neysmith, 2000; Roeher, 2000; Traustadottir, 2000).

Newfoundland and Labrador, depending heavily on federal dollars to support social and health care services, has been significantly affected by cutbacks in provincial transfer payments for social and health care services to help vulnerable populations. Home support services available to families have diminished in scope due to enforcement of strict eligibility guidelines. In addition, services available to adult children, such as support to education, employment, recreation and other community inclusive activities, have diminished significantly over the years. Residential options available for them are generally limited to continued living at home with their parents or living with other families (U. Tucker, Disabilities Consultant, Department of Health and Community Services, Government of Newfoundland and Labrador, personal communication, June 14, 2007).

The afore mentioned study by Roeher (2000) of 50 mothers who are caregivers to their children with developmental disabilities reports that over 70% of those mothers did not believe they received adequate community support. Fewer than 25% had extended family support in their caregiving roles and this support was occasional where it did exist. This group of mothers included 12% who did not know of anyone who would provide care for their children if they were unable to do so. This study's sample did not include mothers from Newfoundland and Labrador. However, the results shed light on the Canadian parental caregiving experience.

Many of the caregiving functions mothers perform are not valued as employment or work by society. They are frequently viewed as simply an expression of a mother's love. Thus, caregiving is often invisible. It takes place within private homes and familial relationships where obligations, responsibilities, and feelings come into play (Hansen, 2005; Neysmith, 2000; Parks, 2003). As such, it is seen as a private matter. Being seen as a private matter renders this work invisible and undervalued by the larger society leading to exploitation and even oppression of women. In this, society in general and social workers in particular have failed these women, in that the requisite supports and services are lacking (Baines et al., 1998). The evolution of social work, as a caring profession, provides some insight into this state of affairs.

Care and caregiving is a key concept within the history and evolution of the social work profession (Baines, 1998). Social work is viewed as primarily a women's profession and an extension of female care from the home into the workplace. In Canada, most social workers are women, and male social workers typically occupy the more senior administrative social work positions. It is female social workers who predominantly occupy lower paid, direct service positions concerned with caring for and about marginalized populations (Baines, 1998).

One vision of social work sees its mission inextricably linked to the emancipation of members of society who are vulnerable or oppressed. Here, the focus is on parent caregivers of persons with developmental disabilities a neglected, vulnerable population of women. Social workers, who serve this population, need a solid understanding of knowledge, values, and skills pertaining to women's caring. Parental caregivers of individuals with developmental disabilities can contribute to this understanding. Hence, their perspectives on social work knowledge, values, and skills are central to this study.

Knowledge, Values, and Skills

Caregivers have a special expertise, knowledge, and insight into what is helpful and detrimental in caregiving for their children with developmental disabilities. Social workers can learn from their expertise. For parental caregivers, it is important that social workers have this knowledge to fully understand their issues, values that result in respectful and dignified intervention, and skills to work with them and others to bring about desired results. A review of social work knowledge, values, and skills illuminates each independently, and demonstrates the interconnectedness of all three in providing effective social work intervention.

According to Siporin (1975), "Knowledge is cognitive mental content (ideas and beliefs) concerning reality that we take to be true (perceive with certainty based on adequate evidence), or that we decide is confirmable and has a high probability of truth" (p. 363). Social work considers three areas of knowledge, knowledge derived from theory, factual knowledge, and practice knowledge. Moreover, praxis is deemed important to ensure that social work practice remains relevant to those needing help while being grounded in sound theoretical constructs (Trevithick, 2005).

Social work is a value driven profession based on humanitarian and egalitarian ideals (Canadian Association of Social Workers, 2005). Social workers' personal and professional values influence their work with others. Rokeach (1973) defines a value as an "enduring belief that a specific mode or end state of existence is personally or socially preferable to an opposite or converse mode or state of existence" (p.5). Values guide social workers interactions with caregivers. The respect social workers demonstrate for people has a significant impact on relationships. Respect is particularly relevant when dealing with caregiver parents of persons who have developmental disabilities because these individuals do not appear to be valued in our society. Their parents feel their oppression and isolation. They are negatively affected by how their children are perceived and treated (Vanier, 1998).

Johnson, McCelland, and Austin (1998) define a social work skill as a "practice component that brings knowledge and values together and converts them into action as a response to concern and need" (p.51). They purport that skilfulness develops over time through the use of different techniques and methods. Skills encompass knowledge and values, and are enhanced through the development of a unique personal style.

Important skills in working with caregivers include those used with oppressed populations (e.g., empowerment and advocacy skills). Such skills, promoting the eradication of gender inequality and discrimination against women, are important for creating non-oppressive and non-discriminatory policies, services, programs, and interventions (Kravetz, 2004). In addition, skills that address oppression of persons with developmental disabilities are important for these caregivers. Such skills can be used to lessen the burden of care assumed by caregivers.

The knowledge, values, and skills addressed in the current study are in relation to vulnerable and oppressed populations. Caregivers are oppressed by the burden of care and their daughters and sons with developmental disabilities are viewed as vulnerable and oppressed. The ideology of oppression and the concept of women's caring can be appropriately viewed from a feminist social work theoretical perspective.

Feminist Social Work Theory

Dominelli (2002) defines feminist social work as,

> a form of social work practice that takes women's experiences of the world as a starting point for it's analysis and by focusing on the links between a woman's position in society and her individual predicament, responds to her specific needs, creates egalitarian relations in 'client' – worker interactions and examines structural inequalities" (p.7).

Feminist theory addresses inequality and oppression for women and other groups, including primary caregivers and their children. According to hooks (2000), if a person is oppressed that means they do not have choices. She notes the phrase 'the person is political' to emphasize "that women's everyday reality is informed and shaped by politics and is necessarily political" (p.26). This is not a matter of personal choice. Caregivers in the current study are limited in the choices they have with respect to their own goals and aspirations. Moreover, they often do not have access to support and services to keep their caregiving work from becoming a personal burden.

Social work, based on feminist social work theory, informs practice about ways to eradicate sexism. hooks (2000) professes, "Between women and men, sexism is most often expressed in the form of male domination, which leads to discrimination, exploitation, or oppression" (p. 48). She maintains that sexism and other forms of oppression can be addressed through "a recognition of the need to eradicate the underlying cultural basis and causes of sexism and other forms of group oppression" (p. 33). Male domination experienced by caregivers may be attributed to a patriarchal approach or perspective to women's caregiving. Caregiving is women's responsibility. In Canada, support and services to ease the burden of care are controlled by a male dominated, political, and bureaucratic system (Baines et al., 1991, 1998).

Summary

This introduction has provided an overview of the rationale, purpose, method, as well as the theoretical and conceptual framework of this study. The study seeks to enhance our understanding and knowledge of social work intervention with parental caregivers of persons with developmental disabilities. This is accomplished by caregivers identifying, through the lens of their experiences, the social work knowledge, values, and skills that are necessary for them to have access to meaningful social work services. The study is fundamentally concerned with how social workers can more effectively serve these caregivers. The study is conducted and the findings are interpreted within a feminist social work theoretical perspective.

The next chapter provides a literature review relevant to the background and context of this study. Areas that are reviewed include care and caregiving, developmental disabilities, feminist social work theory, and social work knowledge, values, and skills relevant to professional practice and social work education.

CHAPTER TWO:

LITERATURE REVIEW

This chapter provides context for understanding the study's central concepts, parental care and caregiving for persons with developmental disabilities, and social work knowledge, values, and skills related to this field of social work practice. The specific areas of review are care and caregiving, developmental disabilities, feminist social work, professional social work practice, and social work education. The literature review includes specific reference to the Newfoundland and Labrador context.

Care and Caregiving

Care and caregiving are complex phenomena involving relationships between those who are cared for as well as those providing care. Caregiving involves specific activities carried out by one or more individuals to meet another's needs, including many areas of that individual's life. Caregiving encompasses a range of emotions depending on the persons involved, the situations, and the circumstances (Armstrong and Armstrong, 2004; Hansen, 2005).

Caregiving can be viewed as being interdependent because it is transactional. Those cared for and those providing care both give and receive benefit from caregiving and the caregiving relationship. For example, the care recipient benefits by having her/his personal needs met and the care provider can benefit through altruistic feelings of helping someone to meet their needs. Caregiving occurs in public and private settings and can be paid or unpaid work. Because of its complexity, caregiving is difficult to define in terms of what happens, how it happens, and the time involved (Armstrong & Armstrong, 2004).

Care and Caregiving Dimensions

The study of care and caregiving is complicated because of its nature and the number of different configurations of care and caregiving. Thomas (1993) identifies seven dimensions of care relevant to all types of care and caregiving. Thomas' first care dimension is the social identity of the caregiver. Socially, caregivers can be defined in terms of familial or private roles (e.g., mother, daughter, or wife). They can also be socially defined according to public roles (e.g., social worker, home care worker, or citizen volunteer). Irrespective of this private or public role, the most important social identifier is gender since caregivers are predominantly women (Thomas, 1993).

According to Thomas (1993), the second dimension is the social identity of care recipients - the other group of participants in the care relationship. Care recipients can be socially defined through two descriptors: group categorization and/or dependency. For example, the care recipients in this study have a group categorization of developmental disability. Persons with developmental disabilities have varying degrees of dependency, some being relatively independent, while others are quite dependent. Thomas maintains that the most predominant social descriptor of the two is the degree of dependency.

The social relationship between the caregiver and the care recipient is the third dimension of care. Social relationships between the caregiver and the care recipient are bonds signifying varying degrees of personal familiarity, connectedness, and reciprocal obligations. Family bonds are usually the most significant, but close bonds also exist with those outside the family including friends, volunteers, and paid caregivers (Thomas, 1993).

The fourth care dimension profiles the nature of the actual care being provided. Understanding what is meant by care can be problematic because of the dual meaning of care. Care can involve feelings, often referred to as 'caring about someone' or can mean caregiving activities falling in the realm of 'caring for someone'. Thomas (1993) states that actual care is most often defined as an activity but it is sometimes described as both an activity and an emotional bond (i.e., caring for and/or caring about).

The social place where care happens is Thomas' (1993) fifth dimension. Social place refers to the division of work between the home and public places. Care is different depending on the social location. Care at home is private and usually informal, whereas care in the public domain is usually formal.

The sixth dimension of care is the economic status of the care relationship. This is an extension of the fifth dimension, the social place of care. Care can be provided through family obligation or through a paid arrangement. Although the former is typically located in the home, paid care can also take place in the home. Volunteer work involving care within the public sector means care work in the public sector is not exclusively paid work. The literature emphasis seems to be on one or the other, although most attention is given to unpaid care (Thomas, 1993).

The seventh and final dimension of care is the physical location of care activities. When care is provided by family members, the home is often the center of concentration. A wider range of care settings outside the family home, like hospitals and residential settings, are also noted (Thomas, 1993).

To summarize, Thomas (1993) captures the essence of care by examining the social identity of the caregiver and the care recipient, their relationship, specifics of the actual care provided, social location, economic aspects, and physical location. Different types of caregivers and a wide variety of care recipients create many kinds of care and caregiving. These seven care dimensions are relevant to all. The type of care and caregiving explored in this study is informal, unpaid, home-based care governed by parental obligation.

Caregiving: A One Hundred Year Review

Armstrong and Kits (2004), in a review of caregiving in Canada over the past hundred years, note similarities and differences in care and caregiving practices today compared to a century ago. Informal caregiving has been the most predominant form of caregiving within our society. One hundred years ago, like today, most individuals requiring care lived in private households. According to Armstrong and Kits, at the end of the 19th century, there was a demand from families for help with caregiving while at the same time the government was promoting fiscal restraint and blaming families for shirking their caregiving responsibilities. At the beginning of the 21st century, families still advocate for services to help with caregiving while the government still espouses caregiving as primarily a family responsibility (Armstrong and Kits, 2004).

This emphasis on family care is based on the assumption that most families are nuclear families - a heterosexual couple raising children with the husband working outside the home and the wife providing care within the home (Hansen, 2005). Armstrong and Kits (2004) comment that this contention was and continues to be a misconception. Diverse family structures and multiple work roles for women have been a constant throughout the past one hundred years. During the early years of the 20th century, prior to significant advances in health care, sickness and deaths caused by accidents or during childbirth created many lone-parent families throughout Canada. Additionally, immigration contributed to the predominance of blended and extended families in many areas, with two or more generations often living in the same household. Moreover, many women worked outside the home as well as in the home. For example those who lived in rural areas often worked on the family farm. Plus, in urban settings women worked outside the home to help with the family finances (Armstrong & Kits, 2004; Hansen, 2005).

Newfoundland and Labrador families, throughout the 20th century, reflected many of the attributes noted above. Extended families existed in the early years when generations of families often lived in the same household. Further, lone-parent families were not uncommon because of a lack of medical services to treat illness, especially in rural, isolated areas of the province. As well, women worked outside the home helping with the fishing and farming process to provide food for the family (Brett, 1997; Hardy Cox, 1997). In the early years, and today, many Newfoundland and Labrador families do not fit what is considered to be the traditional or nuclear family.

Armstrong and Kits (2004) contend that while there are similarities in caregiving over the past century there are also differences. In the 19th century social and health services were seen as charity and few of these services were available to Canadians. By contrast, the 20th century witnessed significant advancement in what has been referred to as the welfare state. Overall, the health, working conditions, and education of Canadians improved greatly. Social welfare legislation and related programs improved the quality of life for citizens creating benefits for caregivers and care recipients. Of particular significance for individuals with disabilities is their inclusion in the Canadian Charter of Rights and Freedoms, Constitution Act, (1982). Human rights legislation furthered equality and promoted affirmative action (Armstrong & Kits, 2004; Baines et al., 1991, 1998). Newfoundland joined Canada in 1949, subsequently benefiting from social, educational, and health benefits. The province became more connected to the rest of Canada and the western way of life throughout the second half of the 20th century (Brett, 1997; Hardy Cox, 1997). While many Canadian social welfare programs were created in the mid 20th century, the last quarter of the century saw social programs and services being reduced and eliminated in some cases as governments entered a time of fiscal restraint. This continues to be the case today (Armstrong & Kits, 2004; Carniol, 2005; Nachshen, 2005; Neysmith, 2000; Rossiter, 2005).

Armstrong and Kit's (2004) review of one hundred years of care and caregiving reveals that by the end of the 20th century a decrease in services combined with increasing expectations for family-based care caused caregiving to be experienced in some cases as the burden it was a century ago. Three aspects of care warrant further exploration within the context of caregiving experienced by caregivers today. They are a) care as a women's issue, b) the issue of dependency and care recipient, and c) caregiving as a social concern.

Care as a Women's Issue

The literature is clear that care and caregiving is viewed by society as a women's issue. It is also seen by women, in particular, as a women's issue (Armstrong & Kits, 2004; Baines et al., 1991, 1998; Cummins, 2001; Daly & Rake, 2003; Fort-Cowles, 2004; Gilligan, 1982; Guberman, 2004; Kittay, 2002; Neysmith, 2000; Parks, 2003; Roeher, 2000; Seltzer, Kraus, Larson, Makuch, & Robinson, 2000; Sevenhuijsen, 2002; Thomas, 1993; Traustadottir, 2000; Tronto, 1993, 1995; Tyyska, 1995). Research shows that caregiving was and continues to be primarily women's work. This is true irrespective of age, income, employment status, and cultural or physical locations. While women's values influence their workload, there is significant evidence to show that legislation, regulation, and policy define women as caregivers, linking the caregiver role to women in our society (Armstrong & Kits, 2004; Neysmith, 2000). Our patriarchal society defines care as women's work. This is evidenced through repeated messages that home care is the preferred method of care. Women's willingness to provide free labour is taken for granted. The family is held accountable through affirming care as a private responsibility and not a public concern (Baines et al., 1991, 1998; Bashevkin, 2002; Hansen, 2005; Neysmith, 2000; Parks, 2003; Tronto, 1993).

Women have traditionally been the ones who have taken care of the home and family, so the task of providing care fell to them. Women have seen the provision of care as their responsibility. Since caregiving has traditionally been a women's role, most women felt morally responsible for care. This responsibility, however, can result in an unhappy situation for some women caregivers (Parks, 2003; Tronto, 1993). According to

Gilligan (1982), women have an ethic of care that is possibly developed from gendered socialization, which saw women socialized in a different way than men. This ethic of care results in women using a caring lens for moral reasoning. Women internalize caring and feel guilty when accused of not providing care. As a result, women can become burdened with care when they do not have the necessary supports and services to help with caregiving (Parks, 2003).

In 1999, 3% of women in Canada who had full-time jobs lost time at work due to family responsibilities, compared to one 1% of men (Statistics Canada, 2000). Women gave up paid employment to provide care. They were more likely to leave the work force than men, partly because their jobs paid less. Women were also predominantly in part-time and temporary jobs. The increase of women in non-standard work may in part be explained by their increased caregiving responsibilities. Instead of losing time at work many took part-time jobs with fewer hours or did work that could be done at home. Many women did not have a pension because of the type of work they did. As a result, the majority of the female elderly had only a public pension. For many, the lack of a private pension and the financial loss associated with this was seen as being the direct result of caregiving (Townson, & Canadian Advisory Counsel on the Status of Women, 1995, reported by Armstrong & Kits, 2004). Parish, Seltzer, Greenberg, and Floyd (2004), in a study done in the United States, found that "[m]others of children with disabilities were less likely to have job spells lasting more than 5 years and had lower earnings when they were 36 years old. Further, there was a trend for them to be less likely to have full-time jobs as their children grew older" (p. 413). This research may have implications for the

Canadian caregiving experience.

According to Statistics Canada (2000), men and women are working longer hours, often having two jobs. This leaves fewer families with the time or resources to provide caregiving while caregiving demands grow. Further, changes in family patterns result in fewer family members available to provide care. Caregiving is often a burden under these conditions. This burden compromises caregivers and care recipients' health. It also strains relationships and current and future finances (Armstrong & Kits, 2004).

This burden can, in fact, go beyond traditional care and caregiving. Women, who are parental caregivers for individuals with developmental disabilities, accept additional caregiving responsibilities. These women work to help their children become an integral part of life at school, work, and in neighbourhoods and communities (Nachshen & Jamieson, 2000). Their work of caregiving and advocacy is largely unrecognized (Roeher, 2000; Traustadottir, 2000). For mothers of children who have disabilities, this lack of recognition for their work is exacerbated by negative social views towards them because they have children who will be dependent on society throughout their lifetime. Dependency, as a social issue, is not easily addressed because being dependent is negatively viewed in our society (Baines et al., 1991, 1998; Condeluci, 1995; Kittay, 2002).

The Care Recipient and Dependency

In Western society, those who receive care are seen as dependent by virtue of their care needs. The social perception of a person's worth is directly proportional to perceived dependency. Dependency is generally considered to be morally offensive except for the very young (Hansen, 2005). Independence on the other hand is applauded and is a generally accepted measure of worth. However, some writers consider the negative view of dependence to be erroneous. From their perspective everyone is dependent on others for particular aspects of their social functioning on a day-to-day basis (Condeluci, 1995; Dominelli, 2002; Feder & Kittay, 2002; Hansen, 2005; Parks, 2003; Tronto, 1993; Wolfensberger, 1984). The traditional esteem accorded independence is challenged by a very different value orientation, espousing all persons to be dependent on others or interdependent throughout their lifetime (Condeluci, 1995). According to Feder and Kittay (2002),

> ...what seems to be independence results from invisible or unacknowledged dependencies on others, or on economic or political institutions and on social understandings of what constitutes dependence and independence. As long as we maintain the fiction of the 'normal' moral/political/legal/economic agent as the independent actor, dependency will continue to be seen as a peripheral concern when in fact it is central in all of our lives (p. 4).

People remain dependent on others to a greater or lesser extent throughout their lives, sometimes they need to provide care to others and sometimes they need care themselves. A pivotal issue is how people deal with dependency, including the resources they have available to help them to achieve and maintain a satisfactory quality of life. Those who are affluent have more choices, and therefore, more control over their life situation than those who are poor and vulnerable. Recognizing some measure of dependency in every person's life means all people are viewed as interdependent. This belief of interdependence helps eradicate the negative connotations of dependency. Plus it helps one recognize the socially interconnected nature of life for all people, thereby honoring caregiving work (Hansen, 2005). This belief of interdependence is a matter of expanding caregiving perceptions to include those activities that are performed by one person to help meet the needs of another in everyday life.

Embracing a view of interdependence shifts the focus from achieving and maintaining independence to how to resolve issues of dependency that all people face (Condeluci, 1995). The assumption that all people need other people to varying degrees bestows value on those who need care and those who provide care (Tronto, 1993).

If interdependence became a central tenet defining citizenship, caring for others would be more readily seen as a responsibility of the state. Recognizing citizens as interdependent, the government would eradicate the division between those who are now considered dependent or independent, which would pave the way for more social support and services to help meet individual needs as a right of citizenship (Condeluci, 1995; Kittay, 2002; Kittay & Feder, 2002; Roeher, 1996; Vanier, 1998).

Care and Caregiving: A Social Concern

New health care policies in Canada increasingly place caregiving responsibilities and their associated costs with families (Neysmith, 2000). Armstrong and Armstrong (2004) identify caregiving costs including costs of time, costs related to social and emotional needs, and the costs of lost opportunities as undervalued. Featherstone (2005) argues that work done in caring *for* individuals and caring *about* individuals merits honor, respect, and appropriate financial compensation. Nonetheless, Baines et al. (1991, 1998) profess that a change in societal attitude to valuing and creating collective responsibility for caregiving to be a significant challenge. Current social policies and programs associated with care assume the family to be the most appropriate social location for caregiving.

The deinstitutionalization movement saw caregiving shift from statutory to voluntary obligation, from formal to informal structures, and from paid to unpaid work. A romanticized view of care within the family has been financially advantageous for government, and has promoted a societal myth that people prefer to be cared for at home (Armstrong & Kits, 2004). Given the current situation, individuals, who require care, have little choice but to stay within the family structure (Daly & Rake, 2003).

A number of researchers suggest that people do not necessarily want to be cared for at home by family members. Frequently, people, who can afford to, will purchase personal care services rather than rely on family and friends. In addition, some individuals with disabilities express a desire to live outside the family home. They do not want to be a burden to their family and welcome the idea of having an opportunity to live on their own (Barnes & Mercer, 2003; Guberman, 2004; Mackelprang & Salsgiver, 1999). Responsive support services can provide options for individuals, leading to effective social care.

Mackelprang & Salsgiver (1999) and Neysmith (1991, 1998) discuss assumptions that underpin a responsible and responsive social care approach. First, a responsive social care approach views public services as a right of citizenship enjoyed by all. Support services are available, as needed, without financial or social assessment as to degree of hardship. Second, service consumers are empowered to choose what services best meet their needs and how these services can be tailored to their unique individual circumstances. Third, caregiving is a partnership that includes all stakeholders (i.e., care recipients, caregivers, the public sector, the voluntary sector, and the community). This partnership is fostered by the state and includes a significant public presence where service consumers are given a say in policies and procedures that govern caregiving. Fourth, caregivers are not subjected to unfair labour practices, financial burden, or career loss. Fifth, the private sector's role is clear and public home care services remain a central feature of social policy.

Social care connotes the idea of shared responsibility between the state, family, and the community. However, Neysmith (1998) maintains this idea is at odds with government assumptions about private families, a market based economy, and government policies of minimal interference. Canadian policymakers' belief that caregiving is a private responsibility does not auger well for creating a social care approach with a government committed to care as a public responsibility and a basic right of citizenship (Armstrong & Armstrong, 2004; Neysmith, 1991, 1998).

Neysmith (1998) views an optimal social care approach as having three essential components: degendered caregiving roles, social care (not private care), and guaranteed services. Degendering care necessitates men and women having equal responsibility in caring decisions so that caregiving roles can be interchangeable, assumed by both men and women. Moving from private care to social care requires a negotiated approach where those involved have an equal say, share resources, and work collaboratively. Finally, the provision of guaranteed services, while a challenge during periods of fiscal restraint, is essential in this approach. Creating feasible alternatives requires an active government presence. It also means that caregivers and those receiving care are actively involved in decisions about the support services affecting their lives (Condeluci, 1995; Neysmith, 1998).

Care and caregiving present many challenges for policy makers. Daly and Rake (2003) contend that no established policy is apparent in any country concerning the appropriate allocation of care costs or location of caregiving responsibility between the state, the family, and the market. In Western society, social and economic considerations are coloured by societal values about individual worth, views of dependence and independence, and patriarchal notions about female roles and their familial responsibilities and obligations. A social care approach demands change that affords dignity, empowerment, and real choice for all members of society including those most vulnerable (i.e., persons with developmental disabilities) (Kittay, 2002; Roeher, 1996).

Parental Caregiving of Persons with Developmental Disabilities

Roberto (1993) compares the research between mother caregivers of aging children with developmental disabilities and wives providing caregiving for elderly spouses. In addressing points of commonality, she identified diminished health status for both caregiver groups as an issue. These women may be dealing with their own health concerns that accompany aging. In addition, individuals in both caregiver groups may have their health compromised as a result of the stress and strain associated with caregiving responsibilities. Finally, the provision of care is on the assumption that such responsibility naturally falls to the mother or wife. This expectation places caregivers of both groups in a position of potential conflict with their families.

The most obvious difference in caregiving between both groups is the time of onset of caregiving responsibilities (Roberto, 1993). Spouses assume caregiving responsibilities, for their partners, usually after many years of independent, healthy lives, whereas mothers of persons with developmental disabilities assume this responsibility at their child's birth. This typically leads to a much longer period of caregiving. Long term caregiving provided by mothers of aging individuals is reported as negative due to the stress and strain over a long period of time (Trute, Hiebert-Murphy, & Levine, 2007), while other research shows the positive side of long term caregiving with adaptation leading to improvement in caregiver attitude over time (Seltzer et al., 2000) Also, the nature of the relationship between parents and their children with developmental disabilities is obviously different than the relationship between spouses. Both parents and spouses are influenced by varying feelings of obligation and responsibility related to the nature of their relationship. However, for parents, there may be additional issues pertaining to guilt or perceptions of the on-going, lifelong assumption of the parental role (Roberto, 1993).

Lifelong caring can be life defining for mothers who have children with developmental disabilities. Seltzer et al. (2000), in a study on caregiver adjustment, found that mothers have a favourable level of personal and social well being after an average of 35 years of caregiving. Their research shows that parents are proud of their life's work and the quality of life they are able to provide for their daughter/son.

Trute et al. (2007), in their research on the impact of having a child with a developmental disability on a family, found that parents, who perceive the situation negatively, are more likely to experience less long term family well-being than families who have positive views. In this study, a mother's level of self esteem during the first few years is also found to be proportional to her early assessment of the family impacts of having a family member with a developmental disability.

Cummins' (2001) review of research found the quality of life for caregivers and their families, caring for a person with a severe disability, to be low. Further, his review indicated that the level of disability is a defining factor. Individuals with a severe disability have significantly higher care needs. In addition, there are not enough public resources allocated to provide adequate services to support their care. Cummins (2001) notes that the government has saved billions of dollars through the deinstitutionalization program and shifting of responsibilities to families, mostly mothers, who provide the free labor. The literature indicates that parental caregivers of children with severe disabilities are at high risk for significant stress, clinical depression, and a quality of life that is significantly below normal. Also, Cummins (2001) points out that many studies, which show parental caregiving to be a positive and rewarding experience, did not consider the level of care needed, or the availability of necessary support services, thereby bringing into question the value of these studies in providing a full and accurate picture of their situation.

A study by Gupta (2007) reveals that, for parents who had children with different disabilities, those who are primary caregivers of children with developmental disabilities rank highest for parental stress along with parents of children with attention deficit hyperactivity disorder. Mothers of children with developmental disabilities rank highest in stress caused by isolation from formal and informal emotional support systems. They express that the visibility of developmental disabilities contributes to the caregivers' social isolation. Finally, the caregivers demonstrate being overwhelmed by the care of their children and indicate that they may benefit from home care services.

Caregivers with children who have developmental disabilities have additional responsibilities. Seltzer et al. (2000) found that these mothers have the primary responsibility for ensuring their adult children have a social life. Cummins (2001), as well, identifies mothers' concern with their child's community engagement and social life. Nachshen and Jamieson (2000) conclude they also feel responsible to advocate for educational and other supports and services needed by themselves and their children. The need for enhanced support services and a quality social life require action to ameliorate such conditions.

Advocacy is a significant activity for parental caregivers of children with developmental disabilities. It can be positive or negative. Research by Nachshen and Jamieson (2000) demonstrates that parents involved in advocacy can experience a reduction in stress or an increase in stress depending on a number of factors including, what parents believe is the role of advocacy, the outcome of advocacy activities, parents relationship with professionals, the objective of particular advocacy activities, how being an advocate affects individual's personal lives, and parents' feelings about what it is like for them to be the parent of a child who has a developmental disability. Positive attitudes and experiences lead to less stress, while negative attitudes and experiences can exacerbate caregiving stress.

Dempsey and Dunst (2004) suggest parents stress can be reduced when they feel a sense of empowerment. Empowerment is a benefit to caregivers and others who are in a socially and/or financially disadvantaged position within society (Dempsey and Dunst, 2004). Dempsey and Foreman (1997) purport the importance of clarifying empowerment as necessary work for professionals in the provision of service in the area of disability. Empowerment, while viewed as important for those who require support, is yet to be promoted as part of everyday professional practice with those who are intimately affected by disability (Dempsey and Foreman, 1997; Nachshen, 2005).

Dempsey and Dunst (2004), reporting on a survey completed in Australia and the United States, show the relationship between the way help is provided and the resulting empowerment for parents who have children with developmental disabilities. For this group, they found that empowerment involves more than personal control. It includes knowledge about resources and alternatives, positive feelings about personal and family circumstances, as well as the ability to demonstrate relevant and appropriate behaviour. This study further demonstrates that those who provide help should have concern for participatory and relational empowerment activities. Participatory or help giving practices include activities to enhance individual competencies and opportunities for joint decision-making between caregivers and service providers. Relational practice influences the relationship between those who give help and those who receive it. Helping skills that promote positive relational behaviour include empathy, active listening, and the perceptions by service consumers of the extent to which they are viewed as competent by service providers.

According to Nachshen (2005), a study of the current theoretical and empirical literature suggests, "The combination of tightened fiscal policies, increased participation by parents in the care of their child, and the coincident decreased availability and increased demand for services have increased demand on parents to accrue the knowledge, beliefs and behaviours of empowerment" (p. 73). Caregiving for family members with developmental disabilities brings special challenges that further the need for caregivers to be empowered. Individuals with severe developmental disabilities and/or concurrent physical disabilities need significant support in activities of daily living. Because they need this extra assistance, family members can be an important source of their support, advocacy, and affection throughout childhood and into adult years. Maintaining family provision of this important emotional and physical support must be complimented by the resources of the larger community, to help nurture emotional ties and adaptation to caregiving from the onset (Singer & Irvin, 1989). As most caregivers of persons with developmental disabilities are mothers, it seems that social work efforts need to be especially directed to the continued well being of this group. Feminist social work theory provides a conceptual framework that is relevant to the practice of social work and the needs of parental caregivers of persons with developmental disabilities.

Developmental Disability

In this study the term developmental disability is used to refer to the traditional nomenclature 'mental retardation'. It was not until the 19th century that clear distinctions were made between developmental disabilities and other forms of disability. Indeed, throughout history, and even today, disabilities are often treated as one entity with developmental disabilities included as part of a single concept (Roeher, 1996).

Historical Overview of Social Response to Developmental Disability

Throughout history, individuals who had developmental disabilities were seen through various lenses determined by the needs and expectations of a given society at a particular time (Oliver, 1990; Schreenberger, 1983). For example, in ancient Spartan society strength and intelligence were the primary measures of human worth. Because of this society's need for its members to possess these qualities, children born with disabilities, being seen as possessing neither, were thrown off mountains to their death. This practice was not unlike that of other practices of earliest civilizations (Oliver, 1990; Scheerenberger, 1983). What is considered today to be extreme cruelty was (in the ancient past) inflicted upon many persons with disabilities. However, in some societies individuals with disabilities were seen as holy innocents or eternal children resulting in attempts at protection and caring that led to different social responses, albeit still resulting in impoverished life conditions (Sheerenberger, 1983).

Individuals with developmental disabilities are seen as significantly different. According to Wolfensberger (1972), "[a] person can be said to be deviant if he [or she] is perceived as being significantly different from others in some aspect that is considered of relative importance, and if this difference is negatively valued" (p. 13). Many espouse that individuals who are seen as different in a negatively valued or deviant way create a fear of difference (Mackelprang & Salsgiver, 1999; Vanier, 1998; Wolfensberger, 1972).

Wolfensberger (1972) captures the number of different ways that persons with developmental disabilities were seen as being deviant throughout history by labeling historical role perceptions of such persons. These role perceptions include subhuman species, a menace, an unspeakable object of dread, an object of pity, a holy innocent, a diseased organism, an object of ridicule, and an eternal child. Kurtz (1981) adds, developing person, as another role perception emerging in more recent times. The role of the developing person evolved from research and other work that begun in the 1800s and has continued since that time helping to promote a true understanding of persons with developmental disabilities. This historical perception of roles helps to clarify how society in general views persons with developmental disabilities. Such social views help clarify how people were treated based upon the others' perception about them.

Schreenberger (1983) describes the 1800s as an era of progress in the area of developmental disabilities. At the beginning of the century, a French physician, Jean-Marc-Gaspard Itard, taught a boy named Victor. His work promoted an understanding that even those most severely affected with developmental disability were capable of learning. Itard's work was carried on by Edouard Sequin, who reportedly made the greatest contribution to knowledge of developmental disabilities in the first half of the 19th century. He came to be referred to as the father of special education. During his career he started a school to educate persons with developmental disabilities and worked as an educator in institutions in France. He later moved to the United States and in the 1850s assisted in the development of several institutions there (Schreenberger, 1983).

Sequin's work inspired others. It resulted in the establishment of residential training schools in the second half of the 1800s (National Institute on Mental Retardation, 1981; Schreenberger, 1983). These schools, while developed on the basis of educational goals designed to teach skills to persons with developmental disabilities, did not attain the anticipated independence envisaged for such persons. According to Johnson (1898), "the early hopes of the first promoters of the training of the feebleminded were not realized. It has not been found practical to discharge large numbers of the educated imbeciles to care for themselves and direct their own course of life" (p. 469). Because of this type of thinking, by the 20th century these residential schools evolved into large custodial institutions for the most part. The focus within the institutions moved from education to the provision of care for those who could not be cared for by their families. The focus was also on the protection of society. These institutions were usually located away from communities in country settings (Scheerenberger, 1983; Wolfensberger, 1972).

In the 1900s, however, a number of events, predicated on the eugenics movement, reinforced negative opinions about persons with developmental disabilities. Eugenics, rooted in Darwinism, sought to improve the human race by preventing the birth of individuals with developmental disabilities. In the early 1900s, Henry Goddard's research, based on eugenics, concluded that individuals with developmental disabilities were a menace to society, and as such should be removed, controlled, and sterilized (Roeher, 1996; Scheerenberger, 1983). Goddard's research, before it was discounted, created a eugenics scare causing people to be afraid of having persons with developmental disabilities live in their community. For example, in 1916 thousands of Canadians petitioned the Prime Minister to have persons with developmental disabilities removed from communities and placed in farm colonies. This petition also requested a study to explore ways of controlling this perceived menace. Further, as a result of beliefs based on eugenics, sterilization laws were passed in the 1920s in two Canadian provinces, Alberta and British Columbia, and policies of routine sterilization were enacted in several other provinces. These policies remained in place for most of the 20th century (Roeher, 1996). Eugenics was further promoted by the Nazis in 1939 through the initiation of Hitler's pure race policy, which resulted in the death of thousands of persons with developmental disabilities, first through euthanasia and later through massive lethal gassing (Barnes & Mercer, 2003; Hanes, 2006; Roeher, 1996; Schreenberger 1983).

These events not withstanding, there were gains made in the possibilities and potential for persons with developmental disabilities in the 1920s and 1930s. The possibilities for education and development were explored and furthered in a positive light. Kurt Lewin (1935) concludes that the social behavior of persons with developmental disabilities is a function of the interaction between personal attributes and environmental conditions. The environment plays a role in the behaviour of person's with developmental disabilities. Lewin's work set the stage for others to address the disability

- environment connection. For instance, Barker (1948) puts forth the idea that physically disabled adults have a social status that is marked by underprivilege and marginalization, and in this respect they are similar to minority groups. He also contends that "[t]he fact which the physically disabled person has to face is that in some respects he [or she] is an inferior person. The reality of the racial and religious group member on the other hand, involves only social rejection" (p. 32). Meyerson (1948) concludes that the reported undesirable behaviour of physically handicapped persons is not a result of disabled individuals being different than others, but is rather, a result of them having been subjected to different kinds of life experiences. Moreover, Dembo, Leviton, and Wright (1956) declare that most limitations experienced by persons with a physical disability were of a social nature and not a product of the person's functional deficit. These findings in relation to persons with physical disabilities may warrant consideration with respect to persons with developmental disabilities (Bradley, Ashbaugh & Blaney, 1994).

Individuals who have disabilities, as noted previously, are often treated as one group irrespective of the type of disability. Therefore, when considering the social conditions of a particular category of disability linkages can often be found to all persons who have a disability. As the 20th century progressed, researchers demonstrated commonality between persons with disabilities and disenfranchised minority groups. They put forward the idea that the lowered social status of persons with disabilities may be crucial in understanding their behavior (Mackelprang & Salsgiver, 1999; Meyerson, 1988).

Care for persons with developmental disabilities within institutional settings and through community support services were based on a perception of disability as a medical condition. This view led to the medicalization of developmental disabilities. Services provided to individuals with developmental disabilities evolved based on what is typically referred to as the medical model. As such, the care and treatment of such persons fell within the realm of medical professionals and were predicated on fundamental assumptions underpinning medicine (Barnes & Mercer, 2003; Hanes, 2006; Oliver, 1990).

The general principle within Western medicine was to cure ailments. Developmental disability could not be cured, therefore basic custodial care (under the direction and control of medical professionals) became the accepted practice. The medical approach to providing service to such individuals and their families led to care based on what has become known as the personal tragedy theory (Oliver, 1990, 1996). The personal tragedy theory posits that issues pertaining to developmental disabilities are inherent in the individual and linked to personal deficits. From this deficit perspective, developmental disability is a personal tragedy that individuals, and their families have to come to terms with. This personal deficit perspective became the avenue for medical personnel to determine appropriate care and treatment (Barnes and Mercer, 2003; Hanes, 2006; Oliver, 1990).

From the 1940s to the 1960s social care institutions increased in number. They provided the specialized care, seen as needed, for persons who had developmental disabilities. Professionals, parents, politicians, and others supported the movement toward increased institutionalization throughout much of the 20th century. However, during the second half of the 20th century, changing opinions about institutional care became the precursors to deinstitutionalization (Barnes & Mercer, 2003; Blatt, 1981; Bradley et al., 1994; Mackelprang & Salsgiver, 1999; Roeher, 1996). Initial support for deinstitutionalization came from the mental health field (Bassuk & Gerson, 1978). However, most individuals living in institutions, irrespective of diagnosis, were affected. Three factors led to the decline in institutional living for individuals with developmental disabilities. First, in the 1950s and 1960s parents and volunteer support groups lobbied for an end to the social isolation imposed through institutional care (National Institute on Mental Retardation, 1981; Roeher, 1996). Second, social and educational research demonstrated that individual progress is made possible through educational and employment support opportunities. These findings renewed the focus on rehabilitation (Bradley et al., 1994; Roeher, 1996). Third, possibilities were identified for individuals with developmental disabilities to become like others in society. This new means for integration was termed normalization.

Normalization, a concept that had its genesis in Scandinavia, is defined by Wolfensberger (1972) as "utilization of means that are as culturally normative as possible in order to establish and/or maintain personal behaviors and circumstances that are as culturally normative as possible" (p. 28). He talks about the ways to achieve physical and social integration that could result in community inclusion. Later, Wolfensberger (1984) reframed the concept of normalization to social role valorization, in recognition of a perceived need to create valued social roles for persons with developmental disabilities as opposed to making them look and act like others so they could be viewed as 'normal'.

These factors, together with exposure of the deplorable living conditions and rising costs within institutions, paved the way for a community alternative, By the 1970s a social policy of institutionalization was replaced by a policy of deinstitutionalization. The deinstitutionalization era was marked by the development of group homes, sheltered workshops, and community-based services. Special services were offered, albeit in segregated settings. Towards the end of the 20th century the goal became community inclusion (Barnes & Mercer, 2003; Bradley et al., 1994; Hanes, 2006; Roeher, 1996).

Community Living

Community living presents individuals with developmental disabilities and their caregivers with unique challenges pertaining to their care and attainment of social acceptance. According to Finkelstein (1981) the movement of people into communities has exposed persons with developmental disabilities to ridicule and social exclusion. He goes further to point out "society uncontaminated by their presence for centuries, has designed a world which does not recognize their existence" (p. 63). Jean Vanier (1998) forcefully captures the plight of persons with developmental disabilities and their families with these words, " those with intellectual disabilities are among the most oppressed and excluded people in the world. Even their own parents are frequently ashamed to have given birth to a child 'like that' " (p. 72). Community living challenges service providers to meet differing needs, as well as communities to grapple with the notion of acceptance of those who are viewed as significantly different from everyone else.

Independent Living Movement.

The Independent Living Movement (ILM), a consumer driven movement which originated in the United states in the 1970s, has been instrumental in changing the perspective that disability is a personal deficit or personal tragedy. This movement had its genesis at the University of California, the first university campus to provide accommodations for students with disabilities. This group of students, through their own consciousness raising, realized that medical and rehabilitation professionals controlled their lives. Subsequently, they started a process of advocacy to gain control over issues and situations that affected their lives (Hanes, 2006).

Through the efforts of the ILM and other consumer groups there has been a concentrated effort to have persons with disabilities recognized as members of a minority group. As such, their issues are seen as social issues and not individual personal deficit issues. Individuals with disabilities are viewed as an oppressed minority group who face the same challenges as other minority groups (Dominelli, 2002; hooks, 1984; Oliver, 1991; Pharr, 1988). The ILM movement works to eradicate social issues of oppression and exclusion for persons with disabilities.

The ILM was introduced in Canada in 1979. This movement, in keeping with a social minority perspective, views disability as a social construct defined by society. It is seen as a social and economic issue. The social construction of disability defines the parameters, perspective, and treatment paradigms of those so labelled (Oliver, 1990). The ILM and others, who promote a socio-political view of disability, see individuals with disabilities as persons living in a society where the services and supports they need to enjoy their rights as full participating citizens are not available to them (Barnes & Mercer, 2003; Hanes, 2006; Mackelprang & Salsgiver, 1999).

Individuals with disabilities are an oppressed population because of the scarcity of support services needed by individuals in this group. This oppression leads to a marginal existence within our society. The ILM has three main ways to combat oppression and marginalization: a) an empowering approach for individuals; b) organizational values that include consumer control, cross disability, and full inclusion and; c) professional service delivery created for and by consumers (Hanes, 2006; Mackelprang & Salsgiver, 1999). In keeping with the goals of the ILM, persons with developmental disabilities, their caregivers, and their advocates seek continued and varied supports that move beyond a physical presence in the community to include a commitment to community participation through functional, individually tailored supports. The aim is toward full inclusion and equal participation as a right of citizenship (Bradley et al., 1994; Hanes, 2006; Mackelprang & Salsgiver, 1999; Roeher, 1996).

The Social Minority View.

In 1982, the Canadian Charter of Rights and Freedoms enshrined the rights of persons with disabilities. Canadian human rights legislation protects the rights of persons with disabilities at federal and provincial levels, thereby securing the right to inclusive community living. Unfortunately, while citizens' rights and legislation support community inclusion, the current reality suggests a long journey before this goal is reached (Hanes, 2006; Roeher, 1996). As an acknowledged minority group, persons with developmental disabilities have a great ability to create a future of full community membership (Chappell, 2006; Condeluci, 1995, 1996; Mackelprang & Salsgiver, 1999; Oliver & Barnes, 1998).

Adopting a social minority perspective is a challenge. Social responses have a long history of deeply imbedded prejudice. In addition, these prejudices are ingrained in the culture, and therefore are often not recognized as such. According to Mackelprang & Salsgiver (1999) one example of a deeply embedded prejudice is the belief that people with disabilities cannot work. This belief can be traced back to the Elizabethan Poor Laws of 1601, when persons with disabilities were viewed as unable to work and, therefore, classified as 'deserving poor' were able to depend on the state for support. The long term outcome of these laws is a social service system today that actually makes it difficult for people who have disabilities to work. Individuals, with disabilities in Canada, are able to obtain the supports and services necessary to sustain life, at least at a subsistence level, if they are not working. However, if they are working, low wages and the reduction in government support services that accompany employment make it impossible to obtain the necessities of life. Such poor working conditions force individuals with disabilities to remain powerless and dependent (Condeluci, 1995, 1996; Mackelprang & Salsgiver, 1999).

Today, many persons with developmental disabilities continue to live unemployed and in relative isolation. They spend much of their time with parent caregivers and other family members, paid caregivers, and other people who have developmental disabilities. The social minority view, that sees such persons as members of a minority group in our society, can be used to promote interdependent living and recognize everybody's value and ability to contribute positively to community life (Chappell, 2006; Condeluci, 1995, 1996; Hanes, 2006; Lutrell, 1997; Mackelprang & Salsgiver, 1999; McKnight, 1995; Schwartz, 1992; Vanier, 1998).

Dudley (1987) provides some insight into how persons with developmental disabilities feel about the way they are treated and what they wish for themselves. He contends there is a common belief in society that individuals with developmental disabilities do not have an awareness or understanding of their situation. On the contrary, he notes most individuals with developmental disabilities do have an awareness of their situation and can describe their disability in detail. According to Dudley, it is assumed that the labels used to describe individuals with developmental disabilities, such as the label 'mentally retarded' do not bother persons living with developmental disabilities when, in fact, most individuals living with developmental disabilities do not like to be negatively labeled and find labels offensive. Further, there is a belief among some that individuals with developmental disabilities are not really conscious of the degrading treatment they receive in society. In truth, people living with developmental disabilities do not like to be kept in institutions, told how to live their lives, stared at, ridiculed, or patronized by professionals (Dudley, 1987).

Historical Overview of Social Response to Developmental Disability and Services to Families in Newfoundland and Labrador

Throughout Newfoundland and Labrador's history, most individuals with developmental disabilities lived at home, although there were those who did not have a home or who could not be supported at home. In the early 1800s the civilian hospital in St. John's provided housing for so-called 'defectives' and 'idiots' (O'Brien, 1989). Throughout the 1900s those who were not living at home were confined to the institution designated for individuals with mental illness. However, subsequent to confederation in 1949, the citizens of this province availed of new social programs as well as enhanced medical and educational services. The advent of the welfare state in Newfoundland and Labrador led to improved conditions for everyone (Philpott, 2002).

By 1966, there was a feeling that institutions could help families and their family members with developmental disabilities. As a result, an institution for children, Children's Home, was designated to provide custodial care for 55 children who had physical and developmental disabilities. Another 'special home' to care for ten children was opened in 1967. By 1968, there were 77 children in Children's Home, 14 in the other 'special home', and 110 on an urgent waiting list. This situation led to the opening of a second institution, Exon House, in 1969 (Department of Social Services and Rehabilitation, Government of Newfoundland and Labrador, 1970).

In the "Study of Mentally Handicapped Children in Newfoundland and Labrador" (1970) government officials contend that institutional placement is a last resort. The report maintains that institutions have an obligation to promote children's growth and development. Children, who are institutionalized, are to receive parenting within the institution to the fullest extent possible, while maintaining as much contact as possible with their natural family. The report goes on to say that critical factors in assessing the need for institutional care are the socio-economic conditions in the home and the availability of community resources to help parents. Moreover, day care and homemaker services are necessary to keeping children in their homes (Department of Social Services and Rehabilitation, Government of Newfoundland and Labrador, 1970).

By the late 1970s, problems within Exon House had reached a level that resulted in public outcry. In response, the Newfoundland and Labrador Government commissioned the first of two studies that saw the closure of the children's institutions and the eventual movement of many adults with developmental disabilities from the Waterford Hospital, the provincial psychiatric hospital, to community residences (Canadian Association for the Mentally Retarded, 1977, 1981). In 1977, *A report of an assessment of Exon House and related programs* reinforces the preservation of the family home as the best option for children with developmental disabilities. It concludes that children were removed from their home due to families not being able to cope, because of a lack of in-home developmental services, in-home homemaker services, counseling, and day programs, which would have provided appropriate support. The report further states that services "for parents of mentally retarded children and grown mentally retarded persons are relatively sparse" (Canadian Association for the Mentally Retarded, 1977, p. 48).

A second report in 1981, *People and communities* supports these findings and states "the lack of community supports to help families led to institutional placement. There was nothing inherent in the handicapping conditions of people that required them to be institutionalized" (pp. 1-2). This report recommends the closure of the institutions and the development of more services in the community to help families in caring for their children at home. The report suggests community involvement and further specifies that "until the development of services becomes problems for the community to solve, the possibility of community living will be frustrated" (Canadian Association for the Mentally Retarded, 1981, v. II, p. II, 11).

The recommendations of these reports led to the two institutions being actively phased out and concurrent development of supports to families. By 1990, the two institutions had closed, and services to help with parental caregiving included respite services, direct home services, behaviour management services, social work services, special child welfare allowances, and special funding for adults (Efford, 1990). A Department of Social Services Minister's report in 1990 outlines the deinstitutionalization program accomplishments and the government's commitment to continued and enhanced community living for individuals who have developmental disabilities and their families. This report states that the government would work towards further program development that would see families and individuals adequately supported to be able to live within the community.

With respect to social work services, Efford (1990) notes, "a significant development has been the ability to provide adequate case management/service planning to families through our District Social Work staff" (p. 3). A plan was developed to enhance services throughout the 1990s that would see continued commitment to deinstitutionalization based on the premise that community living and concomitant support service models are far superior to institutional models (Efford, 1990).

In 1998, the Department of Social Services was reconfigured to become the Department of Human Resources and Employment, (later renamed the Department of Human Resources, Labour and Employment). Concurrently, the former Department of Health became the Department of Health and Community Services, and social services for persons with developmental disabilities and their families were transferred to this new department. This change resulted in the responsibility for social work services for persons with developmental disabilities being devolved to community-based organizations. Until 1998, social workers and managers working in the field of developmental disabilities received on-going competency-based orientation and training. This practice was not continued after 1998, therefore social workers and their managers became less able to effectively work with families who had children with developmental disabilities. In addition, there was a separation of financial services and casework social services in 1998. Social workers no longer assumed responsibility for financial assessments, which resulted in less time being spent with families, thereby diminishing the ability to develop a close working relationship. Social worker caseloads increased, and, as a result, many social work services were delivered over the telephone (U. Tucker, personal communication, Disabilities Consultant, Department of Health and Community Services, Government of Newfoundland and Labrador, June 14, 2007).

Services were affected by budget restraints enacted in the 1990s and continuing into the 21st century. Strict eligibility criteria became applied to home support services that provided respite to families. Moreover, services initially designed to provide support to individuals with a developmental disability and their families evolved to include other vulnerable populations without sufficient budgetary increases to accommodate the expansion. This evolution led to longer waitlists for service, and less service overall (U.Tucker, Disabilities Consultant, Department of Health and Community Services, Government of Newfoundland and Labrador, personal communication, 2007).

Over the last decade, there have been some gains in services to families. Changes made to special child welfare allowance eligibility criteria have helped families qualify for more financial support. There have been significantly enhanced services offered in the area of autism for young children. Also, in 2007, a monthly board and lodging supplement to a maximum of $362.00 became available for adults with developmental disabilities who are living with relatives. This funding is in addition to the $269 monthly board and lodging funds previously available and, as such, is seen as a significant improvement in support services (U.Tucker, Disabilities Consultant, Department of Health and Community Services, Government of Newfoundland and Labrador, personal communication, June 14, 2007).

In addition to family social services progress in the second half of the 20th century, there were advances as well in the areas of pre-school, school services for children, and employment services for adults. In 1954, the first class for children with developmental disabilities was founded by Vera Perlin, a St. John's philanthropist. In 1957, the Newfoundland Association for Mental Retardation, a grassroots advocacy organization (later re-named the Newfoundland and Labrador Association for Community Living), was formed. By the late 1960s, under pressure from parents, schools were legislatively given the option to introduce education for children with 'special needs'. In 1979, this legislation was changed to mandate schools to provide education to children with developmental disabilities (Philpott, 2002).

In the 1990s, restructuring with the Newfoundland and Labrador Government involved the Departments of Education, Social Services, Health, and Justice. At that time, an interdepartmental review concerning services to children with challenging needs sought to bring coordination and collaboration to services provided to children and youth through these departments. The result was the Model for the Coordination of Services to Children and Youth with Special Needs in Newfoundland and Labrador (Government of Newfoundland and Labrador, 1996). The process that emerged from this model was the Individual Support Services Plan (ISSP), which can be initiated for any child with special needs, and can involve any or all of these government departments. The ISSP process has been promoted extensively as an effective collaborative method for working with children who have special needs. The parent and the child are central to the process with parents having the final say on the plan for their child. This process continues to be in use today (Government of Newfoundland and Labrador, 1996).

Advances were made for adults with developmental disabilities in vocational and employment services. The Vera Perlin Society started Vera Industries, a vocational day program, in 1966. In addition, they established a Work Oriented Rehabilitation Centre in 1979. In the 1980s, a Supported Employment Program was initiated in St. John's. Three Supported Employment Programs are available in the city and surrounding areas (M. Wall, Employment Manager, Vera Perlin Society, personal communication, June 13, 2007).

In summary, today in Newfoundland and Labrador most individuals with developmental disabilities are living in their own home or a community home with some support services to assist individuals and families. Individuals applying for services are required to take a means test to ensure that undue hardship is avoided by service provision. Long waiting lists for services is problematic for families and individuals, and social workers struggle to meet individual and family needs because of high caseload numbers and diminishing funds to provide needed services. All children with developmental disabilities have the right to attend school, however opportunities for vocational and employment services are meagre. The Newfoundland and Labrador Association for Community Living, in their mission statement, continues to advocate for individuals and families with a goal of supporting all persons with developmental disabilities to live and work in the community achieving their full potential as valued Canadian citizens (http://www.nlacl.ca/community_living.html).

Feminist Social Work Theory

Feminist social work theory has its roots in the philosophical and theoretical underpinnings of feminism. This section defines feminism, outlines salient features and various orientations of feminism, and delineates the key concepts and features of feminist social work practice. Finally, feminist social work theory is discussed in relation to care and caregiving.

Feminism

According to Collins (1986) "[f]eminism at its most elemental level, is a recognition and critique of patriarchy and sexual politics (and their relation to other class oppressions – capitalism, imperialism, racism, heterosexualism); *and* a set of beliefs, values and ideas about the desired direction for change" (p. 214). hooks (2000) purports that the feminist movement grew out of an uprising that began in the late 1960s when women began rebelling against sexism. Initially feminism and women's rebellious activities were unrelated. However, when women came together in dialogue, this collective initiative became known as women's liberation and, later, the feminist movement. The feminist movement has been described as one of the most powerful arenas for social justice in the world (hooks, 2000).

Saulnier (1996) describes some diverse feminist approaches, including liberal feminism, radical feminism, socialist feminism, lesbian feminist theory, cultural and ecofeminist theories, womanism, African-American Women's Feminist thought, and global feminism. Although there are numerous variations of feminism, it seems the most prominent views are embedded in liberal feminism, radical feminism, and socialist feminism (Dominelli, 2002; Nes & Iadicola, 1989; Sands & Nuccio, 1992; Saulnier, 1996; Van Den Bergh, 1995).

Liberal feminists see men and women as having the same basic nature, with women's development hindered by social conditions. Liberal feminists believe women can achieve equality within a patriarchal, capitalistic society if male attitudes and actions change to ensure equality (Nes & Iadicola, 1989; Saulnier, 1996). Radical feminists, on the other hand, believe women's fundamental nature differs from men. Further, that patriarchy is the basis of their oppression. They believe society needs a radical transformation involving the elimination of male supremacy and all hierarchies (Nes & Iadicola, 1989; Saulnier, 1996). Socialist feminists, the third predominant feminist group, believe class oppression causes inequality. They believe capitalism to be the primary source of this inequality. Resolution is seen in the overthrow of patriarchy, class, and all other forms of oppression (Nes & Iadicola, 1989; Saulnier, 1996).

Regardless of their differing perspectives, feminists share several common principles. These include integrating the personal and political aspects of life, respecting women's diversity, promoting more egalitarian social relationships, and transforming the existing social order because of its harm to women, men, and children. While sharing common principles, diversity among feminists brings several challenges. These include varying backgrounds associated with social and class differences, the intimate relationships shared between men and women, and the public and private divisions in women and men's lives (Dominelli, 2002).

Key Feminist Concepts

Feminism is complex and diverse. Key concepts include patriarchy and power. Most feminist theories see patriarchy as being at the center of female social oppression. According to Ruth, (1990 quoted in Shriver 1998) " a patriarchy is a society in which formal power over public decision and policy making is held by adult men" (p. 62). Nes and Iadicola (1989) define patriarchy as " the institutionalized system of male dominance over and control over women" (p. 14). These views of patriarchy acknowledge the power and control imbalance between men and women with men exerting power and control in public and private domains. Thus, patriarchy may be seen as male dominance that includes control over production in the public sphere and reproduction in the private sphere. Values, beliefs, socialization, education, and culture in a patriarchal society are all seen as determined through the vision of men (Dominelli, 1996, 2002; hooks, 2000; Mullaly, 2007; Nes & Iadicola, 1989; Shriver, 1998; Van Den Bergh, 1995).

Gil (1998) defines oppression as "a mode of human relations involving domination and exploitation – economic, social and psychologic – between individuals; between social groups and classes within and beyond societies; and, globally, between entire societies" (p. 10). Feminism addresses all forms of oppression. Power, which is integral to patriarchy, is seen by feminists as being at the core of oppression. Those struggling to reclaim or gain freedom from domination or oppression become marginalized and controlled (Dominelli & Collins, 1997). The notion of power is complex. For example, male caregivers have power by virtue of their male status. However, their power is diminished compared to other men due to their caregiving work which is generally unpaid, seen as women's work, and having less status than traditional paid male occupations (Dominelli, 2002; Dominelli & Collins, 1997). Patriarchy and power within the framework of feminism is central to feminist social work theory.

Feminist Social Work Theory

Feminist social workers were the first social workers to locate women's problems within the social context of status, positions, and female roles. Feminist social work theory brings women's issues to the forefront of social work practice. Traditionally, social work theory and practice have been shaped and guided by a dominant, patriarchal view. Feminist social work theory considers gender a significant issue with important implications for social work practice. The theory is based on feminist elements that resonate with the goals and objectives of social work practice (Baines et al., 1991, 1998; Carniol, 2005; Collins, 2000; Dominelli, 2002; Mullaly, 2007; Van Den Bergh, 1995).

Feminist social work theory addresses the influence of patriarchy, gender relations, and the social construction of gender, illuminating male hegemony and women's subordinate roles. The dearth of social services available to help vulnerable people provides evidence of connections between private circumstances and public social policy. By exploring these connections, the notions that the 'person is political' and the 'private is public' emerge as critical components of feminist social work theory and practice. In this context, female oppression is seen as a result of social policies developed by men. (Baines et al., 1991, 1998; Collins, 2000; Dominelli, 1996, 2002; hooks, 2000; Land, 1995; Nes & Iadicola, 1989; Saulnier, 1996).

In traditional modes of social work intervention problems are located within the person and the social worker is considered to be the expert. S/he defines the problem and determines appropriate intervention strategies. Within this context, difference is constructed as a deficit. Intervention strategies based on this assumption are designed to correct or compensate for individual deficits. Feminist social work intervention strategies, on the other hand, are designed to embrace difference. Diversity is considered a strength, and the service consumer is at the center of intervention development and implementation. Practice within this framework is focused on problem identification, solution creation, and the implementation of strategies from the consumers' perspective. People are acknowledged as the experts in their own lives (Baines et al., 1991, 1998; Dominelli, 1996, 2002; Nes & Iadicola, 1989; Pardeck, Murphy & Choi, 1994; Saulnier, 1996; Scott, 1990).

A holistic approach is fundamental to feminist social work. Individuals interact with social workers within the context of their total life circumstances. All aspects of the individual's life including how one aspect influences another aspect are considered important to understanding the individual's situation. In addition, there is recognition that individual situations change depending on when and where they happen. A holistic approach recognizes the interconnectedness of life and the interdependence of all persons within society. Individuals are viewed as interdependent rather than independent or dependent on others. Such a perspective promotes the notion that all individuals are valued and appreciated (Collins, 2000; Dominelli, 1996, 2002; Ife, 1999; Land, 1995; Nes & Iadicola, 1989; Saulnier, 1996).

A central process to feminist social work is consciousness-raising. Women come to realize their value by defining their multiple strengths. This process enables women to understand and acknowledge their own agency. Dominelli and Collins (1997), define women's agency as "the capacity to influence or shape life events at the personal level"

(p. 405). Consciousness-raising involves the use of discourse and deconstruction. These post-modern concepts prove to be useful in illuminating hidden bias and prejudice in social relations and communication. Women, through dialogue, deconstruct historical assumptions of a patriarchal society. This deconstruction leads to an understanding of dominant discourses which can enable those who experience oppression to shift from positions of weakness to positions of strength. They come to understand their own agency, realize their capacity to resist oppression, and explore their strengths. They learn how their strength can be used to create opportunities for individual and collective action against oppressive practices. Such awareness leads to empowerment, confidence, and conviction in an ability to bring about change (Collins, 2000; Dominelli 1996, 2002; Dominelli & Collins, 1997; Land, 1995; Nes & Iadicola, 1989; Rondeau, 2000; Rose, 2000; Saulnier, 1996).

Confidence and belief in one's personal ability to bring about change fosters a sense of self-determination and empowerment. Feminist social work practice helps people exercise freedom, and make decisions and take charge of their own life. An example in caregiving is service provision being viewed as an entitlement causing caregivers to be stronger in making their own decisions. Caregivers come to believe they have a right to support services and are willing to take action to change their life situations. Change can be achieved through social transformation (i.e., change with the intent to alleviate oppression, both individually and collectively). Individuals can be supported in making individual life-altering decisions, while coalitions and social movements can promote social and political change (Collins, 1986; Dominelli, 1996, 2002; Land, 1995; Nes & Iadicola, 1989; Saulnier, 1996).

Feminist social work is part of anti-oppressive social work practice. Dominelli (1994, quoted in Dominelli, 1996) defines anti-oppressive practice (AOP) as follows:

> a form of social work practice which addresses social divisions and structural inequalities in the work that is done with people whether they be users ('clients') or workers. AOP aims to provide more appropriate and sensitive services by responding to people's needs regardless of their social status. AOP embodies a person centred philosophy; an egalitarian value system concerned with reducing the deleterious effects of structural inequalities upon people's lives; a methodology focusing on both process and outcome; and a way of structuring relationships between individuals that aims to empower users by reducing the negative effects of social hierarchies on their interaction and the work they do together (pp. 170-171).

Dominelli's (1994) description of anti-oppressive practice captures the various components of anti-oppressive practice that are also fundamental to feminist social work practice. It brings together the need to address oppression, acknowledging the person as the expert, the importance of relationship in feminist social work practice, and the goals of empowerment.

Feminist social workers, through self-evaluation, reflexivity, being cognizant of their privileged position, and acknowledging the dominant discourses that affect their thoughts and actions, endeavor to create egalitarian relationships with those seeking their service. Through advocacy, they aim to create more responsive social policies, thereby enabling social workers to provide more effective services. Feminist social workers engage with others to deconstruct the notion of community, identify and add to the historical, social, and political factors that maintain and promote oppression. Social workers who practice from a feminist social work perspective can provide meaningful service to caregivers. They recognize the need to reform conditions under which women provide such work (Baines et al., 1991, 1998; Dominelli, 1996, 2002; Parks, 2003).

Feminist social work theory resonates with elements of structural social work, critical social work, social work constructivist theory, social work empowerment theory, as well as other theories where client issues are structural issues, issues of client oppression, and issues that need to be dealt with from the client's perspective. Feminist social work is a process whereby the social worker helps the client to find their own truth and become empowered to take care of themselves, so they can work towards individual and collective responses to oppressive conditions. In feminist social work theory, the theory of constructivism - the notion that reality is dynamic and subjectively created as opposed to being an objective, constant concept - is important (Fisher, 1991; Rodwell, 1998). Cooper (2001) calls for social work practice from a constructivist approach to "focus upon the co-construction of viable working relationships with service users as the basis for an anti-oppressive and participative professionalism" (p. 721).

The social worker, who uses a constructivist approach, works with the client to understand the construct of her/his world. Social work practice in this vein entails a collaborative relationship between the client and the social worker as the social worker seeks to know the client's experience. The social worker also engages in reflective thought so as to somewhat suspend her/his own social constructs in order to enter the world of the client (Gallant, 1990). Thus, as with feminist social work, the social worker engages with the client to understand the client's life circumstances from the client's perspective (Bricker-Jenkins, 1990; Cooper, 2001; Gallant, 1990; Payne, 1997; Rodwell, 1998). While constructivism and other noted theories, are valid for work with maternal caregivers of individuals with developmental disabilities, this study finds feminist social work as the more inclusive theoretical framework.

Feminist Social Work Theory and Care/Caregiving

Caregiving is a feminist issue because women, either through familial obligations, or for minimum wage, predominantly provide care, and often under impoverished conditions. Feminist social workers strive to acknowledge the value of caregiving without reinforcing the notion of caregiving as women's natural work, or as work devalued. Caregiving reframed through feminist social work practice can become a source of women's strength.

Feminist social workers emphasize the importance of taking caregivers' interests and concerns seriously. For them, this is a human rights issue. Caring work is work of value. Caregiving has been re-conceptualized as a right to provide care and a right to receive care. Social workers use feminist social work knowledge, values, and skills to create egalitarian relationships, recognize the caregiver as the expert in their own lives, and to work with caregivers to raise their consciousness, promote empowerment, and explore the ways and means of alleviating the stress that often accompanies caregiving work (Baines et al., 1991, 1998; Dominelli, 1996, 2002; Parks, 2003).

Hillyer (1993), in a review of feminism and disability, presents a number of feminist issues pertaining to mothers of children with developmental disabilities. First, there is concern that the reality for mothers of children with developmental disabilities may not be recognized, thereby leaving these caregivers without the necessary emotional and other support. These mothers experience strong cultural pressure to 'normalize' their child's and family's life. As they succeed in doing this, they make the burden of caregiving invisible and reinforce the mother's social caregiving role. Further, comments about a mother's superior coping skills or unrealistic praise about how great her child is progressing from another, may allow that other person to feel comfortable, but it denies the reality as perceived by the caregiver who may not be coping well at all. Second, the high social value placed on giving to others makes it difficult for people to receive help, or to ask for help to meet their needs. The third issue Hillyer points out is that reciprocity is fundamental to the relationship. Parental caregivers of children who have significant developmental disabilities may be hampered in their ability to develop a reciprocal relationship with their child because of the child's limited ability to communicate effectively. Both individuals are thus denied the opportunity to reciprocally delve into the full depth of their emotions in their relationship.

Hillyer (1993) purports that mothers of disabled children have great potential to illuminate caregiving experiences. However, she contends this contribution is often not recognized, and may be discounted by professionals and disability advocacy groups. Professionals sometimes express the belief that mothers can do more to promote their child's development, while disability advocacy groups accuse mothers of being overprotective. It is noteworthy that mothers and professionals are often at odds. As well, there are often tensions between disability advocates and professionals. Sometimes mothers find themselves in a no-win situation for they may be criticized by professionals, on the one hand, for not contributing to their child's development and, on the other hand, they may raise professional concerns about parents being in denial about their child's condition if they work diligently to have their child 'fit in' or try to 'normalize' their child (Hillyer, 1993).

At times these mothers are especially challenged. Their caregiving includes heavy physical, economical, and emotional burdens accompanied by strong social pressure not to acknowledge these strains. Hillyer (1993) captures this situation well when she states, "[t]he requirement of heroism coupled with an equally strong requirement to treat the experience as 'normal' and to incorporate the roles of trainer and therapist into that of nurturer are compounded by the probability of 'perpetual parenthood' " (p. 98).

Hillyer (1993) goes on to discuss the importance of a feminist analysis in relation to these mothers' experiences. Her comments point to the importance of recognizing the uniqueness of individual situations. Indeed, it is important to recognize the differences between disabilities and how that affects the approach to advocating for social policy change. The issue of listening to mothers and emphasis on believing their stories is fundamental to knowing what social work service will be meaningful to them.

Individuals with severe disabilities may not be able to communicate or determine what they need to live a quality life. Their mothers are often the people who know them and their aspirations better than anyone else. Mothers' descriptions of their own experiences provide access to the individual lives of their children, especially for those most severely disabled. Also, they give insight into their own life, which otherwise goes unnoticed. Mothers have a close personal involvement with their child, and although they are not the person with the disability, they know the complexity and the psychological and emotional relationships that are involved. The whole notion of blaming mothers for their situations suggests to feminists that mothers' own realities are being distorted or ignored. The study of disabilities from a feminist perspective is incomplete without hearing the stories of nondisabled people who also live with the disability (Hillyer, 1993). Lorde (1984) contends that there is much to learn about women's different experiences through dialogue with mothers of persons with disabilities if one seeks to move beyond society's traditional role assignments for these women.

Addressing the issue of mothers' caregiving of persons with disabilities from a feminist perspective requires recognition of issues that come into play because of the interface between the entities of disability and caregiving within the feminist's arena. The literature cites difference of opinions between feminism's treatise of disability and caregiving. This dichotomy is set up as it relates to the different issues that are faced by women and the person who has a disability for whom they provide care. The waters get even murkier as women with disabilities who care for children with disabilities are addressed from a feminist perspective (Hughes, McKie, Hopkins, & Watson, 2005; Lloyd, 2001; Wamsley, 1993; Watson, McKie, Hughes, Hopkins, & Gregory, 2004).

Generally, feminist literature focuses on the caregivers while disabilities literature is primarily concerned with the person who has a disability (Hughes et al., 2005). There is common ground, however, between both groups since they have been subjected to marginalization and oppression because of their respective place in the social order. According to a study by Wickham-Searle (1992), mothers and their children with developmental disabilities are devalued. They experience devaluation because of their caregiving role and share the stigma of devaluation with their children. Further, the literature in both areas addresses these realities, albeit from different perspectives. Those who promote disability rights discredit the notion of caregiving because they contend that the caregiving terminology reinforces the dependent, personal tragedy, perspective of disability (Oliver, 1990, Hanes, 2006, Barnes & Mercer, 2003). Whereas, feminist literature asserts that care and caregiving is the core of women's social role. Hence, it needs to be addressed for its contribution to women's place in society and the oppressive roles they are often forced into (Baines et al., 1991, 1998; Traustadottir, 2000).

The feminist approach highlights the importance of reciprocity in a caregiving relationship, whereas, the disability movement stresses the importance of viewing persons with disabilities as independent actors who contract the service they need. There is a debate between feminists and disability activists with respect rights and needs of caregivers versus persons with disabilities. Subsequently, a call has been made for the recognition of interdependency as a platform from which to initiate the bringing together of these differing standpoints. The recognition that people are interdependent, requiring care of varying sorts and to varying degrees throughout their lifetime, provides a point of common interest from which to begin to address oppressive conditions experienced by those who provide care and those who receive care (Hughes et al., 2005; Lloyd, 2001; Wamsley, 1993; Watson et al., 2004;).

Up to this point, this literature review has addressed care and caregiving, developmental disabilities, and feminist social work theory and practice including its relationship to care and caregiving. In exploring this study's question, it is also important to review the literature pertaining to social work practice in general and social work education. Social work knowledge, values, and skills form the basis of social work practice. In the next section, social work practice and the historical antecedents which have shaped the way for social work intervention are explored. In this context, social work's unique perspective on care and caregiving is examined, together with the preparation of social workers for practice through an overview of social work education.

Social Work Practice

Historically, social work in North America was patterned after social work in Great Britain. There are points of overlap with the development of social work in Canada and the United States as well as points of distinction. However, it is fair to say that social work in Canada has traditionally followed the developments of its neighbour to the south. Two historical tracks (i.e., therapeutic social work and social action oriented social work) and the quest for professionalism are highlighted here. Also, care and caregiving are discussed within the context of social work practice.

Historical Roots

Conceptually, social work practice in its broadest sense is individuals helping others in times of need. A belief in the value of caring for others is found in the early history of the human race. Aristotle (384-322 BC cited in Trattner, 1999, p. 1) spoke about the social component of life and the need for cooperative living. Throughout history there is evidence of people helping others when the need arose. The method and extent of help that was provided, varied through time. Initially, people depended on each other for survival in what is described as hunting and agrarian societies (Trattner, 1999).

According to Trattner (1999), the onset of industrialization was a catalyst for a new way of living. Industrialization led to urbanization and a cash exchange economy with individuals becoming increasingly able to care for themselves and thus attain some measure of independence. Those who were not able to care for themselves became socially isolated. Often they were not able to turn to their neighbour for help. As society became more urbanized and complex, the social responsibility to help those in need became more of an organized church and state responsibility. The English Poor Law of 1601 was landmark legislation. It marked the need for public intervention to address the issue of poverty (Trattner, 1999). Because of this legislation the 'deserving poor', including persons with developmental disabilities, were grudgingly given public aid from the 1600s through to the 1800s. In the 1800s welfare organizations became more formal with the appearance of almshouses, asylums, Charity Organization Societies and Settlement Houses (Colby & Dziegielewski, 2001; Rothman, 1971).

Modern Social Work Practice

Social work practice in North America emerged in the second half of the 1800s. Intervention followed the models of Charity Organization Societies and the Settlement House Movement. While social workers worked with both of these organizations, practice within each was quite different (Colby & Dziegielewski, 2001; Trattner, 1999). The Charity Organization Societies were important in furthering the notion of poverty and destitution as an individual concern. The Charity Organization Society's philosophy was predicated on a belief that those who were poor made a choice not to work (Colby & Dziegielewski, 2001; Trattner, 1999). The societies were initially run by volunteers, but as time progressed the Charity Organization Societies replaced volunteer friendly visitors with full-time workers who were taught the skills to do what is termed as 'scientific inquiry'. Leaders within the societies believed it was important for their workers to be knowledgeable about investigation, diagnosis, preparation of case records, and treatment. Through their work which was based on scientific inquiry, Charity Organization Society workers contributed to social work research and the development of casework (Colby & Dziegielewski, 2001; Trattner, 1999).

Trattner (1999) notes, that the Settlement House Movement was important in furthering the notion of poverty and destitution as an economic and a social issue. This movement saw poverty as a public concern rooted in social justice. People in need were viewed as victims of circumstances beyond their control. The philosophy of the Settlement House Movement was to help the poor through social and economic change. Settlement House workers worked closely with community groups and neighbourhood organizations. They moved into neighbourhood settlement houses and lived among the poor. They stressed interdependence, people helping each other, and worked with people to establish social services. Their interest was in social action and they were instrumental in bringing about social reform (Colby & Dziegielewski 2001; Trattner, 1999).

Interest in seeking professional status emerged early in social work history and has had a profound effect on both social work practice and education. In 1915, the National Conference of Charities and Corrections, the annual social work education forum, became a landmark event in the quest for professionalization in social work. At this conference, Abraham Flexner (1915), guest speaker and noted expert in the area of professional education, proclaimed that social work did not qualify for professional status. Being a powerful figure in professional education, his opening disclaimer that he knew little about social work was overlooked. The proclamation that social work did not qualify for professional status caused much concern for those involved in social work practice and education. Many believe Flexner's proclamation became the driving force in the development of social work in North America since 1915 (Austin, 1983; Germain & Gitterman, 1996; Haynes, 1998; Leighninger, 1987).

After the Flexner address, social workers endeavored to gain professional status. Casework became the primary method of social work and the stamp of professionalism. In the 1920s the Settlement House Movement declined as social work changed from a social focus to an emphasis on individual rehabilitation. Within a relatively few years after Flexner's paper, social work had practically excluded all skills related to social action and social policy from social work practice and social work education (Popple &

Leighninger, 1998).

According to Trattner (1999), in the 1920s the casework model in the United States became the defining feature of social work practice. However, the Great Depression of the 1930s resulted in new jobs for social workers in the area of social action. Once again, social workers, concerned with social conditions, called for social reform. From the late 1940s to the 1960s attention in social work practice returned to a preoccupation with social casework and maintaining a course to solidify social work as a profession. In the middle of the 1960s, poor economic and social conditions in the United States prompted widespread civil unrest leading to a re-emerging interest in social reform in the 1970s. Since the 1980s, there has been continued decline in service to those in need. As a result, interest in social reform and social action re-emerged (Colby & Dziegielewski, 2001; Trattner, 1999). However, social work practice continues to be primarily concerned with the individual therapeutic approach (Colby & Dziegielewski, 2001; Specht & Courtney, 1994).

The Canadian Perspective.

In Canada, the evolution of social work services began later than in the United States. Industrialization and urbanization evolved later in Canada, and thus a delay in the need for organized social services. Also, the role of Settlement Houses in Canada was different. These Settlement Houses were more involved in social service provision than social action activities (Heinonen & Spearman, 2006). From the 1930s to the 1960s social work in Canada closely followed social work practice of the United States in that individual casework was predominant for much of that time. Strong economic growth in

Canada during the 1950s and 1960s meant the growth of social programs as well. In the 1970s economic growth declined. By the mid 1970s, the government's expansion of social programs stopped. Towards the end of that decade a significant restructuring of the social welfare program and cutbacks in social spending had begun (Chappell, 2006). Re-structuring and cutbacks continued from the late 1970s into the 21st century. In the 1990s there was a full-fledged overhaul of the Canadian welfare system resulting in further social program cuts. Devolution of responsibility for social welfare services to the provincial and local level, privatization of public services, and the contracting out of government services started in the 1990s (Neysmith, 2000). While these events created a renewed interest in social action in Canada, the emphasis continues to be on individual therapeutic intervention. The trend toward privatization continues and social work increasingly emphasizes individual therapy (Chappell, 2006).

Social Work in Newfoundland and Labrador.

Being under British rule until confederation with Canada in 1949, social work in Newfoundland and Labrador was influenced by events in England and Canada. For instance, in keeping with the British Charity House Society tradition, Jubilee Guilds were established in Newfoundland in 1935 (Cullum, 1997). Initially, run by upper class women living in St. John's, the primary goal of the Jubilee Guilds was to help outport women to become better mothers, caregivers, and homemakers. During difficult times they provided government aid to the poor. The women in outport communities, through initiatives of the Jubilee Guilds, benefited from material goods, crafts, and educational materials and programs. Further, they had the opportunity for socialization that they would not have had it were not for the Jubilee Guilds. The guilds subsequent to confederation they became affiliated with the Associated Country Women of the World, and the Federated Women's Institute of Canada. In 1968 they changed their name to the Women's Institute of Newfoundland and Labrador and continue to further women's interests today (Cullum, 1997).

Social work in Newfoundland and Labrador in the tradition of the Settlement House Movement was evident through the work of some churches and charitable organizations. For example, Stella Burry, who studied at the Methodist Training School in Toronto to become a deaconess, began to do social work in Newfoundland in 1938. Her work was strongly influenced by the Settlement Houses in New York where she visited while furthering her studies in Christian education and counselling. She focused on the use of group work to address individual's needs, develop a residence to support those with special needs, and other areas of community development. She worked to promote women's issues and has been described as an early feminist (Burford, 1997).

In 1965, another social worker, Vira Walsh became the Director of Social Work for the Children's Rehabilitation Centre, a medical centre for the treatment of physically disabled children. A government sponsored social work program at the Children's Rehabilitation Centre was concerned primarily with individual casework which is based on a medical model. Yet, the philosophy of the centre's social work department was (and continues to be) based on social work services within the context of family and community, thereby recognizing the importance of community work. The centre has had an outreach program since the early days of its operation, and Ms. Walsh ensured that social workers were always part of the travelling rehabilitation team. The focus was to support even the most disabled child living home at with their families and in their communities by working with parent caregivers, schools, and other community professionals and officials (Dawe, 1997).

From 1933 to 1949 there was a Commission Government in Newfoundland and a Commissioner was made responsible for Health and Public Welfare. During this time, there were few resources and little administrative attention given to public welfare. In 1949, this changed when health and welfare were separated by the *Public Welfare Act, 1949*. At that time, it was declared that confederation would mean increased benefits for persons with disabilities (Godfrey, 1985). Also at that time, the creation of an administrative network of social services that would serve public welfare needs throughout the province began. As a result, in-service training for welfare officers was needed and the government partnered with the School of Social Work at the University of Toronto in an unprecedented program that would provide in-service training to those hired as welfare officers in 1951. This training was intended to improve the standard of government social services in the province. Welfare officers throughout the province became not only the representative for the Department of Public Welfare but, indeed, for the government itself. It was envisaged that welfare officers would be social servants of the people, concerned with people's needs. These welfare officers were provided with on-going training and worked in conjunction with other essential government and community services (Godfrey, 1985).

Social Work Practice and Care/Caregiving

Social work practice with parent caregivers of individuals with developmental disabilities is relatively new. Until the deinstitutionalization movement of the 1970s, social work had little involvement in this area except to assess the need for institutional placement and provide social work functions within institutions (National Institute on Mental Retardation, 1981). The deinstitutionalization movement provided an initiative for social workers to become more involved in supporting parent caregivers as well as persons with developmental disabilities living in communities.

Traditionally, social work practice focuses on the personal adjustment of the caregiver and the care recipient through counseling and the provision of supportive services and case management. The social workers, who practice this type of social work in keeping with the medical model's 'personal tragedy' view of disability, are more involved with counseling to promote acceptance of living with a disability, and assisting caregivers and care recipients to obtain resources rather than with the promotion of individual rights and social action (Oliver, 1990; 1996). This traditional social work focus has drawn attention and criticism from advocacy groups. They have been critical of social work's inattention to social action in their work with individuals who have developmental disabilities and their families (Hanes, 2002).

The support services needed to help caregivers provide quality care are often not available. While DeWeaver (1983) views social work as being best suited to help both caregivers and care recipients receive the services they need, the necessary funding and community supports are often not available. Interesting, indeed, is the most recent sector study of Canadian social work (Stephenson, Rondeau, Michaud, & Fiddler, 2000), which explores the changing landscape of social work practice and resulting impacts on the social work labour force. It does not specifically address care and caregiving or developmental disabilities. This omission fails to acknowledge social work as a valuable resource in the lives of parental caregivers.

Social Work Education

An examination of social work education and its historical antecedents provide insight into the preparation of social workers for practice. Broadly speaking, social work knowledge, values, and skills are the essential ingredients of professional education. A review of social work education provides a frame of reference to understanding knowledge, values, and that are relevant to social work in general and parental caregivers of persons with developmental disabilities in particular.

Historical Roots of Social Work Education

According to Austin (1983), Flexner's commentary about the social work profession became central to initiating changes in social work practice, and especially in social work education. A committee, struck shortly after Flexner's address, concluded that social casework represented an educationally communicable technique (Trattner, 1999). Hence, for much of the 20th century social work education in the United States supported the method of social casework. Further, the writings of Mary Richmond (1917) and Virginia Robinson (1930) and the theoretical contributions of psychiatry and psychoanalysis aided the beginning of a casework approach (Austin, 1983; Brieland, 1995; Germain, 1970; Germain & Gitterman, 1996). Although the primary educational emphasis was individual casework, there were times during the 20th century when social work education acknowledged the relevance of social justice and social action (Trattner, 1999). The 1929 Milford Conference, a Conference of the National Charities and Corrections Society, was one such occasion. At this conference, Porter Lee (1930), a noted social work educator, presented the concepts of what he called the 'cause' and 'function' dimensions of social work. The cause dimension of social work refers to the social work mandate to promote social justice through advocacy and other social action activities. Lee cautioned against social work abandoning its mission to fight for social justice (i.e., cause). The function dimension of social work, on the other hand, refers to therapeutic social work practice, individual casework. According to Lee, exclusive attention to individual casework (i.e., function) was drawing social work away from its mission to be concerned with social justice as well as individual casework.

A landmark initiative for social work education in North America was the Curriculum Study mandated by the Council on Social Work Education (Boehm, 1959). This study set the course for teaching social work knowledge, values, and skills for the second half of the 20th century (Guzetta, 1996). The Boehm study, as it was referred to, recommended a single goal for social work; that of enhancing social functioning to ensure individuals are able to fit in social groups (Brieland, 1995). Almost half a century later, Chappell (2006) acknowledges the continued centrality of individual therapeutic intervention in social work education.

Social work education was confronted with the need for social action in the 1970's because of conditions of social unrest and cuts to services for marginalized groups (Brieland, 1995). This has continued into the 21st century because of social conditions and declining social programs. Social action theories have been incorporated into the curriculum of schools of social work both in Canada and the United States. These include feminist theory, structural theory, critical theory, empowerment theory, radical theory, constructivist theory and others. All of these espouse the necessity of the profession working from a strengths-based and social action perspective (Carniol, 2005; Condeluci, 1996; Cooper, 2005; Haynes, 1998; Hick et al., 2005; Hopmeyer, Kimberly, & Hawkins, 1995; McKnight, 1995; Mullaly, 2007; Salleebey, 1996; Specht & Courtney, 1995).

In many respects, social work education in Canada has been heavily influenced by development in the United States. Until the late 1940s and early 1950s, many Canadian students attended universities in the United States to obtain professional social work education. In addition, Canadian universities' social work programs were similar to the social work education models developed in the United States. In fact, the Council on Social Work Education (CSWE) accredited most Canadian social work programs until the late 1960s. In 1967, professional social work education gained prominence and increased independence from the United States influence through the formation of the Canadian Association of Schools of Social Work (CASSW). In 1970, the CASSW assumed responsibility for accreditation of Canadian social work university programs. Since that time social work education in Canada has developed its own identity in keeping with the perceived current realities within Canadian society (Heinonen &

Spearman, 2006).

In 1951, social work education in Newfoundland and Labrador began as in-service training for welfare officers employed by the Department of Public Welfare. At that time, the University of Toronto's School of Social Work provided a special in-service program for these employees, as well as education through attendance at the School of Social Work in Toronto and later the Maritime School of Social Work (Godfrey, 1985). In 1963 Memorial University of Newfoundland started a two-year diploma program in social work. This was followed by a Bachelor of Arts Degree with a Social Work option in 1967 and a professional Bachelor of Social Work Degree in 1969. This Bachelor of Social Work program was patterned after other such programs developed at Schools of Social Work in Canada (Brett, 1974).

Social Work Education Components

The corner stones of social work education are knowledge, values, and skills. While each concept is reviewed separately it is important to be cognizant of the interconnectedness of the three (Boyle et al., 2006; Gordon, 1965; Johnson, 1998).

Knowledge.

Social work knowledge is a composite of borrowed and in-house knowledge. It includes concepts, theories, models, and practice wisdom. Foundational social work knowledge has been borrowed from other disciplines including sociology, psychology, anthropology, political science, economics, history, biology, and physiology (Brieland, 1995; Johnson et al., 1998; Morales & Sheafor, 1998).

Kadushin (1959) presents the origins of social work knowledge through the use of a model that consists of three major components, social services, social practice, and human growth and behaviour (see Table 1). Social services knowledge includes historical information about social programs, information about social agencies and how they operate, and knowledge about other related agencies and relationships between agencies. Social practice knowledge is about social work as a helping profession incorporating knowledge about helping processes, resources, and attitudes. The third category of knowledge put forth by Kadushin is knowledge about the person. This category includes individual knowledge about the person and the problem, as well as general knowledge about personality development and individual and group behaviour. These knowledge categories capture the basic elements of social casework.

Table 1 Social Work Knowledge

Social Services Knowledge	**Social Practice Knowledge**	**Human Growth and Behavior Knowledge**
Organization	Helping Process	Person and Problem
Administration/Operation	Helping Resources	Personality Development
Inter-Agency Relationships	Helping Attitudes	Individual/Group behavior
Social Program History		
Specific Program Needs		

Moralis and Sheafor (1986) build on the Kadushin model by adding specific knowledge within these broad categories. The result is the inclusion of specific knowledge about fields of practice, practice theories, practice methods, legislation, organizational knowledge, client information, and client interactions. There are many traditional fields of practice within social work (e.g. public welfare, child welfare, corrections, mental health, rehabilitation, disabilities, etc.). Morales and Sheafor include specific knowledge of social work theories, practice methods, and legislation that impact on social work intervention within a particular practice area. Also, they emphasize specific knowledge about individuals and the social workers relationships with individuals within a specific field of practice. Further, they include the importance of specific knowledge about organizations and agencies that are associated with a particular field of practice. The knowledge base expansion that they suggest demonstrates the increased complexity of social work practice over a twenty-five year period between Kadushin's model of knowledge in 1959 and knowledge seen as important in 1986. While Morales and Scheafor help clarify the various facets of knowledge from the general to the specific based on different fields of practice, the knowledge presented remains consistent with a casework approach to social work (Morales & Sheafor, 1986).

During the last quarter of the 20th century, social work education began to address issues of diversity and oppression. The Canadian Association of Schools of Social Work (CASSW) (2000) states; "Each school's curriculum shall provide evidence of on-going identification and critical analysis of contemporary and emerging social issues" (Policy Statement 1.8).

CASSW (2000) standards of accreditation embrace knowledge requirements which include historical components as well as contemporary issues. This is evident in

CASSW's stated expectations with respect to knowledge:

> human development and behavior in the social environment; social work, social welfare history, and social policy and their implications for social work practice; multiple and intersecting bases of oppression; practice methods; theoretical and conceptual basis of social work practice; continued learning; and, ongoing professional development (Policy Statement 3.4).

Knowledge about oppression and the many facets of oppression included in this policy statement shows the emerging place of social justice issues within social work education.

New theories and ways of working with people have added to the knowledge base of social work practice. Emphasis is being placed on anti-oppressive practices, including empowerment and strengths-based approaches that acknowledge the socially constructed oppression of marginalized populations. Within this construct, the person seeking service is considered to be the expert with respect to their life situations. Egalitarian relationships are identified as the key to meaningful social work intervention. Moreover, emphasis is placed on working with many systems and assisting families through social action (Boyle et al., 2006; Carniol, 2005; Chappell, 2006; Hick, 2006; Hick et al., 2005; Kirk & Reid, 2002; Salleebey, 1996).

Values.

Morales and Sheafor (2004) portray values as what ought to be and Rokeach (1968) defines a value as "a type of belief, centrally located in one's belief system, about how one ought or ought not to behave, or about some end state of existence worth or not worth attaining" (p. 124). This definition encompasses two basic types of values, instrumental values and terminal values. Instrumental values are those beliefs that guide both private individual behavior and behavior as social workers. Terminal values are more pragmatic and refer to the anticipated results of what is hoped to be achieved (e.g., social justice for all) (Heinonen & Spearman, 2006; Johnson, 1998; Morales & Sheafor, 2004; Pincus & Minahan, 1973).

According to the Canadian Association of Social Workers (CASW) (2005), the core values for social work include:

- respect for inherent dignity and worth of persons,
- pursuit of social justice,
- service to humanity,
- integrity of professional practice,
- confidentiality in professional practice,
- competence in profession practice (pp. 4-8).

These values are extensively discussed in the literature (Boyle et al., 2006; Heinonen & Spearman, 2006; Johnson, 1998; Morales & Sheafor, 2004; Pincus & Minahan, 1973; Pumphrey, 1959; Siporin, 1989; Smith, 1997; Vass, 1996). Of particular interest within the context of this study is social work's fundamental commitment to social justice. This value includes a responsibility to educate others about social work knowledge and skills (Hayashi, 2007; Reamer, 1998, 1999).

Values are fundamental to social work practice, therefore, values clarification is a critical component of social work education (Boyle et al., 2006; Heinonen & Spearman 2006; Johnson, 1998; Morales & Sheafor, 2004; Pincus & Minahan, 1973; Reamer, 1999;

Vass, 1996). According to Raths, Harmin, and Simon (1966), values clarification describe values as moulded guides to behaviour. Values develop from our social experiences. CASSW (2000) stresses the importance of values in social work. According to the accreditation standards these values include: "appreciation of social work purposes, practices and ethics and development of related social work values and professional judgment, commitment to continued learning and ongoing professional development" (Policy Statement 3.4).

Skills.

Social work skills combine knowledge and values to create expertise in social work practice. Yet amongst the experts in this field, there is no agreement with regard to exactly what constitutes the core skills of social work practice. This is evident by the myriad of social work skill lists found in the literature (Baer, 1979; Baer & Frederico, 1978; Bartlett, 1970; Boehm, 1958; Boyle et al., 2006; Colby & Dziegielewski, 2001; Frederico, 1973; Gordon, 1962; Johnson, 1998; Lowenberg & Dolgoff, 1971; Morales & Sheafor, 2004; Pincus & Minahan, 1973; Trevithick, 2005; Vass, 1996; Zastrow, 1996). Trevithick (2005) provides a synthesis in her list of generic skill categories that include communication, listening and assessment skills, basic interviewing skills, providing help, direction and guidance, empowerment, negotiation and partnership skills, and professional competence and accountability. This is by no means an exhaustive list of relevant skill sets.

Social work skills are increasing in scope with the addition of such skills as working collaboratively, working with diverse populations, anti-oppressive practice skills, and use and management of resources (Boyle et al., 2006; Collins, 1986; Dominelli, 1996, 2002; Vass, 1996; Zastrow, 1996). The CASSW (2000) accreditation standards require that social work education programs teach skills to enable social workers to work collaboratively with others, address issues of oppression, and develop critical thinking capacity of appropriate intervention and self- evaluation. At the secondary educational level, these skills are enhanced to include skills to analyze social work intervention within the diverse Canadian societal context. Specifically the CASSW standards include:

> transferable analysis of the multiple and intersecting bases of oppression and related practice skills; intellectual skills and scholarly attitudes of curiosity, open mindedness, and reasoning; practice skills required to analyze situations, to establish accountable relationships and to intervene appropriately with clients and related systems and to evaluate one's social work intervention (Policy Statement 3.4).

> CASSW (2000) skills required at the second university level include, critical analysis of the assumptions and the implications of current social work goals, theories and intervention approaches in the context of a diverse Canadian society with multiple and intersecting bases of oppression, research, creative and innovative approaches, and contributions to scholarship and professional practice (Policy Statement 5.5).

Social work skills have been described as an artistic creation, technical acumen, and/or a combination of both. They can be an artistic creation (Boehm, 1958; Siporin, 1988). As an art, social work skills focus on the attributes of the individual and the development of a unique personal style. The art of social work skills also includes the use of creativity and imagination in dealing with difficult, complex, and multifaceted problems (Johnson, 1998; Johnson et al., 1998; Trevithick. 2005).

Social work skills are viewed from a scientific perspective as practice techniques. Bartlett (1970) views skill as technical expertise, for instance. Implicit in this view is the importance of using knowledge and values in making a choice among a number of alternative actions.

Some describe social work practice as an art and a science (Morales and Sheafor, 1986). The science component includes the use of knowledge and skills to bring about a desired outcome. The art component is the social worker's selection of unique techniques and skills based on special personal knowledge and values. Johnson (1998) suggests that skilfulness develops over time and involves not only the use of knowledge and values but includes individual attributes and a unique personal style. According to Gordon (1962) skill involves continuously evaluating the relationship between the individual receiving service and the social worker, including the effects on both parties. Further Zastrow (1996), purports that skill development is influenced by innate ability and past learning experience as well as curriculum content.

Social Work Education and Care and Caregiving

Social work education pertaining to care and care giving requires an appropriate combination of knowledge, values, and skills. Social workers need knowledge with respect to care and caregiving. Caregivers and care recipients are members of oppressed, marginalized populations. Knowledge about anti-oppressive social work practice with caregivers and those they care for and care about is a prerequisite to effective social work intervention. (Baines et al., 1991, 1998; Collins, 1986; Dominelli, 1996, 2002; Mullaly, 2007; Nes & Iadicola, 1989; Van Voorhis, 1998).

Feminist social work theory provides a foundation to social work knowledge for caregivers including knowledge about anti-oppressive practice. Identifying women's issues, the social construction of women's roles, women's duty to care, and their place in a patriarchal society are endemic to social work with caregivers (Baines et al., 1991, 1998). In addition, knowledge related to the ecological nature of processes between the individual and the environment, multi/inter/transdisciplinary knowledge, interdependence and connectedness of individuals, and the promotion of societal transformation is important (Collins, 1986; Ife, 1999). For caregivers such as those involved in this study, Roeher (2000) underscores the necessity of knowledge about the field of developmental disabilities and available resources.

Social work values in the field of caregiving include appreciating the uniqueness of each individual, their inherent worth and dignity, egalitarianism, self-determination, mutual interdependence and caring, empowerment, and embracing rights of citizenship (Chappell, 2006; Collins, 1986; Hick, 2002; Kirst-Ashman & Hull, 2003; Roeher Institute, 1996). Roeher (2000) reports that caregivers appreciate those who support inclusion and who are sensitive and responsive. Additionally, Shulman (1992) maintains that the social worker understanding an individual's feelings and sharing her/his feelings are traits service consumers view as essential for effective practice.

Social workers sometimes have negative attitudes towards persons with developmental disabilities and their parent caregivers because they do not learn about these areas in social work. In such situations, values and beliefs can be channelled in a positive direction from positive personal experiences (Barnes & Mercer, 2003; Begab, 1970; Burge et al., 1998; Cole et al., 1989; Mackelprang & Salsgiver, 1999; Vanier, 1998). Social work education can prepare social workers for work in the field of caregiving and developmental disabilities through curriculum enhancement and field experience. When social workers sit with individuals they have an opportunity to appreciate their value and their life experiences (Baines et al., 1991, 1998; Begab, 1970; Burge et al., 1998; Cole et al., 1989; DeWeaver & Kropf, 1992; Dickerson, 1981; Dunn et al., 2006).

Important skills for social work with caregivers include communication skills, assessing psychosocial effects of oppression, intervention skills to enhance individual identity and change oppressive social conditions (e.g., advocacy skills), and skills to evaluate effective service provision (e.g., case management) (Kirst –Ashman & Hull, 2003; Van Voorhis, 1998). According to Becker and Becker (1986 cited in Fort-Cowles, 2000) and Fisher (1991) parents can benefit from these social work skills as soon as a diagnosis of developmental disability is made. Kravetz (2004) adds that skills in using the ecosystems model “ensures that we fully understand how women’s personal issues and problems are inextricably connected to larger social, political, and economic structures and cultural beliefs” (p. 240). Moreover, Ife (1999) promotes the importance of ecosystems in discussion of skills that incorporate holistic approaches. Mackelprang and Salsgiver (1999) note that social workers require necessary skills to help persons understand their rights, maximize their potential, and develop resources they need. Gutierez (1990) maintains that skills working with small groups of women are beneficial in consciousness-raising. Skills in group work include identifying and building on strengths, helping individuals analyze power, teaching particular skills such as problem solving and parenting, organizing and creating collectives, and advocating in a way that helps them do this for themselves. Hanes (2006) insists that it important for social workers to acquire advocacy skills for social and political change.

Summary

This literature review addressed components central to the study's question: *From the perspective of caregivers, what knowledge, values, and skills are necessary for social workers to provide meaningful services to them in caring for their daughters and sons who have developmental disabilities?* The review defines and explores the concepts of care and caregiving issues and avenues for addressing these issues. An overview of developmental disabilities, including concerns particular to persons with this disability and their parent caregivers, mostly women, focuses on the area of caregiving relevant to this question. Further, the review examines feminist social work theory from the perspective of several conceptual positions, assumptions, practice principles, and key values relevant to the purpose of this study. As well, through exploring social work feminist theory the rationale for defining knowledge, values, and skills from the caregiver's perspective is illuminated.

Social work practice components describe social work services and their relevance to these caregivers. A review of social work practice within this field provides a background for what the caregivers define as necessary knowledge, values, and skills in comparison to their experience with social work practice. As noted previously, knowledge, values, and skills are the corner stones for social work education. Providing a brief overview of the literature relevant to social work education creates a basis for understanding of the specific knowledge, values, and skills that are taught to social workers to prepare them to work with caregivers who have daughters and sons with developmental disabilities. This information can then be discussed in light of the study's findings - what parental caregivers identify as needed by social workers to provide optimum service to them.

Each topic includes specific reference to parental caregivers of persons with developmental disabilities. Historical information is provided when deemed necessary to enhance a comprehensive understanding of the topics discussed. Finally, since this study was completed in St. John's, Newfoundland and Labrador, it was important to provide some information on the history and development of this province pertinent to the location of this study in the capital - St. John's. In the next chapter, a description of the study's methodology, explains the process used to complete the study and ethical considerations pertaining to the study.

CHAPTER THREE:
METHODOLOGY

This chapter addresses the procedural and ethical dimensions of this study. The particular research methods used to identify social work knowledge, values, and skills are discussed. A description of the participants and the method of selection are outlined, followed by a delineation of the study process, including data collection and analysis. Ethical considerations are addressed in the final section. The study originally focused on knowledge, values, and skills pertaining to social work practice with individuals who had developmental disabilities. The focus changed, however, to knowledge, values, and skills in social work practice with parental caregivers of persons with developmental disabilities. This change in focus and the methodological implications of the change are addressed in this chapter.

This study is designed to identify, from the perspective of caregivers who have children with developmental disabilities, the knowledge, values, and skills that are necessary to provide meaningful social work services to these caregiver parents. A fundamental assumption of this study is that the caregivers are experts, with respect to their issues and concerns. As a result of their life experiences they have tacit knowledge and can thus contribute to ontological and epistemological perspectives that inform social work education and professional practice.

Research Design

A qualitative research design is used in this study. Padgett (1998) reports qualitative research has emerged as a predominant research paradigm within the social sciences and is an effective avenue to enhance understanding of our social world. Qualitative methods are inherently inductive and seek to illuminate rather than test theories. They connote a degree of closeness, an absence of controlled situations, and an interest in a holistic approach using ‘thick description’. Qualitative studies are built on a dynamic reality acknowledging the researcher as the central instrument of the research. They rely on first-hand observation and data collection to guide findings. Further, qualitative research uses scientific inquiry and is systematic (Padgett, 1998).

According to Padgett (1998), qualitative research is appropriate in situations where little is known. This does not mean that nothing is known, but rather that too little is known and an in-depth understanding is beneficial. The knowledge, values, and skills social workers need to work effectively with parent caregivers of persons with developmental disabilities can be enriched through a more in-depth review. Therefore, the use of qualitative methods is considered appropriate for this study. Most qualitative studies involve open-ended interviewing techniques where the results emphasize the personal experiences and viewpoints of the participants (Gilgun, 1994). Such an approach is congruent with the purpose and nature of this study.

Interview Methodology

A method of intensive interviews was used for this study. Padgett (1998) defines the interview as "a goal directed conversation" (p. 59). Seidman (1998) describes interviewing as a "basic mode of inquiry" (p. 3). He goes on to note that interviews provide a window to people's behavior and a way for researchers to understand behavior. The process of interviewing demonstrates an interest in individuals' stories and is based on the assumption that "the meaning people make of their experience affects the way they carry out that experience" (Seidman, 1998, p. 3).

The selection of the in-depth interview as the method of inquiry for this study is predicated on the need to obtain a solid understanding of the lived experiences of caregivers who have children with developmental disabilities and what they make of those experiences. Detailed information about the respondents' lives and the impact of caregiving on them provides a wealth of information to inform social work knowledge, values, and skills in professional practice.

In-depth interviews provide an opportunity for people to tell their stories. An opportunity for the interviewer to sit with these parent caregivers and hear their life stories in a way that allows for sufficient clarification is important. Through extended discussion, these caregivers are able to provide an informed understanding which is not possible through observation or documentation review alone.

Research Participants

The research participants were chosen through the use of purposive and convenience sampling procedures. Purposive sampling is used when the researcher requires the subjects to possess particular attributes. A convenience sample is one that is available to the researcher with relative ease. Such a sample, however, must fit in a particular study (Berg, 2001). In this study a convenience sample was secured that met the necessary criteria.

Seidman (1998) provides two criteria for sample size. The first criterion is sufficiency. The sample size is sufficient if the numbers reflect the range of participants and sites so that others who are outside the sample would be likely to relate to the experiences of those inside the sample. The second criterion is saturation of information. When the researcher reaches a point in the interviews where the same information is being repeated then the sample size is large enough. The sample size for this study is 15 primary caregivers, a sufficient number to reflect the range of participants. The data analysis confirmed that the size provided enough information (i.e., information began to be repeated).

Participant Selection

The initial selection of candidates for this research was completed by the Newfoundland and Labrador Association for Community Living (NLACL). The NLACL's mission statement is "[t]o work with and on behalf of individuals with a developmental disability and their families. To advocate for individuals to live as full participants in the community based on the values of Equality, Inclusion and Independence" (http://www.nlacl.ca/start_page.html). This grassroots organization works on behalf of caregiver parents and their children with developmental disabilities. Therefore, they were considered to be an appropriate resource to secure potential participants for this study. A letter was written to NLACL seeking their assistance in the selection of participants for the study. There was, enclosed in this letter, an information document explaining the research and outlining participant requirements (See Appendix G). A follow-up meeting was held with the Executive Director of NLACL. At that meeting, I described my background, the research purpose, as well as, the methodology and ethical considerations. It was agreed that NLACL would identify potential research participants consistent with the outlined criteria (See Appendix G). NLACL personnel were not able to identify all potential participants with young children. They explained that parents are more likely to need NLACL services as their children get older.

I consulted with an independent expert in the field to secure assistance in identifying 3 potential participants with younger children. Subsequently, I met with her, described my background and the research purpose, as well as, the research methodology and ethical considerations. During this meeting, I provided and reviewed with her the same document forwarded to NLACL (See Appendix G). She agreed to identify potential research participants consistent with the outlined criteria (See Appendix G).

Two primary criteria were used to select all participants. First, the caregivers selected were required to have had no dealings with me directly or indirectly through my employment as a senior manager with the Department of Social Services, Government of

Newfoundland and Labrador, and Health and Community Services – St. John's Region. This was important because prior professional involvement with me may have influenced their interview responses, and had the potential to influence my responses during the interview and in analyzing the data. Second, since this study concerns care and caregiving within the area of developmental disabilities, caregivers selected were required to be primary parent caregivers of an individual with a developmental disability. But, other diagnosed conditions pertaining to the care recipient could have existed concurrently. Secondary criteria required that within the group of selected caregivers their children would be i) within one of three particular age range categories, and ii) within one of three designated levels of disability based on a broad categorization.

Caregiver Parents

The caregivers in this study are parents who take a lead role in the provision of care and in the negotiating and advocating for supports and services on behalf of their children with developmental disabilities. A total of 15 parent caregivers were interviewed. Initially, they were chosen to reflect caregiving experiences with children of varying ages and general developmental disability levels. The age ranges are 0-18 years of age, 19- 25 years of age, and over 25 years of age.

The levels of developmental disability were classified according to the three requirements stipulated by the American Association on Mental Retardation (AAMR) (later renamed the American Association on Intellectual and Developmental Disabilities [AAIDD]). Their definition of mental retardation includes "significant limitations in intellectual functioning; significant limitations in adaptive behavior as expressed in conceptual, social and practical adaptive skills; and, originates before the age of 18" (AAMR, 2002, p. 110). Shalock, Buntinx, Brothwick-Duffy, Luckasson, Snell, Tasse and Wehmeyer (2007) defines adaptive behaviour for the AAIDD as "conceptual (e.g., language, reading and writing, money concepts, and self-determination), social (e.g., interpersonal, responsibility, self-esteem, follows rules, and avoids victimization), and practical (e.g., activities of daily living and instrumental activities of daily living) skills" (p. 12). A person's level of developmental disability can be determined by assessing her/his strengths and challenges. Individual adaptive behaviour, as outlined above, serves as a guide to determine the areas of individual strengths and challenges, thereby, assisting in developing a general level of individual disability. The general levels in this study were labeled according to traditional terminology with three classifications; mild, moderate, and severe developmental disability.

I determined which category of developmental disability a particular caregiver's child most appropriately fit via consultation with those involved in helping to develop the participant list. My thirty years of working in the area of developmental disabilities provided a solid frame of reference from which to complete the categorization within the broad categories noted. For example, the individuals I categorized as having a mild developmental disability spent time independently at home and in the community, had good communication skills, and were independent in self care. Individuals classified with a moderate disability had communication challenges but were able to make themselves understood and indicated they understood what was said to them, were able to spend short periods of time alone at home, but needed supervision in the community and limited supervision engaging in personal self-care. Individuals categorized with a severe developmental disability had significant challenges with communication, limited speech, presented significant behavioral concerns, required help to complete daily living activities, and required on-going supervision at home and in the community. Using these indicators 15 parental caregivers were selected so that collectively a child within each age range and level of disability was represented.

Collaboration with the NLACL ensured that these caregivers' children had a primary diagnosis of developmental disability given that their mandate is exclusively for individuals who have developmental disabilities. As stated above, the level of disability was determined by me via discussions with the staff at NLACL and the independent expert, and later confirmed through discussions with prospective participants. A general level of developmental disability was important to explore parental caregiving in light of their child's degree of dependency. In addition, the selection of caregivers based on their child's age and level of dependency allowed for maximum variation with respect to caregiving experiences.

Two NLACL staff and an independent expert identified potential candidates for this study based on their working knowledge of parental caregivers and a review of information in individuals' files. From their knowledge of parent caregivers within the St. John's area, they selected parents who they believed would fit the caregiver criteria. Subsequently, they discussed with me the individual caregiver and her/his child. This discussion was the basis of final selection and tentatively identifying the developmental disability category the child could be broadly classified within. Once potential candidates were identified, one of the two NLACL staff and the independent expert involved in this process contacted the caregiver by telephone, explained the overall purpose of the study, and asked them if they would consider participating in this research. If a caregiver agreed to participate in the study the NLACL staff person or the independent expert asked for her/his permission to provide me with her/his name and a telephone number where s/he could be reached. After receiving an individual's name and telephone number, I contacted the person by telephone, explained the study, confirmed their understanding of the study purpose and process, and determined if the potential candidate met the criteria required for the study. If a person, who had been identified and contacted by me, for some reason was not deemed suitable or decided against participation s/he was thanked for their interest and the process was followed again until the sample was complete.

Study Process

Subsequent to the telephone conversations confirming participants, an information letter and a consent form (see Appendices A and B) was sent, through regular mail, to each participant using the mailing address they had provided. I contacted the caregivers a second time by telephone to confirm they had received the letter, answer questions they had regarding the material forwarded, confirm participation, and to arrange an interview time and place that was convenient and provided necessary privacy for the caregiver. The interview site varied depending on the caregiver's preference. Sites included my university office, my home, the caregiver's office, and her/his home.

All interviews were tape recorded with the permission of the interviewee. Prior to each interview a check was made to ensure the participant's signed consent to participate in the study was on file. The interview duration was typically one and one- half to two hours. After the interviews were completed, I analyzed the taped interviews through repeated listening and making notes that I used to develop the interview summaries. The interview summaries were completed and copies of the summaries were sent, through regular mail, to caregivers for their review and approval with respect to completeness, accuracy, spirit, and intent. Every measure was taken at this stage to ensure that participants had full opportunity to provide a thorough review and detailed feedback to me.

The study process included a second interview to discuss the summaries and determine if the caregivers required any changes to be made to the interview summary. However, all participants did not wish to have a second interview. Instead, they preferred to discuss and approve the summaries through telephone conversations and/or email contact. They provided the telephone and email contact information that they wanted me to use. I adhered to their wishes and ensured that all relevant discussion occurred and clarification was provided where necessary. Participants' summaries were written to their complete satisfaction and they confirmed, either via email or through telephone conversation that the summaries as completed, including incorporation of any changes they requested, were acceptable. For those who provided their approval of the interview summary through a telephone conversation with me, I recorded the receipt and date of each approval. The approved interview summaries were securely stored pending further analysis. This change in process for interview summary approval was approved by Memorial University of Newfoundland's Interdisciplinary Committee on Ethics in Human Research.

Change in Research Focus

A change in research focus occurred subsequent to completion of the initial set of interviews and analysis in 2002. This resulted in some changes to the original Human Subjects Research Protocol as outlined in Appendix D. The rationale for the shift in research focus and the changes are explained in the following paragraphs. A review of the sequence of events leading to the change in the focus of the study explains the incongruence between the Human Subjects Research Protocol (see Appendix D) and how the study proceeded.

The initial study question was: *What knowledge, skills, and values are viewed as necessary, from the perspective of consumers, for meaningful and effective social work services to persons living with developmental disabilities?* To address this question nine parent caregivers, three advocates, and three individuals with developmental disabilities were interviewed. The analysis of this data and subsequent findings resulted in re-thinking the research focus. The most significant issue that emerged as a result of the data analysis and review of the findings pertained to the parent caregivers. The data analysis highlighted developmental disabilities as a caregiving issue and a women's issue. It became apparent that this group of predominantly female parental caregivers (i.e., only one male), play a most significant role in the lives of their children with developmental disabilities.

These parental caregivers, in many respects, are defined by this caregiving role. Caregiving provided by parental caregivers of persons with developmental disabilities became the predominant issue for further exploration. The initial set of interviews provided a picture of the lived experiences of 9 caregivers that could be added to and thereby, further address the social work knowledge, values, and skills necessary to provide meaningful social work services to parent caregivers of persons with developmental disabilities.

In rethinking the research to date, a decision was made, in consultation with my research committee, to continue the study with the same design but with a change in focus from individuals with developmental disabilities to their parent caregivers. The original data was collected throughout 2002 and the additional data was collected in 2004. The new data consisted of six additional parent interviews. The original interview schedule was deemed appropriate for use as all of the relevant areas were adequately covered. The original process for recruitment, selection of participants, and all research aspects as outlined in the Human Subjects Research Protocol (see Appendix D) remained the same. The modified research question became: *From the perspective of caregivers, what knowledge, values, and skills are necessary for social workers to provide meaningful services to them in caring for their daughters and sons who have developmental disabilities?* None of the 15 interviews were transcribed verbatim; rather, the taped interviews were repeatedly listened to and detailed notes for each interview were written. The following changes were incorporated into the handling of the interview data. A typist was hired to type my notes. While I required her to sign a confidentiality agreement, care was taken that she would not have access to any identifying information. These notes were then used by me to create the caregiver interview summaries. In addition, a research assistant, who is a registered and experienced social worker with previous research experience, assisted with the analysis of the initial manual review of the data under my supervision. This involved the review of 9 interview summaries, none of which contained identifying information. The research assistant was not involved in the analysis of the subsequent 6 interviews.

A second analysis was completed by me for all interview summaries. While the research changed focus in the process of analysis, this change did not affect ethical considerations with respect to the Human Subjects Protocol, nor did it compromise the ethics of the research as confirmed by the Interdisciplinary Committee on Ethics in Human Research. Annual written reviews that addressed all ethical areas of concern were submitted to and approved by the Memorial University's Interdisciplinary Committee on Ethics in Human Research.

Interviews

Denzin (1970) describes the type of interview used in this study as a nonscheduled standardized interview. This form of interview requires the same information from each respondent with the questions and the order in which they are addressed being tailored to meet the needs of the respondent. Three assumptions guide this type of interviewing. First, if the meaning of a question is designed to be standardized then it is formatted in a familiar way for the respondent. Second, no particular order of questions works equally well for all respondents. The respondent's readiness and willingness to address a topic as it comes up dictates the order of the questions. Third, the interviewer's training and careful observation of respondents can result in the skills required to craft the questions and their sequence so that all respondents equally understand what the questions mean (Denzin, 1970).

Lofland and Lofland (1995) provide a detailed guide for data logging. Data logging for this study included preparing the interview guide, completing the interview, and writing up the interview. The interview guide contained probes used, as needed, to explore broad topic areas (See Appendix C). The probes were intended to encourage individual stories and accounts to obtain the respondents personal opinions expressed in their own terminology.

Five broad topic areas were used to craft the question probes. They included i) impacts for caregivers, caregiving recipients, and other family members, ii) knowledge about caregiving and developmental disabilities, iii) values about caregiving and developmental disabilities, iv) skills about caregiving and developmental disabilities and, v) relationships between social workers and caregivers as well as social workers and care recipients. As suggested by Lofland and Lofland (1995), a basic demographic profile was completed at the beginning of each interview. Plus, interviews concluded with an invitation to the caregivers to discuss any matter not already addressed in the interview.

There are many social aspects to in-depth interviewing. One of those is setting the stage for the interview. Lofland and Lofland (1995) provide a sample guide of how to do this. This guide was implemented in each interview and contained the following information:

- Explain purpose and nature of the study to the respondent, telling how or through whom he [or she] came to be selected.
- Give assurance that the respondent will remain anonymous in any written reports growing out of the study, and his [or her] responses will be treated in strictest confidence.
- Indicate that he [or she] may find some of the questions farfetched, silly or difficult to answer, the reason being that questions that are appropriate for one person are not always appropriate for another. Since there are no right or wrong answers, he [or she] is not to worry about these and do as best as he [or she] can with them. [The interviewer is] only interested in his [or her] opinions and personal experiences.
- He [or She] is to feel perfectly free to interrupt, ask clarification of the interviewer, criticize a line of questioning, etc.
- Interviewer will tell the respondent something about himself [or herself] – his [or her] background, training and interest in the area of inquiry.
- Interviewer is to ask permission to tape record the interview, explaining why he [or she] wishes to do this (pp. 84-85).

I addressed three critical details throughout the interview process. First, I helped the caregiver to feel comfortable. This was accomplished by doing the interview in a comfortable environment for the caregiver. Dressed appropriately for the interview, I began the interview with general chatting to allow the person to relax and convey a relaxed demeanor myself. Second, I actively listened to what the person was saying and conveyed my listening through nonverbal and verbal responses. Third, I demonstrated my respect and appreciation for the opportunity to do the interview, and treated caregivers in a cordial manner. Adherence to these critical details ensured maximum interview benefit (Berg, 2001; Lofland & Lofland, 1995; Padgett, 1998; Seidman, 1998).

I took notes during the interviews. This activity helped to keep me focused and ensured that all material was covered without repetition. Note taking enabled me to go back to topics and facilitated the use of spontaneous probes. It helped to keep a natural flow to the interview because there was less need to interrupt the respondent (Berg, 2001; Seidman, 1998).

Two practice interviews were conducted with individuals outside the study sample. The purpose of these interviews was to help me become comfortable with the interview process. One interview was completed with a person who had a developmental disability, and the other was completed with an individual who has had several years of social work experience in the field of developmental disabilities. These interviews did not result in any change to the interview probes or how the material would be best covered. However, the opportunity to practice doing the interview was quite valuable because it allowed me to develop a comfort and confidence level for subsequent interviews. I was also able to determine the best way to introduce the interview and maintain a good interview flow.

The interviews were conducted in conversational style, with the probes used to ensure broad topic areas were explored in-depth (through an account of the respondent's experiences). Writing up the interviews entailed repeated listening to the tape-recorded interviews, writing notes about each one, and creating an interview summary. Most notes were done within a day of the interview and all interview notes were completed within a week. Working with the tapes manually was beneficial because each time that I listened to the audio tape it provided an opportunity to re-live the experience and gain additional insight. This was beneficial to clarifying the interview notes and creating accurate narrative interview summaries. The initial data analysis utilized repeated listening, which is a core component of the voice centered relational method of qualitative analysis (Mauthner & Doucet, 1998).

According to Gilligan, Spencer, Weinberg, and Bertsch (2003), the listening guide method is useful when "one's question requires listening to aspects of a person's expression of her or his own complex and multilayered individual experiences and the relational and cultural context within which they occur" (p. 169). Further, this method can be used in conjunction with other methods such as narrative summaries (Way, 2001). Caregivers' approval of the narrative summaries further engaged them in the analysis process.

There are limitations inherent in all in-depth interview methods. First, there is difficulty with delving into a group's language and their mechanisms for symbolization. The researcher cannot be certain of the way the information was understood and responded to. Second, the respondent may not always provide the interviewer with the information the researcher wants to obtain. Third, groups create their own rules and symbols, which are complicated by persons occupying different positions within their own group. All individuals have their own interpretation and views or distortions about group values (Denzin, 1970).

Gubruim and Holstein (1997) further elaborate on these limitations by discussing the integral role of the researcher in the research process. They locate the researcher in the center with the research participant. The researcher is part of the research process and, therefore, has an influence on the outcome. These ideas, expanded, move qualitative research into the constructivist realm. According to Rodwell (1998), in research using a constructivist approach, constructions are valid for only a particular time. Rodwell describes research as a human instrument. Thus she reiterates that research is constructed through a reflective being (i.e., the researcher) whose characteristics and history may be relevant to the process of gathering and interpreting other people's perspectives.

The researcher, being central to the research and, hence, the research outcomes, needs to be cognizant of her/his own assumptions with respect to the research. The process of reflexivity can be beneficial in this regard. Reflexivity means "reflecting upon and understanding our own personal, political and intellectual autobiographies as researchers and making explicit where we are located in relation to our own research. Reflexivity also means acknowledging the critical role we play in creating, interpreting, and theorizing research data" (Mauthner & Doucet, 1998, p. 121). I engaged in reflexivity as a means to create self-awareness of my impact on the process. This was done through recording observations, feelings, and impressions of each interview. I especially attempted to label potential bias that I might bring into the analysis.

Nature of Data

The data is comprised of the initial tape-recorded interviews, detailed notes developed from listening to the tape-recorded interviews, and written summaries of these interviews. Each of the interviews was summarized in written form and each caregiver reviewed her/his prospective summary and gave approval based on factual content, as well as spirit and intent. There were no substantive changes made to the interview summaries by the parents. In one case, a caregiver requested that information be removed, because upon reflection, she realized she did not want to have it included. Three other caregivers made changes to provide clarification. These changes were incorporated as part of the interview summary. Feminist scholars note the importance of keeping the participants close to the research process by involving them in the data analysis to create a collaborative process and negotiate the interpretation of meaning (Mauthner & Doucet, 1998).

Data Analysis

The data analysis began with listening to the taped interviews, making notes, and turning these notes into caregiver approved interview summaries. The next step entailed a composite review of all interview summaries. The data was organized into three categories of information, social work knowledge, values, and skills. These areas were further considered in terms of caregiving data relative to the level of disability and the particular age group. Using these categories to analyze data in the initial analysis stages provided an opportunity to compare data based on parental caregiving of children with developmental disabilities within the particular age groups and levels of disability. While age and level of disability categories were used initially to obtain a picture of knowledge, values, and skills identified for each category, the data was subsequently integrated to provide one picture of the knowledge, values, and skills.

The sample of 15 caregivers allowed for adequate comparison. Included in this were 16 children because 1 caregiver had two children with developmental disabilities. All three levels of disability (i.e., mild, moderate and severe) were represented in each of the age categories selected except in the age category 18-25 years where no individual was placed in the category of moderate developmental disability. This was not considered significant in terms of the study's findings.

An analysis of the data determined the knowledge, values, and skills categories of information as well as emerging predominant themes from these categories. In addition, the data probed for inconsistencies to determine the extent of caregiver continuity with respect to issues arising from the data. The summary data was analyzed according to generally accepted procedures for analysis of in-depth interviews (Lofland & Lofland, 1995; Tutty, Rothery, & Grinnell, 1996).

The data analysis was completed manually. First, the data was categorized in terms of social work knowledge, values, and skills. This was accomplished by coding phrases, sentences, and sometimes paragraphs in the summaries that pertained to these general areas. Second, coding was expanded within each category by sorting the data units into topics within a particular category (e.g., knowledge of available services). Third, throughout the coding process, memoing was used to record thoughts and impressions as units were reviewed that impacted on other units, and to provide context or linkages between the categories and topics of information contributing to the emergence of themes.

The data analysis identified the topics important to the knowledge, values, and skills categories. The topics were not listed in order of importance because it was determined that each was necessary to social work practice. The number of times a topic was raised was considered together with information about the intensity of feelings caregivers expressed with respect to topic areas. The data analysis findings captured these elements.

Themes emerged from the data analysis. For example, caregiver oppression came through as an emerging theme. The parent caregivers' lives were limited because of a lack of support enabling them to participate in community and work life in a way that most take for granted.

Ethical Issues

According to Padgett (1998), ethical issues in qualitative studies rarely entail significant risk to individuals. However, research with vulnerable populations requires special vigilance to maintain the balance between discovery and doing no harm. Padgett puts forth four core elements to ensuring ethical research practice: voluntary participation, doing no harm, informed consent, and confidentiality/anonymity.

Participation in research must be voluntary. Participants need to feel confident that not participating in a study will have no negative consequences. Volunteering is based on being totally informed about the study. Participants have a right to withdraw from the study at any time. They also have a right to review all material related to their involvement and require that portions of the material be erased (Seidman, 1998). All caregivers volunteered to participate in this study and they were fully informed and made aware of their rights.

Informed consent is a central component to ethical research. Berg (2001) describes informed consent as " the knowing consent of individuals to participate as an exercise of their choice, free from any element of fraud, deceit, duress, or similar unfair inducement or manipulation" (p. 56). Informed consent includes the following key elements:

- The participants need to know what they are being asked to do, by whom and for what purpose. Participants should be advised as to who is doing the research, the researcher's affiliations and who to contact if they have questions or concerns about the process.
- The participants should be advised of any risks or vulnerability attached to the research and how the researcher will minimize any potential negative effects.
- The right to participate or not, to withdraw at any time, and to review any material should be made clear to participants.
- Participants need to be advised of measures to protect anonymity and confidentiality.

- Participants need to be aware of the intended purpose of the research and how the material will be disseminated (Padgett, 1998; Seidman, 1998).

Confidentiality attempts to ensure that all information that can identify the participant is removed from the research records. All areas of informed consent and confidentiality were adhered to throughout this study. In most qualitative research the researcher knows the participant's identity hence total anonymity is not possible. This fact makes it very important to ensure a high degree of confidentiality (Rubin & Babbie, 1997).

Ethical issues were a primary consideration in the study. The Human Subjects Research Protocol and the Interdisciplinary Committee on Ethics in Research approval letter deal with the ethical issues of the study (see Appendices D and E). In addition, the information letter sent to participants, consent form for participants, and the confidentiality agreement for the person who typed notes pertaining to six interview summaries were completed (see Appendices A, B, and F). As noted earlier, the focus of the original research changed in order to concentrate on caregiver parents of individuals with developmental disabilities and their issues pertaining to caregiving. This shift in focus did not raise any ethical questions different than those addressed in the original Human Subjects Research Protocol (see Appendix D). I was therefore able to proceed under the originally approved mandate of the Interdisciplinary Committee on Ethics in Human Research.

Assessment of Possible Risks and Benefits to the Participant

The possible risks and benefits for participants are addressed here; they include a discussion of incentives, remuneration, and compensation. Lastly, issues pertaining to my relationship with the participants are considered.

Participant Risks and Benefits.

All interviews were conducted individually and took place in a private location that the caregiver selected. The nature of the interview was relatively low risk with very little emphasis on material that might be considered potentially threatening or harmful. However, it was anticipated that the interviews would be emotionally intensive for most participants.

I took cues from the participants to ensure the appropriate respect and empathy was accorded each individual. My extensive experience working with caregivers of individuals with developmental disabilities and those who have experienced crisis served me well in conducting this research. In the event that a caregiver was adversely affected by this interview, I agreed to direct her/him to an appropriate resource.

This study is potentially beneficial to participants both during the interview and in the future for a number of reasons. Participants can benefit from talking about issues they are attempting to resolve. Through exploring a range of topics these caregivers identify their strengths and areas of challenge. They have the benefit of self-exploration regarding possible sources of support and assistance. Further, this can be a consciousness-raising experience for participants, contributing to empowerment for some. Finally, participants can experience the satisfaction of knowing they are contributing to research designed to ultimately improve social work services to caregivers and persons with developmental disabilities.

Incentive, Remuneration, and Compensation.

Participants were not remunerated for their participation, however, transportation was provided when necessary to ensure participants incurred no costs as a result of participating in the study. For many participants, it was an opportunity to express their opinion with respect to important caregiving issues in the area of developmental disability. Moreover, participation was a means to contribute to enhancing caregivers' lives and the lives of their daughters and sons for whom they care.

Investigator's Relationship to the Participants.

One of the criteria for participants was to have had no prior relationship with me. This criterion was met by using NLACL personnel and an expert in the field to identify and screen potential participants.

Procedures Followed to Obtain Informed Consent.

All participants in the study received a letter (see Appendix A) explaining the purpose and nature of the study as well as its potential use. The letter explained the confidential nature of the study and steps taken to safeguard data. Along with the letter, participants received a consent form (see Appendix B), which they were asked to read and sign to indicate their willingness to participate in the study. Consent forms were collected and securely stored.

Safeguards to Confidentiality.

The information letter accompanying the consent form stated that personal identity would be safeguarded. Participants were also advised in the information letter that their decision whether or not to participate or their withdrawal would have no bearing on service delivery from Health and Community Services - St. John's Region. Further, I would exclude myself from any future decisions related to service for these individuals.

Measures were taken to ensure the documents were presented in a manner that ensured understanding. Since the statements of participants might contain references to social workers within the agency where I worked, participants were cautioned at the beginning of each interview not to identify any social worker by name.

Recording of Information.

All first interviews were tape-recorded and summarized. The analysis was completed manually. Personal names were not used and a different number was used to code each summary. A typist was employed to type the initial notes used to develop the interview summaries for six participant interviews. While the typist was required to sign a confidentiality agreement (see Appendix F), these notes had no identifying information. A research assistant, who is a registered social worker with extensive social work experience and knowledge of research, assisted with the analysis using the number coded summaries. Care was taken that all notes contained no identifying information and all records were stored in a secure office.

Summary

This qualitative research study was completed using unscheduled standardized interviews. The interviews were completed with 15 caregivers who have children with developmental disabilities. The data analysis was completed through listening to the taped interviews, creating agreed upon interview summaries, and manually analyzing the summaries. Particular attention was given to ethical considerations throughout this research activity. In addition, due diligence was paid to assessing and minimizing possible risks. Finally, measures were taken to ensure the procurement of appropriate consent and safeguard confidentiality. The next chapter presents the study's findings.

CHAPTER FOUR:

FINDINGS

The findings of this study delineate information about social work knowledge, values, and skills pertaining to caregiving, in the area of developmental disabilities, as defined by parent caregivers. The parents interviewed provide information by discussing their lived experiences as primary caregivers of persons with developmental disabilities. In the area of social work knowledge, the caregivers present information about the impact of having a child with a developmental disability, the context in which they live their lives, the availability of services and resources to them and their families, information about caregiving and developmental disabilities, their experience of integration and inclusion for them and their children with developmental disabilities, and their perception of the role of the social worker. The social work values that caregivers consider essential are individual value and respect, integration and inclusion, the right to support and services, independence and autonomy, and the right to be part of the community. The caregivers identify social work skills for meaningful service to them including, the influence of individual attributes, advocacy, assessment, education of others, counselling, relationship building, communication, service coordination, and integration and inclusion. The chapter begins with demographic information about the caregivers and their families.

Demographic Information

Caregiving for the parental caregivers has been a lifetime commitment. Some parents have known their child has a developmental disability from the time of the child's birth, while others learned during the child's first years. The demographics for these caregiver parents and their families are outlined in Table 2.

There are 15 caregivers, in this study; 14 are female and 1 is male. The male caregiver does not report issues and concerns different than those of the female caregivers, probably because all caregivers have similar access to social work and other support services. Of the 15 families involved, 9 are two-parent families, while the other 6 are lone-parent families. The caregivers' ages range from 32 years to 70 years of age with an average age of 49 years. There is 1 caregiver less than forty years of age, 10 are between forty and forty-nine years, and 4 are over 50.

With respect to caregivers' educational background, 2 individuals completed high school, 7 individuals attended college, and 6 individuals attended university. At the time of the interview, 12 of the 15 caregivers were employed outside the home with 10 working in traditional female employment. In the two-parent families, 8 of the 9 caregivers were employed, while 4 of 6 caregivers in lone-parent families were employed. Employment experience included 10 caregivers who were employed in a professional or paraprofessional capacity.

The 15 caregivers in this study had a total of 36 children. Family composition included three families with one child, six families with two children, five families with three children and one family with six children. All 15 caregivers had a child with a developmental disability, and 1 of them had two children with a developmental disability. The group of eight female and eight male children ranged in age from 7 years to 38 years with the average age being 20 years of age.

Caregivers were selected for this study based on the age categories of their children with developmental disabilities. There were six children under 18 years of age, five were between the ages of 18 and 24 years, and five were 25 years of age or older. This age stratification provided the opportunity to contrast and compare caregiving experiences of caregivers across different age groups. These children were eligible to attend school until the age of twenty-one years.

The sample was further stratified by three categories of developmental disability: mild, moderate, or severe. Taking age and level of disability into consideration, participants were selected so that there were children within the three age categories who represented each level of disability with one exception. There are no individuals between the ages of 18 and 25 years represented in the category of moderate developmental disability.

Table 2 **Demographic Information: Caregivers and Their Families**

Caregiver	Gender	Age Range[1]	Partner/Spouse	Education	Employed	# of Children	Child with Developmental Disabilities		
							Age	Gender	Level[2] of DD
#1	F	1	Yes	High School	No	1	7	M	SE
#2	F	2	Yes	University	Yes	2	9	F	SE
#3	F	2	Yes	College	Yes	2	9	F	SE
#4	F	2	No	University	Yes	2	9	F	MI
#5	F	2	Yes	College	Yes	1	13	F	MO
#6	F	3	Yes	College	Yes	2	17	M	MO
#7	F	2	No	College	Yes	2	19	F	MI
#8	F	2	Yes	University	Yes	3	20	M	SE
#9	M	2	Yes	University	Yes	3	22	M	SE
#10	F	2	No	College	Yes	3	22	M	MI
							27	F	MO
#11	F	2	No	College	Yes	2	24	M	MI
#12	F	3	Yes	University	Yes	3	25	M	SE
#13	F	2	No	College	Yes	1	27	F	MO
#14	F	3	No	University	No	3	35	F	SE
#15	F	3	No	High School	No	6	38	M	MI

Notes. 1. Caregiver age categories are coded as 1 represents <40 years, 2 represents 40-49 years, and 3 represents >50 years.
2. Levels of developmental disability are coded as Mild – MI, Moderate – MO and Severe – SE

Social Work Knowledge

As noted above, six topical issues emerge as relevant to the area of social work knowledge. They are caregiver impact, contextual awareness, services and resources, caregiving and developmental disabilities, integration and inclusion, and the social work role. The caregivers expressed their beliefs about the relevance of these knowledge areas to social work within the field of caregiving and developmental disabilities. Moreover, they explain why this knowledge is critical to meaningful social work services.

Caregiver Impact

Development Disability Identification.

Caregivers speak about the importance of social work knowledge regarding the implications of having a child with a developmental disability. The effect of having a child with a developmental disability begins at their child's birth or at the time of diagnosis. There is a dramatic change with the birth of a baby who has a developmental disability with respect to the caregivers' wishes, dreams, and aspirations. This is illustrated by a parent's experience following the birth of her child:

> I was advised of my daughter's condition shortly after birth and then received a telephone call from the pediatrician on-call. He did not handle the situation well. It was upsetting for me; I was crying all the time. Somebody came to the door and said, ' I am a social worker is there anything I can do?' She left a card for me to call her...Perhaps if the social worker made more contact and explained what services and supports might be available, that would have been helpful.

Caregiver Responsibility.

Caregivers have different coping mechanisms. Some question *"why me"* others *"why not me"*. Some are living day-to-day, focusing on the present and are afraid to imagine the future. Others worry constantly, thinking about the future. Most caregivers report the burden of caregiving. The burden that some parents feel is captured in comments such as the following: "I feel like I am trapped and can't get out." Another parent reports: "Having children who have developmental disabilities is very difficult". A third parent says, "It changes your whole life." Yet another declares, "There is no break even when he is in bed. I am constantly thinking about what he needs tomorrow, next month, or even thirty years from now." Some parents report positive consequences like, "I would not change one thing about my life."

The most prevalent comments concerning how a caregiver is affected centers on caregiver's responsibilities and the overwhelming time commitment of providing care. One parent ponders, "How has having a child with a developmental disability affected my life? It is my life." While another contends, "The child is going to take over most of your life." Some parents express a need to ensure they are able to share their time with each of their children. In some families, the caregiver assumes major responsibility for the child with a developmental disability, while the other parent assumes responsibility for the other child(ren): "My husband basically took care of our daughter and I took care of our son." Parents and siblings both make sacrifices. One primary caregiver reports the difficulty for everyone when she missed her daughter's birthday because she had to be elsewhere with her son. She reported feeling guilty and deprived because she was not able to be with her daughter on her birthday, while her daughter and other family members expressed disappointment at this turn of events. Those who are employed outside the home (12 of the 15 caregivers) say their life basically consists of work and providing care for their child, with little or no time for themselves or any social life.

Advocacy, Service Coordination and Other Issues.

In addition to caregiving, many caregivers report spending considerable time and effort advocating for appropriate programs and services as well as on-going support for these activities. For example, the time commitment to advocate for an appropriate, well-supported school program is prominent. One caregiver attends weekly meetings at her daughter's school. Another teaches school children about developmental disabilities to promote inclusion, yet another served as a member of the school's parents and teachers committee to advocate for a child's right to attend the neighborhood school. One parent went so far as to ask to be charged with child abuse because she allowed her son to attend a school where he was being bullied. This caregiver's son was physically and emotionally abused because of his developmental disability. One abusive incident resulted in an injury necessitating corrective surgery.

Caregivers say their situation worsens when their children no longer attend school. Educational opportunities in preparation for employment are scarce and possibilities for employment remote. This becomes particularly burdensome due to their child's additional caregiving needs when s/he no longer attends school and they receive no additional support services. The situation is exacerbated by concern for their daughters and sons bleak future as is indicated in the following passage:

> Somebody told me when our son is eighteen he can get $427.00 a month for the rest of his life. ...That is nothing - that really scares me! It is sad. How do you pay your rent, eat, get a bus or go to a movie?

Some children with behavioral concerns, medical conditions, or other issues place additional strain on care and caregiving. Caregivers have less ability to delegate care to others because of the specialized care required by the person with a developmental disability. In addition, caregivers express being subjected to social isolation because others do not feel comfortable in their home or they are embarrassed to have others visit. Such situations can become untenable as illustrated by such comments as, "I take it one day at a time." One parent states, "The family cannot live like this." While another copes this way: "I forget about yesterday and don't think about tomorrow."

Social isolation is identified as a significant issue for most caregivers. They acknowledge their lack of a social network. They have few friends because they are unable to make and/or sustain friendships. They do not go to visit others and others do not come to visit them. For many, the telephone is a lifeline for social support: "Most of my visits are by phone."

Family Issues.

Caregivers note stress inside the family home to be a significant issue for both parents and children: "There were nights we felt we were hanging on a cliff by our finger tips." Marital relationships are affected: "We each say to each other at different times 'I can't take this any more.' Then we work it out and are stronger for that." Couples have very little time to nurture their relationship. One caregiver reports that she and her husband spend time out together only once a week for a couple of hours on Saturday morning. Another says that she and her husband only go out if there is a wedding or some such special occasion. Still, another comments, "We try to go out every three to four months if we can get a sitter."

Caregivers, without a spouse or a partner, see their marital or single status as exacerbating social isolation. They have to assume all the responsibility, often not able to go out socially and, therefore, not able to promote or sustain friendships. In addition to the heavy time commitment to their child, some of these women perceive a considerable reluctance on the part of potential partners to share lifelong responsibility for another person. Lone parent mothers face unique challenges. One such parent summarizes how she perceives her life situation:

> I have been on my own for nine years. This has been hard in a lot of ways, financially, personally, and in other ways. Brothers and sisters and friends often feel uncomfortable and shy away. I have lost a lot of friends because they have seen my daughter become upset and are afraid to be in her company...I work, she works and other than that, the only break I have is through respite.

Some lone caregivers view their having a child with a developmental disability as contributing to their separation/divorce. The following passage captures this issue:

> I have been a single parent for a while. The struggle of living with a developmental disability put a strain on the marriage. My husband felt he could not deal with living with a developmental disability for a lifetime.

Primary caregivers express concern for their other children. Siblings are affected by having a sister or brother with a developmental disability. For instance, socialization is an issue. Sometimes the other children do not feel comfortable bringing friends home because of their sister's or brother's needs, the reaction of their peers, or because of feelings of embarrassment. Sometimes the family is forced to make special accommodations to address the needs of their child with a developmental disability, which results in negative feelings on the part of others (e.g., having to move to obtain support service resulting in siblings having to leave friends, schools, and familiar group activities).

Older siblings often take responsibility for their sister or brother to allow their parents to go out or even to take a holiday. Some caregivers find it difficult to secure the support services that will allow them to take a vacation. They often rely on other family members especially siblings to provide this support: "We do some vacations around the province. This started after his sisters were old enough to provide care. We still have to be close enough to return home on short notice."

Siblings are often protective of their sister/brother in the community and defend their honor. Some siblings expressed an intention to take future responsibility for their brother or sister as indicated by sibling comments that the caregivers report. For example, "Mom, I have to get a good education because I have to have my own company and give my brother a good paying job." or "You don't have to worry I will always take care of her." These comments demonstrate that siblings' lives are affected by having a sister/brother with a developmental disability.

Extended family support is significant in combating social isolation. If they live nearby, some family members are available to talk to about issues and concerns. However, as family members grow older their support often diminishes. This happens when primary caregivers and their children are older, and caregiving support, when most needed, is not available. Those with families living far away feel even more isolated and burdened by their caregiving responsibilities.

The nature and extent of family support varies from family to family. Some caregivers' parents don't visit, while others visit but ignore the child with a developmental disability. Reportedly, one grandparent, upon learning that her grandchild has a developmental disability, said to the parents, "The important thing is don't tell anyone." Another grandparent said, "You have been crucified since you had her."

One caregiver was told by family members of an older generation that they did not believe a mother should keep her child at home or allow the child to be seen in the community. They communicated a sense of shame to the caregiver and expressed disgust when she took her child into the community. In addition, some family members are not able, or not willing, to be present with the person who has a developmental disability. These extended family members contribute to caregivers and their families becoming more socially isolated from the community. If a child with a severe disability is known to exhibit aggressive behaviors or have particular needs (e.g., is noise sensitive), others are less likely to help or visit the family.

Financial Concerns.

In addition to social isolation, fiscal issues are an expressed concern with respect to constraints on both personal and government financial resources. Caregivers talk about the financial strain families experience to purchase supports for their children and the lack of government sponsored support available to their daughters/sons. Families with few or limited financial resources are not able to provide appropriate care and caregiving. A caregiver in talking about her son's need to be involved in a recreation program declares, "He needs physical activity; he's not in any program now because the funds just are not there." Another parent is trying to increase opportunities for her son to be active in the community. Her comments exemplify her concern and inability to help her son in this regard: "I tried to see if I could get some respite hours approved so I could find a boy his own age who could phone up and go to a movie with him or other social events but that got turned down. I was told if I needed a break we could get respite but I can't say that – so that didn't work out but maybe some day." This caregiver is not willing to give false information so that her son can obtain necessary support services.

Contextual Awareness

Being Different.

Caregivers talk about the social stress of living with developmental disabilities, the stress in their lives, in the lives of their families, and especially in the life of the family member who has a developmental disability. As one parent puts it, "The real world is a terribly different place than we were ever led to believe." Caregivers state that social workers need to know about the history of developmental disabilities and the history of caregiving support. This includes the history of being isolated and the shame attached to having a child with a developmental disability. For individuals so affected, disability is a primary life-determining reality. Caregivers view their child's life and situation as different from those most people experience. Many live their life in isolation being excluded from social, developmental, educational, recreational, and employment opportunities that most people take for granted. From the perspective of these caregivers, their child's quality of life is greatly affected by the values and attitudes of others, and the amount and kind of available resources and support for personal development and caregiving.

Level of Disability.

Restrictions in individuals' lives vary depending on the level of disability and affect the life circumstances of both the caregivers and other family members. On one end of the continuum, some individuals are independent in terms of self-care: they spend time on their own at home and in the community. On the other extreme, some individuals are totally dependent for personal care needs and they require supervision all of the time. Moreover, some individuals have their developmental challenges compounded because of communication problems, behaviors that put themselves and others at risk of harm, medical conditions, and/or concurrent physical disabilities. The level of disability and the compounding variables significantly affects caregiving, especially where support service cutbacks reduce access to caregiving help. Caregivers' comments portray a sense of their significant caregiving challenges. A caregiver in describing coping with sleep deprivation said, "Now he is getting up in the night and screaming for me. I cannot leave him unsupervised so I am getting very little sleep." Another caregiver comment pertains to caregiving during times of caregiver illness. "The only place my son allows me to shave him is in the bathtub. When I was sick that was so difficult. I remember trying to do my best and my son ending up with cuts on his face." Further, there is this statement reflecting the difficulty of providing constant supervision, "Sometimes I can leave him for five or ten minutes if he is watching TV but he needs to be watched all the time because he puts things in his mouth."

Marginalization.

Caregivers report social isolation as negatively impacting their child's self-concept. One caregiver notes, "It's a very sad place to be with one foot in one camp and one foot in the other…He's on a quest to be normal. There's no doubt about that." Caregivers view the cost for their children's difference to be isolation and having no friends. Plus, they are teased and ridiculed by others in the community. These caregivers believe that having no friends is one of the hardest things their children have to deal with. One parent discusses her child's comment: " 'I have no friends; nobody will play with me'...The violence started with the rejection." This caregiver's comment portrays the difficulty that individuals face when they are rejected. Her daughter had no behavioral challenges when she was younger. However, as she grew older her friends did not want to play with her or be in her company. This rejection, in her mother's opinion, led to her developing significant behavioral challenges. The rejection of others resulting in an inability to develop friendships is a fear that every caregiver expressed. Beyond all other concerns, every caregiver found their daughter/son's inability to develop and sustain friendship to be the most disturbing issue in their child's life.

Caregivers talk about society's perception of their children as individuals who are different and who, because of their difference, do not fit in with the rest of society. Their comments include the notion that individuals with developmental disabilities cannot enjoy life. As one parent says, "I did not want to be told that our son is mentally retarded because it gives us no hope." Parents have wishes and dreams for their children. Hence, having no hope of a positive life for your child is a heavy burden. These parents believe that limitations often stem from the social perception of others more so than the child's disability. For example, a caregiver has this to say about a social outing with her child: "I went to the park one day and another mother who was there took her child away." In another social setting a caregiver relays a casual conversation she has with another mother: "...in conversation a lady asked about my children. I told her I had a child who had a developmental disability. Her reaction was to say I must have done something awful in my life to have a child like that. That hurt." With respect to reactions from service providers caregivers profess that professionals need to be comfortable with people who have developmental disabilities and have an ability to provide appropriate service. One caregiver proclaims, "Social workers are hesitant when talking to or meeting our son." Another caregiver adds, "The principal said we don't know how to deal with children like that."

Most caregivers believe that the treatment and care of persons with developmental disabilities is much improved from the past: "I have experienced that most people you come in contact with are much more accepting of a disability than was the case many years ago." However, they believe that more improvement is necessary before individuals and those who provide for their care are truly valued: "The cycle of poverty – and whether it be poverty in a financial sense, poverty in ideas, or poverty in opportunities – for many individuals with disabilities, they are on the margins and also then it puts their brothers or their sisters or their friends or their moms or their dads or others in the same vulnerable position." From the caregivers' perspective, individuals with developmental disabilities and their families live on the margins of society without the value that lends or gives appropriate support and services for persons with developmental disabilities or their caregivers.

Services and Resources

The availability of support services and resources reportedly has tremendous repercussions for caregivers' quality of life. Caregivers communicate feelings of frustration as they experience difficulty in obtaining services that leads to caregiving not being a burden. One caregiver says, "Institutions are so much more expensive but there are fewer and fewer services in the community every year and I feel I have to fight for everything I get." While another contends, "At my age I should be free to go wherever I want. I can't go anywhere." Caregivers believe they need more support: "Next month there is a curling tournament here and I would love to go to that. But when I called about getting the home support hours for my son I was told I didn't have enough hours built up."

There is an expressed awareness of cutbacks in service and caregivers see this trend continuing, "I'm afraid we will lose what we have." They believe services and resources need to be available in the community and provided in a timely and respectful manner. Having to disclose personal and private information to obtain services is seen by some as frustrating and distasteful as illustrated by the following comments:

> The experience that I have had just recently when I asked about respite was to be told that I am not going to get it. I don't have time to haul out bills and pass them in only to be turned down because service is frozen. This is invasive....If you are a working person who needs help, you don't get it.

Another caregiver communicates:

> At times I have refused to provide any financial documentation; we have done everything we can. This family has gone the distance to respectfully support our son. I am proud of my son. He has needs and issues and we will do what we can to help him.

Caregivers feel they are exposed to demeaning processes: "It was difficult having to tell them all your financial information and I think it is sad that parents have to go through that."

Many express fear and concern about their children's future, particularly with respect to service availability. One parent whose child was only nine years old had this to say:

> I think of her future sometimes, but mostly I block it out. I think she could be in a group home or something but this is not what I want for her. I would like for her

> to be independent or semi-independent where someone could come in and check on her. I would like for her to be able to look after herself and have a job. I hope she can have a relationship in her future and maybe even get married. I am thinking of getting a house with an apartment. I am afraid of what will happen to her if I die.

Even though home support is needed, hiring, supervising, and scheduling support workers is frequently viewed as a challenge. Some caregivers talk about the difficulties of being an employer: "We have had to supervise his staff and had to let staff go because of concerns about the quality of care that my son received. This too is an additional concern. You can't commit that amount of time and not have it affect the family." Another says, "The parent is left to hire the individual. I had one person who I felt was abusing my son and I had to let him go. I also had to deal with knowing he had abused my son." Still, another example,

> I asked the BMS [behavior management specialist] to go out with the respite worker to teach him on site how to deal appropriately with my son but the BMS only does consultation in the home. This is no good to my son so I work with the respite worker myself...Due to my son's high support requirements I would have to teach every new respite worker. I gave up respite for about a year and then I got sick...

An additional, but related, concern is stress associated with having strangers in the home for several hours a day. The presence of strangers in caregivers' homes compromises the family's privacy for many families. Caregivers express the difficulty of outsiders being privy to family matters: "Having home support workers in your house would drive you!"

Timely and relevant provision of information about services and resources is considered by many to be lacking. In some instances parents feel they are not equipped to know how to determine the services their child needs or how to go about getting them: "This is all new to us, so someone else who has the expertise can give you a nudge. It is important to have a person who could visit periodically and help you figure out where to go from here." In situations where parents are knowledgeable about what needs to be done they are required to plan well in advance and even then the outcome may be less than desirable: "I started negotiation for a pre-vocational placement three years before she finished school. She started one day per week." Further there is concern that social work service availability is not made known to the public. As one parent notes, "I didn't know until my daughter was seven that she could get support and service from the social worker." Or in some cases parents are unable, without help, to deal with unique problems: "There is no one there to teach you what to do when your child bangs his head on the floor."

Caregivers believe social workers should learn to recognize inequities in the distribution of resources or services. One caregiver expresses the view that access to services is based more on "ability to work the system" rather than on assessed needs.

Caregiving and Developmental Disabilities

Caregivers believe that social work knowledge needs to include a basic understanding of caregiving in relation to developmental disability. The caregivers in this study say that social workers need to know the unique challenges of providing care to a child with a developmental disability and how this is different than providing care to other groups. They contend knowledge is important in helping to safely manage problems such as violence and self-abuse, informing others about the relationship between developmental disabilities and medical conditions, and understanding the significance of routine in some individual's lives.

The caregivers believe that ensuring a loving and secure environment is essential for all persons. Social workers need to know the issues associated with balancing independence and protection in caregiving. These caregivers express fears about their children being taken advantage of, particularly sexually and in relationships: "she walks a lot. I have some concern with her being out there on her own, given her age and she says sometimes she was talking to someone on her walk. But most people in the community know her so I think it is fairly safe."

Caregivers underscore the importance of social workers knowing about issues involving life changes and their particular significance for those providing care, including parental fears about their child's future and their aspirations for their child. One person, when asked what she, as a parent, hopes for her child's future says, "Nothing more – nothing less – than everyone else wants." Another speaks more explicitly: "An ideal life for my son includes love, a feeling of accomplishment through work that is meaningful to him and a special person in his life." Some caregivers express fear for their child's future. One person admits reluctance to letting her child go: "I am scared for her future. I don't know how staying somewhere else over night will affect her."

There are strong views with respect to what social workers need to learn about the various aspects of developmental disability. Caregivers espouse that social workers do not have the necessary knowledge about developmental disabilities for them to offer appropriate support and services: "In the beginning social workers need to know more and I don't know how they go about learning this." They point out that social workers can't be expected to know everything about developmental disabilities but they do need to have a working knowledge: "I don't think anyone can know everything about a single disorder...But they have a general knowledge...They [individuals with developmental disabilities] are all going to display different behaviors anyway." The caregivers stress the importance of not placing limitations on developmental potential. For instance, some were told that their daughters and sons would not be able to learn anything. Their personal experience contradicts this. They taught their children many things. Specifically, one parent had this to say: "Some time later I happened to meet a lady doctor...she was interested to see him...she was really surprised and said it is because of you. He has done really well." This mother says she was determined that her son would learn to do things for himself despite being told this was not possible. Through this mother's efforts, her son learned to take care of his personal needs, learned to speak, and went on to do much more.

Integration and Inclusion

Social workers need to be sensitive to issues related to integration and inclusion, and the importance of being part of the community. Caregivers in this study identify this as a concern because their children are isolated from the community. There is a great distance between the espoused philosophy of integration and inclusion and the lived reality apparent in the lives of these individuals. While it is not politically correct to segregate individuals in our society, most of these individuals experience being cut off from the community. Caregivers believe that positive change has occurred, however, there is little in the way of full integration. The following commentary expresses this sentiment:

> Because people are no longer as segregated and as hidden as they used to be – and not living in institutions – everybody thinks the work is done – and it's far from done. Just because you walk down the same street doesn't include you at all.

Caregivers say that individuals and families living with developmental disabilities are not viewed as 'normal'. Some parents try to create possibilities for their daughters and sons appear as 'normal' as possible. One parent says, "I try to make her as normal as possible so people will look at her good points and not see her disability…I try to make her look as normal as possible so she will feel good about herself." Caregivers maintain that service cutbacks reinforce segregation and institutionalization, thereby diminishing opportunities for full inclusion and acceptance by the community. One parent explains:

> Because there is no real federal dollars transferred to the provinces that actually support natural families for persons with developmental disabilities to live very inclusive lives – that resources are very limited and that families – like ourselves – who are struggling feel like they've lost an awful lot of ground.

Parents argue that living an inclusive life in the community requires resources to create opportunities for persons with developmental disabilities to be involved in community life in the same way that others are able to experience.

Social Work Role

The social worker's role is not clear for many caregivers. They view social workers as primarily involved in administrative duties, including the approval of services and financial resources as well as helping with life transition periods through securing alternate residential care when needed. While contact with the social workers occurs during critical times, more contact is desirable, but not expected. It seems workloads do allow for that. Namely, social workers are too busy to maintain regular contact and provide a full scope of meaningful services.

Caregivers see regular and consistent contact with the social worker as important to a comprehensive social work service. Frequent social worker turnover was seen as quite problematic for most caregivers: "Sometimes you get a letter saying that your social worker has changed and you never met the last one." Caregivers consider that it is valuable to have a good working relationship with the social worker. However, it is difficult to establish such a relationship when there is considerable social worker turnover.

Social Work Values

Five categories of social work values emerge from discussion with caregivers. They are individual value and respect, integration and inclusion, the right to support and services, independence and autonomy, and the right to live in the community. Caregivers espouse that if social workers are committed to these values then they are able to provide them with meaningful social work services.

Individual Value and Respect

Caregivers see it as very important for social workers to show courtesy and respect in their contact with those receiving services. Many report experiencing disrespect from some social workers. A caregiver provides illustration of such disrespect: “Recently, the social worker called to have a meeting. Two people whipped through the house and actually wanted to ‘view’ my son. I will go wherever I have to go, to talk about the invasiveness of this process, of reviewing levels of individual support.” Others feel that their value and dignity is undermined by the fact that some social workers do not even take the time to get to know them or provide help to them in a timely way. As one parent says, “It is very difficult to get access to a social worker and when you do, requests for service are oftentimes turned down over the phone.” Another advises, “Here we spent years trying to get service when our daughter was younger and never did get any. It was like knowledge about service was being kept from us.”

Many caregivers struggle with ways to create value in other people’s eyes for their daughters and sons. As one parent reports, “…he has different abilities.” This parent tries to emphasize her son’s strengths so he is viewed positively. Efforts to create this value are a never ending task. Many caregivers are involved in various consumer groups and agencies to advocate on behalf of their children. The following illustrates this point:

> Having a child with a disability is my life. I work and get involved in things to help my daughter. I was a member of the Parent Teacher Association and I was a Brownie and Guide leader. I am involved in the Association for Community Living and the Employment Corporation Board because of my daughter.

Sometimes sadness and grief are expressed by caregivers in relating how their children are viewed by others. One particularly poignant and revealing comment, reportedly made by a professional, is shared by a caregiver: "It's almost like training a pet." Such statements underline the lack of sensitivity encountered by caregivers in their struggle to create a quality life for the child.

Integration and Inclusion

Values promoting integration and inclusion are considered relevant for the primary caregivers, the care recipient, and other family members. Caregivers talk about a commitment to integration and inclusion as an important value that social workers should have. They express the belief that inclusion leads to appreciating individuals and encouraging the development of friendships. They do what they can to promote friendships as demonstrated by comments such as: "I think ahead wondering if she will have friends. If kids come to play in our garden I make sure they have a good time and I bring out a snack for them". Another parent comments, "There is one girl who has called and left a note in her book bag to say give me a call and we will go see a movie on the weekend. Whenever that happens I facilitate that contact as much as possible."

Inclusion, it is noted, honors difference and provides reality-based hope for all those intimately affected by developmental disabilities. Integration and inclusion, caregivers agree, becomes meaningful through being valued and respected and being a part of the group. Caregivers believe that if their child is really valued, their own lives and the lives of other family members would be closer to what it is like to be a real part of society as others in the community. As one caregiver declares, "Inclusion is an appropriate goal – what else is there? The work is far from done."

Right to Support and Services

The caregivers claim everyone has a right to support and services to meet their needs. Most express the view that services are provided, but not without experiencing a struggle. By way of illustration parents reveal their experiences: "Sometimes we have had to put up a fight to get the services but we have gotten them." Another caregiver reports, "We had trouble getting a gate for our yard but between ourselves and the day care we managed to get it…the day care taught us about what rules we could bend and how to get around them." Yet, another parent declares, "They [social workers] treat me like the money we require for service is coming from their own pockets."

Caregivers express the notion that the system must be needs-based rather than money-driven. Services are seen as useful when they are tailored to the individual needs of caregivers and other family members. However, available services are limited in scope and only available based on financial tests. In many cases, this results in the unavailability of much needed services. Thus, the issue is full access to service without the restrictions imposed by strict financial tests. As expressed by one caregiver:

> Whenever there is an economic downturn it is always those who are most vulnerable who are hurt. There are often problems with policies that come down from government; the cycle of poverty puts individuals and families on the margins. It doesn't matter what kind of poverty. Poverty can be poverty in terms of quality of life or access to necessary support services. I believe policy should be determined in the community.

Caregivers emphasize they have a right to know what services are available to support them, how to access these services, and obtain timely responses to their requests. One caregiver's request for service, to allow her son to attend pre-school, took years to approve; the child already started to attend elementary school. Another caregiver declares, "The social worker does not volunteer information. It's like having to haul information from the social worker. Lots of times I don't get answers." These caregivers often express not experiencing support service provision as a right, but rather, a hand-out begrudgingly bestowed upon them.

Independence and Autonomy

Caregivers' independence and autonomy are affected through their caregiving role and responsibilities. Many reveal feelings of being trapped and overburdened by caregiving duties with few support services available. Some report negative impacts on their careers, including situations where they were unable to accept promotions because of caregiving responsibilities. For instance one person says, "Having a child who has a developmental disability has affected both of us in terms of our jobs. We have not been able to take promotions that involved a lot of travel." Another person explains, "It's a barrier for me in terms of my career and my travel."

Others relayed a need to curtail working hours due to caregiving responsibilities: "I cut my hours of work in the summer so I only had to be away from the house for three hours in the morning." Caregiving responsibilities dictate the type of work for one caregiver, while others were not able to work outside the home because of caregiving responsibilities: "I took care of kids in my own home and had social assistance when my kids were growing up." Another parent talks about the fear of having to contemplate leaving employment because of caregiving responsibilities: "Good quality support was crucial because it was getting to the point where I would have to give up my job." Finally, there are the everyday stresses of being a primary caregiver and having a career as exemplified through these comments: "If she didn't have a student assistant then my daughter would probably not be able to stay in school for lunch. That would be a problem for me in terms of work. As it is now I have to pay someone to take her to school and pick her up". A second comment addresses sickness: "When she gets a cold it is significant. She usually will have to be absent from school for up to two weeks and then child care becomes an issue. Right now my mother is a big help during these times; however if she is not available then my work situation becomes difficult for me, as I have no support in providing care."

Social workers are considered essential to help caregivers achieve their goals. Nonetheless, caregivers are adamant that they, themselves, need to define their own goals. As one person put it, "I think the most important value is that social workers understand that this is that person's life. This is not their life and it can't be the way they want it to be." Thus, they emphasize the importance of the right to self-determination for themselves and their children. One caregiver speaks of the gap between their personal aspirations and the realities of what was available:

> The vast majority of individuals and people that I have met and interacted with over the years wish to be contributing members to our society, and wish to seek no more than what is necessary to assist them in enhancing and improving on a quality of life, which in many instances is too marginal or in a category of survival. And that's not what the mainstream many times had for them.

Right to Live in the Community

The right to live in the community is considered by all caregivers to be a basic human right. Because some individuals with developmental disabilities have been institutionalized in Newfoundland and Labrador in the past, some parents have concerns about their sons and daughters being institutionalized: "I totally disagree with people being institutionalized. I totally disagree with it and don't think it ever should have existed." One caregiver expresses fear of a return to institutionalization for some individuals in the future: "I think the lack of services to families will see the institutional doors open again." Caregivers consider the cost of supporting community living to be a determining factor in addressing the right to live in the community.

Some caregivers suggest that individuals be given the supports they need to live in the community regardless of the cost, while others suggested costs have to be considered. Caregivers who have concerns about cost factors contend that the costs for community living need to be reasonable. As one person put it, there is a limit to the resources that can be allocated to support services; it can't be a "pie in the sky" approach. Although it is believed by some that demands can not be made when financial resources are not available, according to one caregiver, the dilemma of "how you decide who gets service and who goes without" is an issue. Some caregivers acknowledge their need for extensive support to enable their child to remain in an appropriate home environment and participate in community life. It is clear that the question of money remains tied to quality of life. One caregiver emphasizes the need to be creative in ensuring quality of life and the importance of everyone reaching out to involve all stakeholders in the process:

> It's not just about money. We have to think more creatively about ways of doing these things. We need to engage everyone in the process. All people should have the opportunity to live the life of their choice. Some of those individuals really require supports in expressing those types of choices. I believe there are many creative ways to look at the whole business of cost.

The caregivers, in this study, are torn between the need for responsible services that enable a quality life for their child in the community and the high costs that may be attached to this goal. The caregiver's suggestion of the importance of involving everyone in the process to look for creative solutions points to the potential benefits that can be achieved when everyone, including the caregivers, works together to support persons with developmental disabilities.

Social Work Skills

The caregivers reveal a number of social work skills necessary to ensure their having access to meaningful social work services. These skills are personal attributes and awareness, advocacy, assessment, education, counseling, relationship building, communication, service coordination, and integration and inclusion. Caregivers identify these skills in conjunction with the knowledge and values described above.

Attributes and Awareness

The attributes of individual social workers together with their having a fundamental awareness of the power differential between them and the caregivers is a concern for many caregivers. Social workers' way of being with caregivers - how they present themselves and how this presentation influences the sense of power and respect caregivers feel - is an issue. Caregivers report that most of their contact with social workers is through telephone conversations. However, they put forward the view that social worker visits, and their "being present", is more helpful. When physically present social workers can gain a fuller understanding of the challenges caregivers face. This is illustrated by one caregiver who contrasts a telephone call with one social worker and a visit from a second social worker:

> When my son needed home care the first social worker said no. The second social worker came to visit. We talked about everything. The service was approved.

> Nothing had changed in my circumstances when I talked to the first and second social worker.

The importance of social workers being sensitive to and aware of the power and control they often exert over caregivers' lives is expressed. Social workers' power to affect quality of life is illustrated through this comment, given by one caregiver: "I feel trapped because I can only go out when the social worker agrees for someone to come in so that I can go out." Caregivers show dismay with frequent changes of social workers assigned to work with their family: "It's hard to tell your story over and over." There is also the feeling that social workers should take initiative and be more active in reaching out and working with families. Some understand this to be a workload issue for social workers. Although they acknowledge this difficulty, they stress the importance of families being accommodated:

> Social workers here tend to be reactive rather than proactive. And I think it's a disservice to the consumer and the social worker. It's hard to always be going and putting out fires...And that's where the frustration comes from with families.

Concerns regarding a lack of respect on the part of social workers are given by some caregivers. One states it this way: "I went to see the social worker at one time and she didn't treat me well. She kept me waiting and didn't even acknowledge that I was there. ...It was as if I wasn't there. I wouldn't treat anyone like that." What is disrespectful about this scenario is that the social worker did not treat the parent in a valued way. Another caregiver tells of a different experience about respect. This example concerns respect for caregivers needs: "We had to have meetings at 4:45 p.m. after my daughter got off work. The social worker refused to come because it was after normal work hours."

A number of personal attributes are cited as positively affecting working relationships between social workers and caregivers. Appreciation is expressed for those social workers who are open, engaging, kind, and friendly. One caregiver highlights the important personal attributes of kindness and understanding: "She is good; it is not being good, it is being kind and understanding what you are going through that is important." Another stresses the need for social workers to have empathy: "Empathy is most important for social workers. They need to be more human and not just tell you about rules and regulations." Still, other positive attributes that caregivers identify include demonstrating compassion, integrity, honesty, flexibility, and being genuine.

Advocacy

Caregivers identify the skills of advocacy as fundamental to the provision of meaningful social work services. The significance of this social work skill is shown in caregivers' comments, such as, "[t]he people in society who get short-changed are the people who cannot speak for themselves." The advocacy role for social workers is also linked to caregivers' advocacy responsibilities and the situations they face that require them to advocate on behalf of their children. Advocacy is seen as necessary in every service area and it involves the ability to advocate for services, within services, and between services. As one caregiver explains:

> It is very intimidating for any parent to go into a meeting with a teacher, a guidance counselor and a principal to discuss what's best for her/his child. An advocate would be very helpful. I think a parent needs to be helped to deal with professionals and supported to attend meetings. The social worker could provide some help.

Further, advocacy, it is felt, can assist caregivers rectify difficult situations with groups/agencies (e.g., advocate for support services and appropriate access to these services). One caregiver states, "The social worker can be an advocate for us at school and in dealing with medical professionals." In another situation, a caregiver reveals the impact of not having a social worker to advocate for timely services:

> Social workers need to understand what families go through. I know you have to go through the necessary steps to get a service but it shouldn't take months and months. I never know until two or three weeks before the summer program begins if I have the necessary support service for my daughter to attend the program. I have needed a consultation for a toilet training program for months and I still don't have one.

Caregivers also talk about advocacy as promoting public awareness. Some believe advocacy is needed at all levels for social change and the promotion of caregiver rights and assistance with caregiving. Social workers need to advocate for caregiving support and services that enable caregivers and other family members to have choices about how they live their lives.

Assessment

Caregivers espouse the importance of social workers talking to those who provide care in order to carefully assess needs. They believe comprehensive assessments look beneath the surface and are more helpful in assessing needs and identifying potential resources. This conviction is evident in one caregiver's statement: "I would really like for the social worker to come in and observe what is happening in my home and talk to me in person, not just on the phone."

The imperative of understanding the care recipient's needs in assessing caregiving requirements is professed by caregivers. They contend that a meaningful assessment of an individual with a developmental disability involves assessing the individual in terms of strengths and abilities, and not simply determining the expected level of development for a particular age. An individualized assessment, they believe, should result in a complete and accurate picture of the level of ability, including verbal and comprehension skills, and the individual's willingness and ability to comply with requests and/or expectations.

A full social work assessment, from the caregiver's perspective, involves looking at all of the individual's characteristics so as to be able to determine the individual's needs, as well as those of the caregiver. Some caregivers note that persons with developmental disabilities present themselves in ways that do not accurately communicate their abilities or potential. Social workers need to work closely with caregivers to obtain a full and accurate picture of both strengths and weaknesses. One caregiver states why this was so important: "My son is an expert at getting people to think he understands everything they say just to be able to finish a meeting; he may not understand what is being said at all." This underlines the importance of an accurate and complete social work assessment.

Education

Social workers providing information and education enable caregivers to know and understand the social worker's role and the supports and services that are available. Some caregivers say they do not know what social workers really do or what supports and services are available to them. Caregivers' comments illustrate the lack of knowledge about social workers and how they are able to be of assistance to them. One caregiver asks: "What is the source of access to social workers? How does the public find out about services?" Another caregiver points out:

> It's a pretty sad commentary that he would be twenty five years old and I would have no knowledge of what a social worker can do and I have had contact with numerous professionals and no one mentioned a social worker before...There must be a lot of individuals doing it on their own as we have.

Yet another caregiver declares: "People who have a child with a developmental disability don't have a clue about what it is that social workers do."

Caregivers believe that social workers need more of a public presence, assuming the role of an information broker for available resources on an on-going basis. They feel that social workers can educate them and other family members on the various aspects of developmental disability. Such information includes possible challenges as well as opportunities for caregivers in obtaining services. Many caregivers report that social workers do provide some information and education; however, they express a need for much more. One person notes social workers can teach them "what to say" in order to access caregiving services. Caregivers sometimes feel uneasy when they meet with a social worker. They are afraid they won't say what needs to be said in order to obtain needed services. One caregiver explains: "I have been in the social worker's office and I am very shy there. I am very careful about what I say." Finally, it is felt that social workers should be engaged in a larger role of public education in relation to persons with developmental disabilities. Many of these parents do what they can to promote public education. They maintain that social workers should work in partnership with them. As one caregiver says, "We are on the same team and we need to be a support to each other...What a catalyst – when you think about it - it is phenomenal!"

Counseling

For most, the birth of a child is a positive and much anticipated experience. But for some the reality can be very different. "I saw my baby after three days of mourning" are the words of one caregiver. According to this parent, counseling is very important and should start at the time of diagnosis. Parents are most concerned that their child, when born, is a normal, healthy child. When this does not happen the effects are traumatic for parents and the family. Following the early stages of diagnosis parents experience all of the phases of loss, grief, and trauma. Many feel that their hopes and dreams have been crushed. In helping caregivers and their spouses, it is considered important to understand the family and the nature of the trauma they are experiencing. This includes identifying the phases of working through the trauma, grief, and finally moving to acceptance. As one caregiver says, "It is important for social workers to be with people, understand and help them through." Social workers really need to be there for the individuals and families at this time when they are in acute pain to offer counseling, understanding, and support.

Counseling can help people deal with crisis by teaching coping strategies, problem solving, working through feelings, and helping people acknowledge both their strengths and limitations. A caregiver illustrates how the social worker can help parents realize their limitations: "It was the social worker who said, 'you are walking a thread, let's look for independent living arrangements'." Another caregiver talks of how a social worker can help during difficult times: "Through all the stressful times if there was a social worker visiting periodically this person would help me realize when I need a break or a social worker might be able to tell me what services are available for me."

Caregivers think that social workers should be there to address other family issues as well. Some see social work to be a potentially powerful, positive force particularly when social workers are caring, supportive, and providing, as one caregiver put it, "a friendly ear". Social workers need to take a holistic approach. A caregiver who experienced this approach reports: "The best thing about dealing with social workers is they have tried to understand my situation." On the other hand, feelings of powerlessness and despair are prevalent for some caregivers. One parent expresses her sense of helplessness with respect to her ability to help her daughter:

> The most difficult thing about her life is not being around other people a lot. The people she spends time with are at the day care and otherwise she doesn't see people. I am satisfied with my daughter's life. I am not going to get anything else for her and what I have is working.

This comment is indicative of a caregiver who has no hope. This caregiver could benefit from social work counseling that takes into consideration the whole family situation.

Life transitions (e.g., beginning school, beginning employment, moving to a new home, and changing caregivers) are identified as areas of social work intervention where counseling can be critical. Social workers, it is felt, can help caregivers and other family members during these times of transition. Transition is especially traumatic with respect to caregiver's planning for their child to move out of the family home, when caregivers themselves can no longer provide the necessary care. Social workers involved in this process can provide counseling to help caregivers deal with their fears and anxieties. One caregiver expressed fear about her daughter moving out of the family home. She says, "Thinking about her living with another family is a big burden for me. I know I have to put my feelings aside and think about what is best for her." In such situations, a social worker can work with the caregiver to explore actions that can help allay the caregiver's concerns.

Relationship Building

Social workers, who take time to visit regularly and schedule regular reviews, help build meaningful relationships with caregivers and their families. The beginning of the relationship, according to one caregiver, sets the stage for developing a positive relationship: "being able to reach a social worker on the phone is a start." Caregivers see social worker visits, their experiencing firsthand what is happening in the home, and talking about everyday challenges and successes, as being important to relationship building. By way of illustration, one caregiver maintains, "The social worker needs contact, meeting face-to-face for the initial meeting is important. There needs to be follow-up. You have to build a good rapport, respect, and show you are on the same team." They contend that relationship building depends on demonstrating interest, understanding, compassion, and empathy. Openness and trust is identified as a fundamental element of relationship building: "For a long time I would not call a social worker because of a bad experience ... I trust the social worker less now even though that was many years ago." The importance of full disclosure concerning services is emphasized in building a positive relationship. As one caregiver espouses, "Sometimes you have a sense that social workers are not supposed to tell you what's available." When caregivers believe social workers are not forthright and honest with them, the possibility of establishing a solid working relationship is jeopardized.

Communication

Good communication is fundamental to effective social work intervention. Social workers who are able to provide clear and concise information are appreciated by caregivers. Effective communication includes the use of understandable language and the avoidance of jargon when talking to caregivers. Caregivers feel that the way social workers communicate demonstrates if they are truly empathetic and caring. This is illustrated by the following comment: "You can cry on someone's shoulder, [and] they say, with no feeling, 'there is nothing we can do'. They don't say 'no' in a way that says I'm sorry...that's difficult." Caregivers consider truly caring social workers to be people with good listening skills, and who demonstrate a real interest in people's life story. They believe that good listening skills are fundamental to effective communication. As one person says, "You can get everything off your chest if the person is a good listener." Some caregivers acknowledge that their communication manner can also affect the level of social work support they receive: "The way you talk to the social worker is important. If you are polite you get more done." They discuss the importance of both social workers and caregivers demonstrating effective communication.

Caregivers believe social workers should be able to communicate, albeit sometimes in a limited way, with their children. This may require options other than verbal communication in some cases. One caregiver talked about how a social worker related to her son: "She was really uncomfortable with him. She was more comfortable talking to me. You could tell because her body language was different. When he approached her she wasn't warm towards him." Caregivers maintain that social workers need to be able to relate positively with their children.

Service Coordination

Social workers can be instrumental in coordinating necessary supports on behalf of caregivers and their children. Service coordination skills require the ability to match individual needs and wants with services and resources, including keeping abreast of new programs and service availability, changes, and services being planned. Social workers are frequently seen as lacking interest and not taking the appropriate initiative. One caregiver cites an example where another professional provides a service that is within the realm of social work services: “The social worker was not the one who referred me to the behavior management specialist, the doctor did.” Many caregivers are dissatisfied with the piecemeal manner in which services are provided. This is illustrated through such comments as: “There were pockets of service.” Or as another says, “My only contact with the social worker was when my daughter needed transportation.” Yet, another reports, “The first social worker saw my son when he was one year old and the second became involved when he started school.” These comments indicate that in some situations on-going service coordination is a missing element in social work practice with these caregivers.

In some instances, primary caregivers lack self-confidence in dealing with social workers. They often do not know, for instance, the questions to ask. As one caregiver explains, “I felt totally uncomfortable seeking services. When respite was mentioned I had no idea what I should be asking for. I am only a mother and I am not in that field. I don’t know all the jargon. How do I know what I need?” This comment clearly shows one caregiver’s feelings of frustration and inadequacy in working with social workers to secure support services.

Social work brokering skills to foster liaisons between caregivers and service systems can improve the quality of relationships and quality of services. Caregivers suggest that social workers can be helpful in navigating and negotiating complex and conflicted systems, and addressing problems associated with service delivery. Moreover, social workers are seen as being able to work around policies and create ways to be flexible and compensate for limitations or gaps in the service system. One caregiver describes a positive service coordination experience with a social worker:

> My social worker is excellent and has a good attitude towards people with a developmental disability. She totally understands our family situation...The social worker wasn't sure I could get the services I needed. My daughter has a respite worker fifteen hours a week. She has a respite worker for forty hours per week for summer program and if I need any other service like behavior management service she will work on that.

According to caregivers, service coordination requires an ability to help plan for an individual's future, including skills in accessing and creating new services. As one person says, "A social worker can be an overseer in her life." The social worker is considered appropriate to help plan for the time when the parent is no longer able to be the caregiver. By way of illustration, a caregiver has this comment:

> I have started to make long term plans for my daughter. I have talked to the behavior management specialist and the social worker about future plans...social workers need to listen to me. They need to listen to what I want for my daughter and how important that is for me.

This works best when social workers and caregivers work together in partnership.

Active and creative transition teams are seen as vital in times of transition and change. For caregivers, teamwork means having everyone who is involved as part of a planning process. One caregiver captures this sentiment in this way:

> This is a whole person. Not a person you can cut up into little pieces to send...one portion off to the health care system, and one portion off to the education system and one portion off to social services and one portion off somewhere else. This is a whole person who has whole needs.

Caregivers are clear about the need for a more holistic approach and the importance of service coordination to improve quality and access to service.

Integration and Inclusion

Caregivers view integration and inclusion as meaning more than simply being in the community with others; it means participating fully in community life. One caregiver who is actively pursuing inclusion wherever possible says, "A social worker could help me figure out possible summer activities for my daughter." In a similar comment, a caregiver states, "She [social worker] would have identified the need to develop friendships in school." Social workers can foster acceptance and inclusion through involvement with the community. According to one caregiver, "They [social workers] need to have education and promote public awareness. Social workers should be out there." These caregivers acknowledge that social workers can promote integration and inclusion.

Summary

This chapter outlines this study's findings regarding parent caregivers' perspectives on meaningful social work services for them in caring for their children with developmental disabilities. This information is presented through the mirror of their lived experiences and what they make of those experiences. The poignant caregiver quotes demonstrate contextualized real life examples that support knowledge, values, and skills necessary for social workers who work with them and on their behalf. The final chapter presents a discussion of these findings.

CHAPTER FIVE:

DISCUSSION

The 15 parent caregivers in this study provide comprehensive information on the nature and extent of social work services experienced over their lifetime of providing care. The emerging issues and concerns are far reaching and provide an in-depth picture of their lives as caregivers, and their struggle to provide some measure of dignity and quality of life for themselves and their children. This chapter addresses a) the study's findings relevant to social work knowledge, values, and skills; b) emergent themes from the findings; c) implications of the findings for social work practice, the profession of social work, social work education, and social service agencies; d) the study's limitations; e) future research relevant to this study; and f) a summary and concluding remarks.

Social Work Knowledge, Values, and Skills

A review and analysis of the findings provide a basis for several conclusions and recommendations regarding the strengths and deficits in the knowledge base, values, and skill sets of social workers working with this specific population. Three main categories are discussed; a) specific and general social work knowledge, b) social work values, and c) social work skills. Discussion, in each category, provides an organizing framework to extrapolate general themes and implications relevant to social work practice and social work education.

Specific Knowledge

Caregivers' perspectives regarding specific knowledge include the areas of caregivers' lives in St. John's, Newfoundland and Labrador, developmental disabilities, and local programs and services. The findings raise questions relevant for this particular group of caregivers, in the context of their geographical location, while suggesting general social work knowledge implications.

Caregivers' Lives in St. John's, NL.

The findings reveal that the social workers involved with these parent caregivers have a limited understanding with respect to the challenges these caregivers face, and how their personal and family lives are affected. This is evident through a perceived lack of social workers' interest and appreciation based on their spending little time with caregivers and, indeed, often providing services via telephone calls. While the caregivers report little involvement with social workers, the research literature supports the importance of social workers having in-depth knowledge of individual caregiver's personal lives and circumstances (Collins, 2000; Cooper, 2001; Dominelli, 1996, 2002; Ife, 1999; Kirst-Ashman, 2003; Land, 1995). For example, Ife (1999) maintains that every event in a person's life needs to be viewed in context and understood as part of a complex system of interconnections. Social workers, having such an understanding, can assist caregivers in moving forward to deal with individual issues in a way that acknowledges the caregiver's construct of reality for each situation (Cooper, 2001).

This finding seems to suggest that social workers are not engaging in the fundamental basis of professional social work practice, that of establishing positive relationships and developing a comprehensive understanding of the individual's life circumstances. It brings into question whether or not they have acquired this knowledge as part of their social work education. Why is this basic social work knowledge not evident in their practice with these caregivers?

There are a number of possibilities that can account for this situation. One, it is possible they did not learn this knowledge as part of their social work education. Two, perhaps the person with a developmental disability, and not the parental caregiver, is seen as the primary client. If this is the case then getting to know the parent caregivers within the context of their lives and needed support services may not be seen as a priority for social workers. Three, it may be that social workers have not been socialized or taught to view parental caregiving as a social concern. Similar to the larger society, they view it as a private issue and, therefore, social work intervention is of minimal concern or importance. Four, perhaps this is a workload issue. It was noted that social workers, who provide service to these caregivers, are responsible to provide services to many individuals and families. In addition, their workload assignments change frequently. Therefore, they may not have the time to get to know the caregivers. Five, it may be that agency policies and procedures place little emphasis on the importance of understanding personal situations and establishing relationships. Six, another possibility is that some social workers practice from a traditional perspective seeing themselves as the experts with all pertinent knowledge, who do not consider establishing a relationship to be essential in determining caregivers' service needs. Irrespective of the rationale, it is imperative that social work education, the profession, and social work agencies come to recognize and address this gap in social worker knowledge.

Developmental Disabilities.

Caregivers report that social workers' knowledge about developmental disabilities is often absent. Their espoused concerns support the timeliness of developmental disabilities emerging as a field of practice for social work, and a concentration within social work education (Dinitto & McNeece, 1997; Dunn et al., 2006; Kirst-Ashman, 2003). It is important for social workers to know about the nature and characteristics of developmental disabilities, its historical origins, and development. Additionally, the lack of social value experienced by persons with developmental disabilities evidenced by marginalization and oppression, rather than, valued social roles, integration and inclusion, is information that is critical to this field of social work practice.

Many caregivers in this study declare that social workers do not fully understand the history of disabilities nor the isolation and shame often attached to being a parent of a child with a developmental disability. Vanier (1998) maintains that people with developmental disabilities are among the most oppressed and excluded people in the world, amplified by the shame many parents feel because they gave birth to such a child. The lack of this specific knowledge, on the part of social workers, makes it difficult for caregivers to obtain helpful and relevant information.

The issue of specialized education within the area of developmental disabilities brings to the fore whether or not social workers need to have knowledge about every area of specialized practice. There are many different fields of social work practice making it difficult to provide education in every area as part of a baccalaureate program. However, knowing about developmental disabilities is critical to helping caregivers from both an ecological and a social justice perspective. The question becomes how does the social worker obtain the requisite knowledge in this area? Is it the responsibility of social workers, agencies or schools of social work? It is imperative that each of these three entities accept joint responsibility to help address the knowledge shortfall.

Local Programs and Services.

Findings in this study suggest that many social workers lack specific knowledge of services available in the community where these caregivers reside. As such, parent caregivers are less than optimally served. They contend that social workers can play an instrumental role in obtaining and coordinating service, especially in situations where caregivers have difficulty doing this for themselves. Caregivers see this role as being essential for social workers. Helping to match service needs with appropriate services requires a thorough knowledge of local agencies, programs, and services. Social workers need to know the people involved in providing services, and essential elements of effective brokering and working collaboratively with others to ensure caregivers' service needs are being addressed on an on-going basis (Boyle et al., 2006). These caregivers also view social workers as falling short in assuming an instrumental case management role. There is clearly a responsibility for agencies, as well as, social workers to ensure that they have knowledge about local programs and services. Moreover, social workers need to learn the elements of effective case management as part of their professional education.

General Knowledge

The general social work knowledge categories are discussed under the headings of social work intervention strategies, social policy, and gender oppression. The findings reveal that each of these categories is important to social work knowledge in working with parent caregivers of persons with developmental disabilities.

Intervention Strategies.

Social work intervention, as experienced by these caregivers, is limited to the social worker deciding what services would be approved in response to caregiver requests. Caregivers feel that social workers need to be more proactive and involved in advocacy and social action with them to advocate on behalf of their children. The empirical literature suggests that advocacy for parent caregivers can increase or reduce the stress in their lives depending on the circumstances, outcome, and relationship they have with professionals (Nachshen & Jamieson, 2000). Services lacking social action are considered to be inappropriate (Armstrong & Armstrong, 2004; Baines et al., 1991, 1998; Collins, 2000; Dominelli, 1996, 2002; hooks, 2000). Caregivers, in this study, provide little evidence to suggest that social workers are either skilled or comfortable in advocacy or social action roles.

Advocacy and social action present a challenge for social workers and for social work education. Although social action is espoused, individual intervention on a case-by-case basis appears to be the predominant mode of practice (Chappell, 2006; Rose, 2000). Caregivers, for the most part, are dissatisfied with social work services being provided in this manner. An alternative is interventions that are driven by feminist social work theory embracing social action as a significant knowledge requirement (Baines et al., 1991, 1998; Collins, 2000; Dominelli, 1996, 2000). While CASSW (2000) accreditation standards stress anti-oppressive practice education, there is little evidence in this study to suggest that social workers use the principles of social justice and anti-oppressive practice. Perhaps the social service agencies do not promote or support this mode of intervention. Or, it may be that while anti-oppressive practice is present in accreditation standards it is not being taught in schools of social work.

Social Policy.

Social policy has significant implications for caregivers. Current social policies governing care are forcing caregivers into an existence that oftentimes is marginal. They do not have access to the resources that allow them to live their lives as others do. Canadian social policies are based on the assumption that the family is the best social location for caregiving (Armstrong & Kits, 2004). Further, caregiving responsibilities, from a social policy perspective, are generally considered a private issue rather than a public concern (Neysmith, 2000). Not connecting the private and public realms creates difficulties for these caregivers given that much of their caregiving is predicated upon available public support services. Viewing caregiving as a public responsibility as well as a private responsibility recognizes this connection (Armstrong & Armstrong, 2004; Neysmith, 2000).

Although caregivers express a need for more public services, they continue to view their role as appropriately located within the venue of the family. Of immediate concern to them is the need for enhanced services and social support as they continue to assume the primary caregiving role. It can be argued that there is a responsibility for social workers to help caregivers deconstruct their traditional social views of caregiving. This can be accomplished by exploring the government caregiving agenda using means such as consciousness raising to assist caregivers to come to view caregiving as work deserving of dignity, respect, and value (Baines et al., 1991, 1998; Dominelli, 1996, 2002).

Working in partnership with social workers to address social policies is seen by some caregivers as a way to obtain optimal support services by availing of every possible opportunity for help. To this end, caregivers express that it is important for social workers to have a comprehensive knowledge of social policy. Kravetz (2004), in exploring issues pertaining to social work with women, underlines the importance of social work knowledge that creates an understanding of the linkages between caregiver problems, social policies, and social, political, and economic structures. Such an understanding can result in social workers helping caregivers become aware of the political and economic realities underpinning social policies pertaining to service availability. Also, this understanding will help to heighten awareness on the part of caregivers about the personal and political disconnect and how this is associated with gender oppression. Social workers do not appear to have knowledge in this area. This gap in knowledge is a significant disservice to these caregivers. Without the knowledge, social workers can not help them to understand their oppression.

Gender Oppression.

The oppression of women is central to feminist social work theory (Collins, 2000; Dominelli, 1996, 2002). According to Dominelli (1996), anti-oppressive elements of feminist social work involve working with caregivers (individually and in groups), raising their consciousness regarding the oppression they experience, and subsequently helping them to become empowered.

Caregivers report experiencing difficulties due to caregiving responsibilities placed upon them without having adequate support. They do not articulate a view of themselves as being oppressed, but rather, as mothers who need more services to fulfil their role as natural caregivers in their family. From their expressed understandings, it appears social workers are not discussing with them issues of gender oppression associated with their status as women and caregivers. If social workers do share such a perspective with them, it has little or no effect on how they view themselves. These caregivers do not express being aware of their oppressed status. They perceive their situations as simply an extension of the disenfranchised status experienced by their children. As noted above, this is a disservice to caregivers because they are denied an opportunity to improve their life situation through exploring their own agency.

An anti-oppressive approach, fundamental to social work feminist theory, is relevant knowledge for social workers who work with parent caregivers. They need to know that caregivers are usually women who have been delegated caring work and have little or no choice in assuming this responsibility. Social workers require an awareness of the ways in which these caregivers experience oppression (e.g., insufficient support services). Moreover, they need to know about modes of intervention that can help raise caregivers' consciousness and assist them to find their own agency and develop an empowered stance.

Values

Social work values, deemed important from the perspective of the caregivers, include the areas of inclusion and integration, strengths-based principles, and power, empowerment and anti-oppressive practice. The values espoused in these areas are fundamental to effective social work practice.

Integration and Inclusion.

The findings in this study attest to what is stated in the literature about the relationship between caregiver parents and their children with disabilities. Caregivers see their children as being isolated, ridiculed, and without essential resources to help them become contributing members of the community. For them, this is a heart-breaking situation. While they acknowledge society to be more tolerant of persons with developmental disabilities today, they believe more acceptance is required. Several researchers give support to the view that persons with developmental disabilities continue to be isolated in the community and need help to become contributing members of society (Condeluci, 1995, 1996; Hanes, 2006; Roeher, 1996, 2000; Vanier, 1998). This study's caregivers see little evidence of social workers valuing integration and inclusion during their contact with them. Rather, social workers' prejudiced beliefs have sometimes negatively affected service provision.

These caregivers concur with the literature that suggests social workers have not played a lead role in promoting social acceptance and inclusion for people with developmental disabilities (Condeluci, 1996; Hanes, 2006). Why is this the case? Is it because social workers like others in our society do not value and respect persons with developmental disabilities? Have they not been given the exposure they need to truly get to know such individuals? Spending more time with vulnerable people can lead to valuing them and their experiences (Begab, 1970; Burge et al., 1998; Cole et al., 1989; DeWeaver & Kropf, 1992; Dickerson, 1981; Dunn et al., 2006). Social work students and social workers need this exposure to witness first hand the social injustice experienced by this group.

In addition to field experience with parental caregivers and their children with developmental disabilities, values clarification education can lead to positive change in one's own values and beliefs with respect to all vulnerable people (Boyle et al. 2006; Heinonen & Spearman, 2006; Johnson, 1998; Reamer, 1994; Vass, 1996). CASSW (2000) accreditation standards strongly support education in the area of anti-oppressive practice. It may be that schools of social work need to closely examine their curricula to determine the extent to which social justice and anti-oppressive practice are incorporated into their curricula. A central component to anti-oppressive practice is a strengths-based orientation.

Strength-Based Principles.

Based on what caregivers report, in this study, they use a strengths-based approach with their own children. Caregivers declare they have taught their children and advocated for them based on a belief in their abilities and strengths. Such efforts often result in success well beyond some professionals' expectations. For example, one caregiver reports that when she brought her child to a health clinic the doctors were amazed at the developmental milestones the child had achieved. They congratulated the mother for having taught her child so much, even though she was told initially that her child had significantly limited developmental potential. These caregivers, based on their belief in their children's potential strengths, could easily adopt a strengths-based perspective with respect to their own lives. Social workers, firmly grounded in strengths-based principles, are able to work with caregivers to identify their strengths and seek solutions that work for them (Baines et al., 1991, 1998; Dominelli, 1996, 2002; Nes & Iadicola, 1989; Pardeck et al., 1994; Saulnier, 1996).

The caregivers, in this study, report that there is little evidence to suggest that the social workers involved with them work from strengths-based principles. The approach they describe is more in keeping with traditional social work intervention, with the worker being the expert, assessing and determining the services that would best serve caregivers' needs. Caregivers provide little commentary about feeling they have an opportunity to explore their talents and their strengths. The caregivers report that a strength-based perspective would have been beneficial in terms of intervention.

Power, Empowerment, and Anti-Oppressive Practice.

Caregivers report feelings of apprehension when dealing with social workers. They indicate being careful of what they say or how they speak, for fear of negatively influencing any service approval. For example, one caregiver reports that other service providers in the community helped her determine what to say to the social worker in order to get a gate that would keep her child safe when he went outside to play. Another caregiver contends that social workers need to understand the power they have in the lives of caregivers. Many caregivers express feeling little personal empowerment. In truth, some experiences they report suggest they are being oppressed by the social worker. For example, one parent was required to wait for long periods of time to obtain social work support even though she could no longer deal with her child's behaviour and keep herself safe from harm. In this situation the inaction of the social worker resulted in harm to the caregiver. The gravity of such a situation requires social workers to re-examine the fundamental purpose and mandate of the profession.

These caregivers' comments support what Dempsey and Foreman (1997) and Nachshen (2005) assert - that empowerment is not evident in social work practice. Anti-oppressive practice supports empowerment and embraces feminist thinking and principles (Baines, 2007; Collins 2000; Dominelli, 1996, 2002). Social workers practicing from these feminist perspectives consider caregivers as partners. Caregivers and the expertise they bring to the relationship are valued. The use of empowerment perspectives provides a basis to deconstruct social and structural issues. Advocacy for positive change within social service agencies and government structures is given prominence (Baines et al., 1991, 1998; Dominelli, 1996).

Empowerment perspectives present challenges for social workers generally, but more so when they are providing services to individuals and families such as the caregivers in this study. Many social workers work in public social welfare systems, and are often preoccupied with enforcing social rules within prescribed fiscal parameters. Social workers in these positions are expected to maintain the status quo rather than advocate for social change (Rose, 2000). This is contrary to the social justice obligation of social workers as outlined in their Code of Ethics (CASW, 2005), and the CASSW (2000), accreditation standards requiring schools of social work to teach skills that enable social workers to engage in empowerment and anti-oppressive practices. Caregivers' experiences suggest that there are benefits to be gained if empowerment and anti-oppressive practices are applied in their particular circumstances. The challenges are the acceptance and application of empowerment principles within social work agencies and ensuring social workers have the requisite practice skills. Caregivers' experiences show strong support for change in these areas.

Skills

Social work skills identified by the caregivers suggest the significance of active empathic listening, counseling from a feminist perspective, service coordination, and advocacy and social action. These skills are relevant to all fields of social work practice. According to these caregivers they are the skills most particularly relevant to social work with them.

Active Empathic Listening.

Caregivers report feeling at ease with social workers whom they experience as being kind and genuine. For example, one caregiver asserts that *how* she is treated means more to her than what services she receives. Skills in empathic listening facilitate positive caregiver feelings about their relationship with a social worker. Active empathic listening is a fundamental skill used in 'listening to individual stories' (Dominelli, 2002; Kirst-Ashman, 2003; Van Voorhis, 1998). These caregivers, as stated previously, are often cautious about what they say to the social worker, afraid this will affect approval of needed services. Social workers must understand caregivers' needs to feel comfortable and open in their discussions with them. Further, they require the skills that will promote this level of comfort. Both, having an opportunity to learn these skills, and practicing them as part of their educational preparation are essential.

Counseling from a Feminist Perspective.

According to the feminist social work literature, it is important for social workers to begin with the caregivers' experiences, respecting their unique expertise and hence promoting egalitarian relationships. Social work counseling from a feminist perspective recognizes caregiving as important work and acknowledges the imperative to change others' views of caregiving from a private to a public responsibility (Baines et al., 1991, 1998; Dominelli, 1996, 2002; Parks, 2003). However, caregivers report caregiving as their personal responsibility and do not perceive caregiving as legitimate work in the traditional sense. This personal responsibility view of caregiving suggests that social workers, themselves, may not understand the legitimacy of such work. The recognition of caregiving as work of value that sustains the health and well being of others is critical to the empowerment of caregivers (Featherstone, 2005; Traustodottir, 2000). Intervention skills that do not explore and emphasize caregivers' awareness of caregiving as legitimate and valued work underscores the importance of increased skill development in this area.

Feminist counselling skills, including anti-oppressive social work skills, are fundamental to help parent caregivers become empowered to positively affect their life situation.

Service Coordination.

The findings of this study suggest that social workers do not consistently practice service coordination skills, even though caregivers cite a high need for help and assistance in this area. Many caregivers do not know what services are available or how these services can be accessed. Social workers seem to be lacking in this area even though caregivers contend this expertise is more appropriately vested with social workers. Social work literature cites brokering and case management skills as key in providing social work services to caregivers (Kirst-Ashman & Hull, 2003; Van Voorhis, 1998). The experiences of caregivers in this study suggest that such concerns merit further attention of the profession and schools of social work.

Advocacy and Social Action.

Caregivers report that they spend considerable time advocating for services on behalf of their children. They believe that social workers can and should provide support for them in this task. While some caregivers benefit from social work advocacy initiatives, advocacy is not viewed as a typical activity carried out by social workers. The study's findings confirm the literature's identification of advocacy skills as important for those who work in this area (Kirst-Ashman & Hull, 2003; Van Voorhis, 1998).

Advocacy and social action are important components in promoting change and securing needed social work services. On a micro level, social workers can advocate within social service agencies for individual support and improved services. Initiatives, at the macro level, can involve advocacy in such areas as social policy and the promotion of citizenship rights. Advocacy and social action can be positive influences for social change and require more attention in social work education and skill development.

Social workers involved in advocacy and social action typically assist caregivers and care recipients to speak out for their rights. If this were the situation, social workers would be involved in reviewing agency policies, advocating for policy changes, and working with communities to help them become more inclusive (Chappell, 2006; Mackelprang & Salsgiver, 1999). Caregivers, in this study, report little evidence suggesting that this occurs at present. This may be a result of what social work education lacks and/or what actions and activities social work agencies are prepared to support.

The literature suggests that while there is a renewed interest in social action in Canada, the emphasis continues to be on individual therapeutic intervention (Chappell, 2006). In fact, social work has been criticized by advocacy groups for its lack of attention to social action (Hanes, 2002). The difference between what advocacy groups recommend and the realities of social work practice is noteworthy. On the one hand, social action is being espoused in the literature, while individual traditional intervention on a case-by-case basis is the more common practice (Boyle et al., 2006; Chappell, 2006).

Historically, development in the area of social work practice and social work education has been influenced by the quest for professionalism (Austin, 1983; Popple & Leighninger, 1998). A preoccupation with professionalism placing considerable emphasis on therapeutic intervention strategies and little attention to social action characterized the profession of social work throughout much of the 20th century. Is it possible that this may still be the case today? If so, the profession needs to recognize the value of advocacy and social action as legitimate and effective functions in professional social work practice. This is particularly important in the area of service to disenfranchised populations where traditional methods have not been effective.

While advocacy and social action are given little profile in the lives of these caregivers, there is clear evidence of the appropriateness of such an approach. Both seek to transform oppressive conditions. The clear linkage between caregiver oppression, social policy, and structural issues points to the need for social reform. Social work that does not provide meaningful advocacy and social action services is a concern for social work education and practice, as the caregivers in this study suggest (Baines et al., 1991 & 1998; Chappell, 2006; Rose, 2000).

Emerging Themes

Reflection and analysis of the caregivers' perception of meaningful social work services and how their perception resonates with the social work literature, social work practice, and social work education suggest three salient themes. These themes include caregiver oppression, social and structural issues affecting social work intervention, and the need for feminist social work practice. The most predominant of the three is caregiver oppression.

Caregiver Oppression

The caregivers talk about their burden of care as affecting all areas of their lives. Many have engaged in a lifetime commitment to their child with no opportunity to pursue personal goals and aspirations. hooks (2000) defines oppression as a lack of choice concerning how people live their lives on a day-to-day basis. In applying hooks definition, these caregivers are surely an oppressed group. While they link scarce support services to negative effects in their lives, their oppressed status is not viewed by them as connected to their gender or social expectations with regard to caregiving. Women have traditionally taken care of the home and family, so caregivers appear to believe the responsibility for care naturally falls to them (Parks, 2003; Tronto, 1993). Gilligan (1982) suggests women, unlike men, have a socialized care ethic that teaches them to assume the caregiving role. This belief about their role as natural care providers reinforces an unquestioning acceptance of their oppressed status.

Gil (1998) defines oppression as "...a mode of human relations involving domination and exploitation – economic, social and psychologic – between individuals; between social groups and classes within and beyond societies; and, globally, between entire societies" (p. 10). In keeping with Gil's definition, many of these caregivers' reported experiences suggest they are economically, socially, and psychologically dominated and exploited.

Thomas (1993) says caregivers' and care recipients' needs are intricately linked. The caregivers in this study clearly articulate this linkage, and the resultant extraordinary caregiving responsibilities. In addition to a huge commitment to advocacy, their children's lifelong dependency often results in a lifetime of caregiver work. Some of these caregivers are of retirement age and still carry the burden of care. Further, 12 of the 15 caregivers are employed in addition to their caring work at home. Although some report working to be a break from their caregiving responsibilities, others experience working outside the home to be an additional but necessary burden.

During the deinstitutionalization movement in Newfoundland and Labrador many individuals with developmental disabilities returned home to receive care (Efford, 1990). Unfortunately, the necessary level of caregiver services and supports did not accompany this move and, in the long term, responsibility for care increasingly fell back to the family. Over time, this responsibility has become truly a burden of care and the situation worsens as support services generally continue to decline. These parents devote their lives to caregiving at great personal cost to themselves and their families, and with no recognition for their valuable work. This cost and burden of care with few social supports is a clear example of caregiver oppression. Caregiver oppression may be seen as a direct result of social and structural conditions.

Social and Structural Issues

As noted earlier, the literature describes care and caregiving as a function that is viewed by society in general, and women in particular, as a woman's issue. It is seen as essentially women's work, irrespective of age, income, employment status, and cultural or physical location. Social policy that places caregiving responsibility with families defines women as caregivers, thereby linking the caregiver role to women in our society

(Armstrong & Kits, 2004; Neysmith, 2000).

The lack of supportive services for care and caregiving is evidence of the little value placed on caregiving roles. While most caregivers are women, social policies that dictate available support and services to help with the caregiving role are determined by governments predominantly led by men (Baines et al., 1991, 1998). This raises the question; if caregiving was men's work would there be more support services to help with this work? Through providing care, men would have an opportunity to experience and thus appreciate the numerous challenges associated with such caring work. Such an appreciation could promote an awareness of the potential public cost of all caring work being performed by paid caregivers. An appreciation for caregiving work and the associated costs, if caregivers had to be paid, has the potential to create a political climate more conducive to supporting this work.

Neysmith (1998), in discussing the transformation of private responsibility for caregiving to a social responsibility, identifies the importance of degendering caregiving (i.e., men and women assuming equal responsibility in caring). This less rigid role definition of caring, as no longer associated with gender, could potentially ease caregiver burden. However, caregiving as a public responsibility has many challenges. Daly and Rake (2003) maintain that no country has yet to establish public policy concerning the appropriate allocation of care costs or location of care responsibility between the state, the family, and the market. This situation is indicative of the complexities of caregiving as a social issue and the tendency to maintain the status quo (i.e., the promotion of caregiving as essentially a family matter).

The assumption that caregiving is primarily provided by nuclear families, where a husband and father works outside the home and a wife and mother stays at home and cares for the children, is the basis for government social policy that designates caregiving as a familial responsibility (Armstrong & Kits, 2004). This study challenges the validity of this assumption: only 1 of 15 families here fits this traditional nuclear family definition. Of the 15 caregivers, 6 are lone parents, and 12 parent caregivers have other employment outside the home in addition to their caregiving responsibilities. These caregivers, who are mostly women, carry the burden of care behind closed doors in family homes because this care is viewed as a private and not a public issue. Making caregiving a social responsibility requires that our community and government be accountable for providing adequate resources and support to caring work.

According to Neysmith (2000), the restructuring of government in Canada has further placed the responsibility for care in the home through downloading health care to families. As service devolution continues, families are required to assume even greater care responsibilities. Governments at the federal and provincial level have realized substantial savings through the deinstitutionalization process and other health care measures resulting in individuals being cared for at home.

The Canadian government acknowledges social responsibility for caregiving, but to a limited degree. For example, the federal government has instituted a universal childcare benefit, which pays $100 monthly for each child under the age of six (Service Canada, 2006). In 2007 the Government of Newfoundland and Labrador provided an increase in board and lodging rates for adults with developmental disabilities who continue to live at home (U. Tucker, Disabilities Consultant, Department of Health and Community Services, Government of Newfoundland and Labrador, personal communication, June 14, 2007). This board and lodging rate increase continues to promote the 'care at home' social agenda. While money is paid to caregivers, there is no extra funding for the adult care recipients to access services that promote community inclusion. Moreover, the extra financial benefit is far from acknowledgement of the true value of caregiving work if parent caregivers were to be paid at the same rate as those providing caregiving within the public sector or through private enterprise. This increase, in fact, may be a further demonstration of government entrenchment in its position that caregiving remain a family responsibility.

Caregiving is receiving more attention as care for older persons looms large on the social policy agenda. An aging population will, in all likelihood, increase the number of individuals who are affected by issues of caregiver burden. This situation may well give this social issue of caregiving more prominence in our society. Not only will those considered dependent in a negatively valued way become vulnerable but those who enjoy a high measure of social value will be also be affected by the challenges of caregiving. Many families are experiencing the burden of caring for elderly parents, and many older persons are in need of services that are not available to them. This reality may create a demand for more government attention to this social policy area, thereby helping to promote a society in which caregiving is seen as a social responsibility needed by most and, as a result, extended to all citizens.

At present, structural issues in social service agencies impede the provision of meaningful social work services. The findings identify that issues include, few available caregiving services, as well as, caregivers not being informed of these services, being subjected to financial tests to qualify for services, and having to wait long periods of time to receive service approval and service delivery. The scarcity of available services can result in a disservice to caregivers. For example, with no companion services available, some caregivers use respite hours to provide a social outing for their child. Respite hours are intended to enable caregivers to care for themselves, and hence when used otherwise may undermine caregiver ability for self care. To help address these structural issues, social workers need to fully inform caregivers about available services, make a concerted effort to work with policies creatively, obtain approvals for exceptional situations, and advocate for improvements in agency and social policies.

Caregivers know that structural realities such as heavy workloads, shrinking human and fiscal resources, and staff turnover make it difficult for social workers to take the time to build supportive relationships and respond in an appropriate and timely manner. However, social workers who are able to incorporate a social action approach into their work create a means to address these social and structural issues. Employing feminist social work practice principles, for example, incorporates ways and means of addressing such issues.

Feminist Social Work Practice with Caregivers

Caregivers believe that social workers can help them identify service needs and navigate through bureaucratic systems to help them advocate, broker, and coordinate service. This support is in keeping with feminist social action based intervention. Feminist social work principles recognize the value of caring work and the need for social transformation that places the responsibility for this valuable work within the public arena (Baines et al., 1991, 1998; Dominelli, 1996, 2002; Parks, 2003).

This transformation can result from individual and/or collective action. Through the use of consciousness raising methods, caregiving can be re-conceptualized. It can become a right, not a privilege, essential and available to all. In this context, the provision of care would be viewed as valuable work worthy of financial compensation (Featherstone, 2005). The goal then becomes a change in government policy that would result in caregiving being viewed as employment meriting full and appropriate financial compensation. This re-conceptualization for caregivers, made possible in part through social work consciousness raising strategies, can help parental caregivers perceive caregiving support as a right to service and see compensation for caregiving work as fair and equitable in our society. Having such a view is empowering. Caregivers, with such a new perspective, think differently about their caregiving role and responsibility which can lead to them having the conviction to seek social justice by taking social action and making positive choices affecting their quality of life.

The majority of caregivers in this study did not report positive and meaningful social work interventions. This may be a reflection of social work practice continuing in the vein of traditional therapeutic intervention and not embracing alternate approaches. Social work practice that starts with viewing the caregiver as the expert in her/his own life, and works collaboratively with the caregiver, provides the basis for more effective social work service. Social work that is strengths-based and incorporates empowerment and anti-oppressive intervention strategies can best help these parents. Social workers who recognize these facts embrace empowerment principles to provide meaningful social work services (Baines, 2007; Baines, et al., 1991, 1998; Dominelli, 1996, 2002; Parks, 2003).

Implications for Social Work Practice and the Profession

The Canadian social work sector study (Stephenson et al., 2000) does not identify caregivers or individuals with developmental disabilities as primary consumers of social work services. Yet, the study's findings demonstrated that social workers have potential to play a pivotal role in the lives of these caregivers and care recipients. This difference suggests a gap between caregivers' needs and social work's awareness of the significance of this practice area. A first step in closing this gap is the recognition that caregivers, such as those in this study (and their children) are legitimate and important consumers of social work services. One way to initiate such recognition is through the formation of provincial study groups under the auspices of the Newfoundland and Labrador Association of Social Workers (NLASW). NLASW needs to facilitate a dialogue among social workers, caregivers, and care recipients.

Caregiver study groups are important to provide an opportunity for social workers and caregivers to share experiences and highlight caregiving issues. The findings of this study demonstrate that these caregivers, through sharing their life experiences, delineate valuable information pertaining to meaningful social work services. Such study groups are poised to take a leadership role to ensure parental caregiving of persons with developmental disabilities is acknowledged and present on social work's professional agenda.

These study groups can be an avenue for NLASW to highlight caregiver oppression, both within the profession and the community at large. A public proclamation of caregiver issues through various means (e.g., media releases) is a forceful way to bring the oppressive life conditions of caregivers into the public arena. NLASW has an opportunity and responsibility to take a leadership role to acknowledge, illuminate, and address this oppression.

Collaboration with allied professional groups such as health and education professionals is yet another avenue for NLASW to give profile to the needs of caregivers. Such collaboration provides opportunities to explore differing perspectives regarding issues facing caregivers. The association can spearhead work with allied professional groups and other community groups to identify issues, propose solutions, and develop strategic implementation plans.

NLASW representatives can advocate for social workers within local social service agencies. The association needs to promote working conditions for social workers that embrace the knowledge, values, and skills identified by the caregivers in this study.

Such dialogue between representatives of the association and social service agencies can help address professional practice and social policy issues, affecting caregivers and social workers, on an on-going basis.

Still, another NLASW action is liaising with Memorial University of Newfoundland's School of Social Work to address the educational implications of social work practice with caregivers and care recipients. The association and school of social work, respectively, have a mandate that encompasses responsibility for effective social work practice, as well as, educational preparation to this end. Hence, it is imperative that collaboration occur with respect to social work intervention with parent caregivers to address the implications for education and practice.

Implications for Social Work Education

The Canadian Association for Social Work Education (CASWE), (formerly CASSW) is mandated to establish standards for professional education in social work and the accreditation of schools of social work based upon these standards. Hence, this association must take a leadership role in addressing the knowledge, values, and skills caregivers identify as necessary for social workers to provide them with meaningful services. CASWE's action through the Persons with Disabilities Caucus, formed in 1993 is a step in the right direction. The formation of this caucus is evidence of this association's recognition of disabilities as a significant area of practice and an acknowledgement that social work education can play an important role. It is possible that the emerging literature addressing the issues of caregiving and developmental disabilities will provide impetus to have caregiving more closely linked to social work (Armstrong & Armstrong, 2004; Chappell, 2006; Collins, 2000; Dominelli, 1996, 2002; Dunn et al., 2006).

The Persons with Disabilities Caucus has social work curriculum, in the field of disabilities, as a part of its mandate. The integral linkage between caregivers, who care for individuals with disabilities, and care recipients, who have disabilities (Thomas, 1993), and the intimate bond created by parent-child relationships, provide rationale for this caucus to include social work education with respect to parental caregivers. These caregivers' lives revolve around providing care for their children. Therefore, it is important to include social work services to them when addressing social work in the field of developmental disabilities. One activity, to this end, would be the disabilities caucus of CASWE reviewing this study's findings in light of schools of social work current disability curricula content.

Social work education for professionals is on-going through continuing education initiatives, workshops and conferences, and personal study. This education includes the participation of schools of social work, social work provincial professional associations, social service agencies, and other social work employers. Social workers also engage in independent study as part of professional registration and licensure requirements in some provinces. Those involved in social work educational initiatives have an opportunity to address the promotion of knowledge, values, and skills to better serve caregivers. For example, schools of social work can liaise locally with caregivers, social workers who work with caregivers, provincial professional association representatives, and social work employers to explore avenues for enhancing social work education in this area of caregiving. Such collaboration can help determine the role of each group in social work education. In addition, schools of social work should include caregivers as an oppressed group in anti-oppressive social work education and encourage research in this area.

Implications for Social Service Agencies

Social service agencies, accountable for establishing and monitoring the quality of social work services, need to develop protocols and standards of practice for social work intervention with caregivers. Such protocols and standards of practice would require social workers to visit when a parent learns that her/his child has a developmental disability and to determine, with the caregiver, appropriate social work intervention. Required social work intervention should include providing information, counseling, and helping to negotiate and coordinate services, as well as developing an inter-disciplinary team to support caregivers. Following agency policy, the social worker assists the parent by working with the inter-disciplinary team to create and monitor a support plan through on-going service coordination, and helping to assess changing needs at critical life stages. Such teams are necessary on an on-going basis for caregivers who have children presenting significant care challenges. In Newfoundland and Labrador, the Individual Support Services Plan (ISSP) process provides such a mechanism for special needs children (Government of Newfoundland and Labrador, 1996). However, given the caregivers' experiences to date, this process needs to be reviewed to ensure it is fulfilling its original purpose, and monitored to be accountable for providing a quality service. A similar process is necessary to provide responsible service to adults with developmental disabilities.

It is imperative that agencies support social workers in social action based practice. Social workers must work collaboratively with caregivers, professionals, groups, agencies, and other community members to encourage and assist with collective initiatives. Value for caregivers and the work they do requires public acknowledgement hence promoting caregiving as a public responsibility (e.g., proclamation of a Caregivers Week). Such initiatives create public awareness, and promote value and acceptance in community life for these caregivers and their children. Social service agencies have a responsibility to ensure that social workers know the policies and procedures associated with providing responsible service. In addition, these agencies need to provide the requisite resources for social workers to carry out their work in accordance with agency protocols and standards of practice that caregivers agree have been effective with them. Agencies can work collaboratively with NLASW representatives and Memorial University's School of Social Work to identify and address such issues. Social workers must be given a clear professional mandate, appropriate educational and training opportunities, and the support they need within social service agencies to provide responsible service. Agencies need to work with caregivers to obtain their views about meaningful social work services through such events as community meetings, and include them as stakeholders in continuous improvement initiatives aimed at creating quality social work services for caregivers.

Limitations of the Study

There are three limitations to this study. First, the sample is restricted to St. John's, NL, which is an urban area, and therefore may not reflect the experiences of parent caregivers who live in rural areas. The research literature indicates that social work practice in rural settings has different dimensions than social work in urban settings (Barter, 1997, 1999; Daley & Avant, 2004; Delaney, Brownlee, & Sellick, 1999). For example, small communities increase the likelihood that most people will know each other. People in rural Newfoundland and Labrador are traditionally known for helping each other when the need arises (Canning & Strong, 2002; House, 1993). This social cohesion related to Newfoundland and Labrador's strong history and tradition of informal caring for its citizens can also lead to more value and respect for individuals with developmental disabilities. Community members know each other more intimately and through frequent interaction can learn to appreciate individual worth.

Second, the caregiver sample does not have a wide variation with respect to i) age, ii) employment outside the home, and iii) education. With respect to age, 10 of 15 caregivers are between the ages of 40 and 49. There are 12 caregivers who work outside the home. With respect to education, 13 caregivers have post secondary education either through attendance at a college or university. The age of the caregivers may affect their perspectives and expectations with respect to social acceptance as well as service availability. Caregivers, who have provided care over a number of decades, have had more varied experiences than those who are younger. This is especially true in light of the changes in programs and services available to families and persons with developmental disabilities over the second half of the 20th century and into the 21st century. With respect to employment, for those caregivers employed outside the home there are the added responsibilities of serving in two places (i.e., work and home). However, for some, employment outside the home provides an opportunity for broadened experiences and respite from the activities of caregiving. Therefore, the caregivers view employment of outside the home, as either positive or negative, may impact their caregiving experience. Further, similar educational backgrounds may affect general caregiving attitudes and perspectives. A more diverse group with respect to these demographics may yield different perspectives.

Third, this study does not include demographics about the social workers who provide services to these caregivers. The social workers' level of education and experience working in this area are relevant factors. This information could enhance delineation of knowledge, values, and skills social workers need to work with these caregivers by reviewing caregivers' comments in consideration of social workers' education and experience in this field. While this information could be helpful, the reported turnover in social workers presents a challenge in creating such a social worker profile.

Future Research

Social work knowledge, values, and skills, from the perspective of parent caregivers, are addressed in this study. Exploring the research question at hand from the perspective of social workers and care recipients to determine their views about necessary knowledge, values, and skills would be beneficial. Such investigation would illuminate this issue from different vantage points providing a clearer picture of helpful social work services and issues pertaining to the provision of such services.

The caregivers in this study identify several gaps in social work knowledge, values, and skills necessary to provide them with meaningful services. It would be helpful to know the number of caregivers and families affected by this issue. Social work is involved in many different areas of practice. If the number of social work service consumers, who are parent caregivers of children with developmental disabilities, was known then this information would help determine the magnitude of needed social work services to support this group. In addition, research to determine current curriculum content pertaining to parental caregivers of persons with developmental disabilities would help in charting future educational directions for this area of social work practice.

This study, if replicated in a rural area, would help determine the applicability of the findings outside the urban setting. In addition, this study, if replicated in other provinces, would determine the extent to which this study's findings are relevant to other areas outside the province.

Finally, it would be beneficial to study social work practice with caregivers using the knowledge, values, and skills that have been identified in this study as a practice template. By using this information as a template the findings of this study can be applied to social work practice within an agency. Such a study would provide an opportunity to test the efficacy of using the particular knowledge, values, and skills identified to provide meaningful services to parent caregivers who have children with developmental disabilities.

Summary

This study explores with parent caregivers, of children with developmental disabilities, their perceptions of the knowledge, values, and skills they believe to be important in the provision of meaningful social work services to them. The study is enlightening in many respects. First, the challenges that these caregivers face and the tremendous sacrifices they make in providing care and advocating for their daughters and sons is heroic. Second, the study highlights a) the value of caregiving work, b) the oppression these caregivers experience, c) caregiving as socially defined and experienced by women as women's work and, d) the benefit of changing from caregiving being a personal responsibility to becoming a social responsibility.

Third, the study illuminates societal attitudes about individuals with developmental disabilities. It demonstrates that they are not valued and respected in the same way as others in our society, and, by extension, neither are their parent caregivers. The study delineates this reality in the lives of these individuals and their families as they strive towards integration and a meaningful life within the mainstream of the community.

Fourth, the valuable role that social workers can play in helping these caregivers is demonstrated. Most caregivers believe that while social work services have been lacking in many instances, social workers have the potential to be most helpful to them. The issues they present suggest the use of empowerment, anti-oppressive, and feminist perspectives as a means of promoting the way to a brighter future for these parent caregivers.

Fifth, the study highlights the social and structural issues that are faced by caregivers and social workers. While there are many gaps identified in social work knowledge, values, and skills for these caregivers, there are also many constraints identified such as those imposed by social policies, fiscal restraint, and structural factors within social service agencies. All of these contribute to the oppressive conditions experienced by caregivers and social workers alike (Baines, 2007).

The information that has surfaced in this study demonstrates the importance of consultation with caregivers in determining the social work knowledge, values, and skills that can best help to provide them and their children with meaningful social work services. Creating positive and empowering change for parental caregivers of persons with developmental disabilities is possible using feminist and anti-oppressive social work practices.

Concluding Remarks

This study has led to conclusions and queries with respect to the knowledge, values, and skills necessary for social workers to provide meaningful social work services to parental caregivers of persons with developmental disabilities. These include; i) the relationship between social work education and practice, ii) whether it is best to address parental caregiver concerns through the feminist caring or the disability socio-political lens, and iii) addressing the cause (i.e., social action) and function (i.e., therapeutic activity) of social work conjointly.

My study activities and reflexivity, including the disability socio-political perspective as espoused by Hughes et al. (2005) has guided my approach to social work practice. It was my experience from the 1970's to 1998 that social workers who worked in the area of disabilities, and particularly developmental disabilities, received education relevant to this field of practice through various in-service events in their agencies. The social work goals were to promote the movement of individuals with developmental disabilities from institutions back to their home community and to assist those who lived at home to continue living there. Further, there was an expectation that social workers would take initiatives to promote community integration and inclusion. Little attention was given to the parental caregiver except to provide support services that were determined by assessing the care recipient's care needs. However, as stated by Hillyer (1993), it was not unusual for social workers to develop a negative view towards parents, especially if parents did not agree with what the social worker deemed to be in the best interests of the caregiver's daughter/son.

The resulting narrow and often negative view I developed towards parents because I believed they were holding their child back, sometimes led to a disservice for these parent caregivers. Listening to caregivers' stories, in this study, I learned to see them as oppressed individuals who went to great lengths to help their children, often at significant personal sacrifice. My opinion has been significantly altered through this process of research. As a social worker, I was taught about the disenfranchisement of persons with developmental disabilities but not about the disenfranchisement of their parents and siblings. Through reflecting on my own approach to social work practice, I question if the negative experiences reported by these caregivers may in part be influenced by social workers addressing social work practice with caregivers from this disability perspective. If this is so, then social workers, who have been taught from a disabilities socio-political perspective, know how to advocate for the rights of persons with developmental disabilities but have not been taught how to practice in a way that best meets the needs of the parent caregivers. Education in the area of feminist caregiving and anti-oppressive social work practice for parental caregivers, of persons with developmental disabilities, would provide social workers with the knowledge, values, and skills they need to provide meaningful social work services to these caregivers.

I question if students, through their education today, receive the social work knowledge, values, and skills that enable them to understand the ecological nature and social justice components of social work with parental caregivers in the area of developmental disabilities. I question if education and practice, today, concentrate on disabilities but do not concentrate on this most significant parental caregiving aspect of disabilities. This is especially true for persons with developmental disabilities who are dependent on their parental caregivers for as long as their parents are able to provide that service.

These findings raise questions as to the place of the caregiver in our society, particularly with respect to persons with disabilities, and how this caregiving can be understood from a theoretical perspective. Caregiving crosses a broad spectrum of the population, from the newborn to older persons. Does the feminist caregiving paradigm which encompasses the notion of empowerment and anti-oppressive practices fit the realities of caregiving within this larger context? Or is its relevancy confined to the more narrow perspective of caring for the disabled? This study has emphasized the latter. Equally relevant is the question of how caregiving fits into the perspective of socio-political rights. Where does social status fit into this paradigm? Do we define the rights of children differently than the rights of older persons or those with disabilities? The social situation and status of persons with developmental disabilities, as revealed in this study, suggest a largely disenfranchised and segregated population, invisible for the most part to the larger community. The question is where do the needs of parental caregivers of persons with developmental disabilities best fit within social work theory and practice?

These caregivers are part of a large group providing care to family members. Is caregiving for these caregivers best understood within the feminist paradigm, suggested in this study, or are their issues best addressed through the disabilities socio-political rights perspective? As noted earlier, parental caregiving for individuals with developmental disabilities has different dimensions than other forms of caregiving. The relationship is unique because the person with a developmental disability has a limited ability to understand and learn. As a result, parents and their children often need to learn to communicate in a different way than most parents and their children. This relationship becomes unique as the level of dependency increases. For example, parent caregivers of children with severe developmental disabilities, who have no language or very limited language, may find it difficult to develop meaningful communication with their child. Such parent caregivers may not be sure of what their child may need or understand their child's behavior. In addition, the lifelong nature of the caregiving, and the advocacy caregivers engage in are added caregiving issues. For these reasons, incorporation of this parental caregiving as part of the broader caregiving picture may not fully address their unique caregiver needs. On the other hand, consideration from a disability socio-political rights perspective does not incorporate or support the value of parental caregiving.

It seems, when closely examined, that parent caregiving of persons with developmental disabilities may not entirely fit within either the feminist caregiving or disability socio-political social work perspective. However, the underpinning assumptions for disability and caregiving, when deconstructed, reveal common interests. Both perspectives see caregivers and persons with disabilities as oppressed and marginalized populations that can benefit from social transformation, consciousness raising, empowerment and strengths-based approaches, necessary supports and services, value and dignity of person, and integration and inclusion. Exploring this common ground may create a path to incorporate the different standpoints for mutual benefit. Social workers who utilize anti-oppressive components of social work can work with both groups.

Both feminist caregiving and disability socio-political approaches are social justice oriented. The feminist, empowerment and anti-oppressive literature seeks recognition for care and caregiving as valuable work that women do necessitating commensurate compensation, support and services, and recognition of caregiving as a social and not a private responsibility (Featherstone, 2005; Neysmith, 2000). The disability literature seeks recognition of persons with disabilities as a social minority with citizenship rights that acknowledge and provide access to services allowing self-directed, independent living and a valued role in community life (Hanes, 2006). Anti-oppressive social work practice resonates with both perspectives (Baines, 2007).

Anti-oppressive social work practice is based on a belief that everyday experiences are shaped by multiple oppressions. It encompasses a number of social justice orientated approaches within the fields of caregiving and disabilities, based on the belief that social work helps individuals while simultaneously seeking to transform the forces that generate oppression and inequity. Utilizing anti-oppressive practices, social workers promote the development of individual and collective social action, while maintaining that there are no politically free areas. (Baines, 2007, Dominelli, 2002). A concentration on anti-oppressive practice provides a basis for social work to move forward to meet the needs of parent caregivers and their children with developmental disabilities.

The two fundamental approaches to social work (i.e., therapeutic social work and social action social work), another area raised in this study, is worthy of comment. The findings of this study point to a need to incorporate both social work approaches to provide a holistic social work service. As noted, historically and today, individual therapeutic social work has been the predominant social work practice mode (Chappell, 2006). However, this reliance on traditional social work practice is in contrast to the CASW (2005), Code of Ethics which includes the pursuit of social justice and CASSW (2000) accreditation standards which strongly emphasize anti-oppressive social work knowledge, values, and skills. Individual therapeutic practice must change to incorporate anti-oppressive social work, and social action practice needs to be added to continue the quest for social justice.

On a final note, this study has shown the efficacy of adherence to a client-centered approach by having parental caregivers of children with developmental disabilities, who are on the receiving end of social work intervention, define what knowledge, values, and skills they believe social workers need to learn, and practice to provide them with meaningful social work services. These caregivers not only identified important knowledge, values, and skills needed by social workers, they also clearly demonstrated the oppression and marginalization experienced by them, their child(ren) with a developmental disability, and their families.

Throughout the course of this study, there were many gaps in social work services and many shortcomings revealed in delivery. However, these caregivers clearly demonstrated their ability to define what services they need social workers to provide to them and the manner in which those services need to be provided. Through their lived experiences, as described in their stories, they demonstrated that, while social work services are lacking, there is a place for social workers in the lives of parent caregivers of children with developmental disabilities. This is truly fertile ground for social workers to engage in the practice of anti-oppressive social work in collaboration with parent caregivers of persons with developmental disabilities.

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APPENDIX A

LETTER TO PARTICIPANT

Karen Pollett
Unit 201
134 Portugal Cove Road
St. John's, NL
A1B 2N2

April 25, 2002

Dear Participant:

My name is Karen Pollett. I am presently studying social work as a full-time Ph.D. student at Memorial University of Newfoundland. I am conducting research on the knowledge, skills, and values social workers need to provide effective social work on behalf of individuals and families who live with developmental disabilities. I am hopeful that this information will be beneficial to the future education of social workers. This research is being used as part of my Social Work Ph.D. dissertation. I am writing to ask your assistance by participating in this research. I am asking individuals with developmental disabilities, parents, and community advocates to participate in the research.

You will need to participate in two interviews. The first interview will be tape-recorded. I will write a summary of the interview. Then I will meet with you again so that you can review the summary. This second interview will make sure that I have correctly recorded your views. Also, you will be able to add new comments in the second interview, if you wish.

I will be meeting with you to do the interview. The interview will be done in a conversation style without set questions and answers, as such. The interview will help me learn about your experiences as a consumer, parent, or community advocate. Special attention will be given to the knowledge, skills, and values you think are important for social workers in order to provide effective social work services to you or those you represent. The first interview will be approximately an hour and a half, and the second interview will be approximately half an hour.

Before you agree to participate, please read the following information:

1. Your participation is entirely voluntary. You are free to withdraw from the research at any time.

2. Your decision to participate or not to participate, or your withdrawal will not affect any services you or those you represent obtain from Health and Community Services now or in the future. Also, I will exclude myself from any future decisions relating to individuals who participate in the research.
3. Your identity will not be revealed in any report.
4. The information that you provide will be treated confidentially. All records will be stored in a locked office. The records will be destroyed after the Ph.D. dissertation is completed or if the research is cancelled.
5. Information that you provide will be used toward the Ph.D. dissertation described above. It may also be used for related scholarly papers and journal articles.

If you have any questions, please contact me at (709) 738-3470. If you would like to discuss this research with my research advisor at Memorial University, you can contact Dr. Ross Klein through email at rklein@mun.ca, or by phone at (709) 737-8165.

The Interdisciplinary Committee on Ethics in Human Research (ICEHR) has approved the proposal for this research. If you have any ethical concerns about the research that are not addressed by the researcher, you may contact the Chairperson of ICEHR at ice@mun.ca or by telephone at 737-8368.

If you wish to participate in this research please complete the attached consent form and keep this letter for your records.

If you wish you could mail your consent to the researcher in the enclosed envelope or you may indicate your consent by telephone at 738-3470. If you indicate consent by telephone you will need to bring your consent form with you to the interview.

Sincerely Yours,

Karen Pollett

APPENDIX B

CONSENT FORM TO PARTICIPANTS

Research Project Title: Social Work Knowledge, Skills and Values: Improving Services to Individuals and Families Who Live With Developmental Disabilities

Participant's Name (Please Print): ____

I understand that I have been asked to participate in two interviews about my views and experiences regarding social work knowledge, skills and values in working with individuals and families who are living with developmental disabilities. These interviews will explore several topics about living with developmental disabilities. These topics will include the relationship between consumers and social workers.

I understand that if I agree, I will be asked to participate in two interviews. The first interview will last for approximately one hour and a half and the second will last for approximately half an hour. The questions will cover many topics dealing with life issues about developmental disabilities and social work involvement in the area of developmental disabilities, including my experiences living with developmental disability.

I understand that I can choose not to answer any question that might make me feel uncomfortable. If, for any reason, any of the questions asked make me feel uncomfortable or concerned, either during or following the interview, the researcher will assist me to connect with a qualified professional counselor.

The first interview will be tape-recorded and transcribed by a person who has experience working with confidential social work documents. The second interview will not be tape-recorded.

My privacy and confidentiality will be protected. I understand that I will not be identified in any written or verbal report. I understand that all materials related to the research will be kept in a locked office. All materials related to the research will be destroyed when the dissertation is completed or the research cancelled. I understand that I am free to withdraw from this research at any time without consequence.

_____ I AGREE TO PARTICIPATE AND HAVE READ THE STATEMENT ABOVE

Signature: ____________________________ Date: ________________________________

If you would like to receive a copy of the results of this study, please provide your mailing address.

APPENDIX C

INTERVIEW GUIDE: PARENT

Demographic Information

1. Age
2. Marital Status
3. Number, Age and Sex of Children
4. Educational Background
5. Employment History
6. Partner's Educational Background and Employment History

Living With Developmental Disabilities

1. How long has developmental disability been part of your life?
2. What can you tell me about the developmental disability you are living with?
3. How has the disability affected your child? Abilities? Self-concept?
4. How has it affected other's lives, for example:
    - a) parent(s)
    - b) siblings
    - c) relationships in the family, relatives and friends
    - d) romantic relationships
    - e) relationship with others in your community
5. Can you describe how your child spends his/her time? For example,
    - a) your child's favorite activities
    - b) with whom time is spent
    - c) typical day/week activity
6. How would you describe your child's activities compared with activities of other children her/his age? Sex?
7. What was your child's experience with school? For example,
    - a) how was it like other children/youth
    - b) how was it different from other children/youth
    - c) describe the first day of school
    - d) experiences that stand out in your mind about school
8. Describe your child's experience with work. For example,
    - a) how did your child decide to do what s/he is doing now
    - b) what are some particular events or experiences that you/your child had in getting work
    - c) if your child is not working, why not
    - d) what does your child do in the daytime while others work

9. How has working or not working affected your/your child's life (e.g., having a daily routine; ability to buy, participate in and do things; the number of friends; activities and hobbies)?
10. What kind of help does your child need to complete everyday activities of living, such as washing, getting dressed, eating, going to the washroom, etc.? Are there other areas where your child needs supervision or help?
11. What are your child's health problems, if any? Are there other disabilities?
12. What are the most positive things about your child's life?
13. What are the most challenging things about your child's life?
14. What do you think your child's future will be like? How is this different than what you would ideally like?

Knowledge about Living With Developmental Disabilities

1. Where does your family normally go to get information about developmental disabilities?
2. What would your family like to know about developmental disabilities that you don't know?
3. How do you think your child will be affected by important times in her/his life, e.g. starting work, becoming an adult, living independently?
4. What help do you think you and your family will need during these times?
5. Are you aware of other disabilities or physical problems that are common for persons living with developmental disabilities?
6. What is the most important information to have about developmental disabilities?
7. What is the most important information to have about other disabilities or physical problems?

Skills to Successful Living With Developmental Disabilities

What skills do social workers need to promote maximum development potential and enhance life quality? What skills are needed:

1. Helping your child:
    a) live a healthy and fulfilling life
    b) get a job
    c) plan for her/his future
2. Ensuring your child:
    a) gets the right education
    b) participates in the community
    c) gets the necessary help to complete personal care activities
    d) can play with other children his/her own age
3. Ensuring you as a parent can go where you want and do what you want
4. Planning for your future

Values About Living With a Developmental Disability

The values social workers need to have to work effectively with and on behalf of persons who have developmental disabilities.

1. What do you know about the history of people with developmental disabilities, especially how they were treated in the past?
2. How are people with developmental disabilities treated today?
3. What has changed?
4. Having a developmental disability may not be viewed by others the same as having any other sort of disability, why might this be the case?
5. What do you see as the purpose of the Canadian Association for Community Living?
6. How does this association fulfil its purpose?
7. The association seeks inclusion in the community for individuals who have developmental disabilities; do you think that the association should be trying to make sure that people with developmental disabilities are a part of the community?
8. Some people would say that the biggest problem people with developmental disabilities have is that they are not valued by others, what do you think about that?
9. How do you feel about the statement " everyone should be given whatever supports they need to live active lives in the community regardless of the cost"?
10. What would an ideal life look like for your child?

Relationships Between Social Workers and People Living With Developmental Disabilities

What has been your experience in dealing with social workers? For example,

1. How have social workers from different work places been involved with you and your family?
2. How long has your child been involved with public social workers, those from social services/health and community services?
3. How has the number of different social workers, you have had, affected your relationship with public social workers?
4. What was the event that caused public social workers to become involved in your life?
5. What was your first impression of public social workers?
6. What kind of help have public social workers provided since your first contact?
7. What did you like the most about your dealings with the social workers?

8. What did you like the least about your dealings with the social workers?
9. Overall how would you describe your relationship with the public social workers?
10. How have social workers shown you that they are committed to enhancing life for your child?

Social workers can provide many services including, information, counseling, advocacy, service coordination, education, service negotiation and providing a friendly ear during individual and family crisis.

1. Which of these services do you feel you get from the public social worker?
2. What other ways do you think public social workers can be of help to you?
3. What can you do to make sure you have a good relationship with your social worker?
4. What can social workers from social services/health and community services do to make sure they have a good relationship with you?

APPENDIX D

HUMAN SUBJECTS RESEARCH PROTOCOL

Title of the Proposed Research

Social Work Knowledge, Skills and Values: Improving Services to Individuals and Families Who Live With Developmental Disabilities

Name and Position of the Investigator

Karen Pollett,
Ph.D. Student, School of Social Work, Memorial University of Newfoundland
Assistant Executive Director, Health and Community Services, St. John's Region

Statement of the Purpose of the Research

Individuals with developmental disabilities often experience difficulty developing and maintaining positive relationships with social workers that provide public social services. This research addresses this issue by answering the question: what knowledge, skills, and values are viewed as necessary, from the perspective of consumers, for meaningful and effective social work services to persons living with developmental disabilities?

Developmental disability, as it is used in this research, is intended to replace the more traditional term, mental retardation. Canadian social policy supports community living on behalf of individuals who have developmental disabilities, however, these individuals require supportive services to maximize their developmental potential and to maintain community presence. The majority of supportive services are provided through public social service agencies.

The public social worker, as the primary agent for the provision and coordination of social services, plays an important role in the lives of individuals with developmental disabilities, and their families. Hence, the relationship between the social worker and the individual and family is a significant determinant of quality of life. Three overarching issues challenge the development and maintenance of positive working relationships between persons with developmental disabilities and their families:

- There is a lack of recognition by professionals of the nature of developmental disabilities, relevant issues and problems. This is clearly reflected in the most recent sector study of Canadian social work, "In Critical Demand: Social Work in Canada" (Stephenson, Rondeau, Michaud, & Fiddler, 2000). This document pays minimal attention to disabilities in general and makes no mention of developmental disabilities.

- The nature and content of education for social workers employed to work with this population is weak. Cole, Pear and Welsch (1989) expressed concern for the lack of educational preparation to work with this population.

- The resources available for support and intervention are scarce. There have been significant cutbacks in the services available and social work caseloads continue to grow. Without the time or the resources, social workers have difficulty nurturing supportive relationships with individuals and their families.

Persons, who have developmental disabilities and their families often, depend on social workers and the social services they provide for survival. Such persons are at risk of harm if social work fails to provide optimal service. Individuals who have developmental disabilities are among the most vulnerable in our society. They depend on others for survival throughout their lives. In addition, persons with developmental disabilities are devalued and at high risk for human rights violations (Roeher, 1996).

This study touches on all three of these issues, but is mainly concerned with the content of social work education. The three components of social work education are knowledge, skills and values (Morales and Scheafor, 2001). By knowledge we mean information and facts germane to social work practice. Skills refer to actions and activities that reflect expertise in the application of social work-based knowledge. Values are important in that they guide social work practice. Values encompass attitudes and feelings. The focus of this study is to identify curriculum content in each of these areas that is needed to prepare social workers for effective work with persons and families living with developmental disabilities.

Procedures to be Used in the Conduct of the Research

Using a qualitative research design, the proposed research will explore consumers' perceptions of necessary knowledge, skills and values needed for effective social work intervention. A small representative sample of consumers will be interviewed in depth to explore unique life experiences of persons living with developmental disabilities. The research involves the following steps:

Using convenience and purposive sampling strategies 14 individuals will be invited to participate in the research. The selected individuals will be divided into three different categories:

- Individuals who have developmental disabilities,
- Parents of individuals who have developmental disabilities,

- Community advocates.

Community advocates are included to provide a voice for individuals with developmental disabilities who are not able to speak for themselves but who need to heard as individuals, independent of their parents' views. The researcher will use collegial contacts to solicit the support of the Newfoundland and Labrador Association of Community Living (NLACL) in this research. NLACL will advertise the research within the identified population segment and secure the volunteers names. The researcher will provide NLACL staff with invitation text using wording from the information letter that will be forwarded to participants (Appendix 1). Subsequent to obtaining a list of potential participants, NLACL will provide the researcher with names and contact information for those interested in pursuing participation. The researcher will then contact potential participants by telephone to provide more detail about the research and determine the willingness and suitability of each participant. Subsequent to this telephone conversation those who are willing and suitable will be forwarded an Information Letter (Appendix1) and a Consent Form (Appendix 2). Telephone contact will be made by the researcher to answer any questions regarding the material forwarded, confirm participation, and arrange an interview time and place that is convenient for the participant.

Each participant will be interviewed individually by the researcher. The first, an in-depth, nonstandardized interview of 1.5 – 2 hours' duration, will take place in a private location of the participant's choosing. The researcher's office will be available if the participant wishes to be interviewed there.

There will be two interviews with each participant. The first, a 1.5 – 2 hour interview, will obtain the participant's response to probes designed to identify general and specialized knowledge, skills and values. The use of a nonstandardized interview format will provide an ability for the client to freely discuss topics germane to knowledge, skills and abilities necessary to provide effective social work practice for individuals living with developmental disabilities. Probes will be used to the extent necessary to prompt the participant in providing comprehensive coverage of the topic areas. The topic areas will include: personal life experience living with developmental disabilities, important knowledge about developmental disabilities, necessary skills in dealing with issues pertaining to living with developmental disabilities, values identification regarding persons living with developmental disabilities, and the relationship between the social worker providing social services and individuals living with developmental disabilities (Appendix 4). Interviews will be audio-taped and transcribed.

A second interview of up to 1-hour will be held to review a summary of the interview compiled by the researcher. This process will ensure that the researcher has recorded the participant's responses correctly and provide an opportunity to clarify or add to the information from the first interview.

Subject Population

Individuals who have developmental disabilities vary considerably in terms of the abilities they have and the challenges they present. This variation is evidenced in the level of independence or dependence. It is important to capture various independence levels because of the impact on the amount and type of necessary social work intervention on behalf of the individual and the family. There will be a total of fourteen people interviewed categorized as follows:

Consumers who have Developmental Disabilities

It is important to interview persons living with developmental disabilities to obtain direct consumer experience. It is often the case that individuals with developmental disabilities are denied the opportunity to speak on their own behalf. Three individuals who have developmental disabilities will be interviewed.

Three criteria will be used in selection of consumers who have a developmental disability. First, the individual will be twenty years of age or older and able to provide an informed consent as an independent adult. Second, the respondent will have had direct experience with public social workers and the social service system. Third, the respondent will have pre-requisite skills including the ability to live and travel independently in the community and, to understand the concepts being explored and articulate a perspective with respect to support services and social work services based on personal experience.

Advocates

The researcher does not have an ability to interview consumers with more extreme developmental disabilities because they are comprised of individuals who are language challenged. Due to this limitation, community advocates will be interviewed to represent the views of this population. Three advocates will be interviewed. The advocates' view of individuals needs and, service and social work responses will be explored.

Advocates who work for NLACL are well versed in the needs of individuals who have developmental disabilities and, the programs and support services available for this population. They are quite familiar with the role of the social worker who practices in this program area. Therefore, they are in a strong position to speak to issues pertaining to support services and social worker's knowledge, skills and values.

Parents

Parents are an important group in the research because they are providing care for the person who has the disability. Moreover, individuals with developmental disabilities have a high probability of needing care throughout their lifetime. In many situations parents provide primary care until they are no longer able to do so. A total of nine parents will be interviewed. There will be three parent groups with three respondents per group. The first group will have a daughter/son able to comprehend and respond to interview questions. These parents, however, will not be the parents of the consumers with developmental disabilities who are interviewed. The second and third parent groups will be representative of parents with children who progressively have more severe developmental disabilities.

The Investigator's Relationship to the Subjects

One of the inclusion criteria for participants is that they do not have a prior relationship with the researcher. The researcher has had a long history of working in the area of developmental disabilities. Most of this work has been in policy and senior administrative positions. Some potential participants may be familiar with the researcher through her work. This issue will be addressed through NLACL identifying participants. The voluntary nature of this sampling strategy, together with researcher screening of potential participants, will minimize the possibility of any previous involvement with the researcher.

The population will be drawn from the city of St. John's. The advocates will be NLACL employees and will serve as key informants. The researcher has had minimal professional involvement with the current NLACL advocates.

Assessment of Possible Risks and Benefits to the Subject

All interviews will be conducted individually and will take place in a location of the participant's choosing provided that it is sufficiently private. The researcher's office at Memorial University will be used for interviews where no other place is available or deemed to be suitable. The nature of the interview is relatively low risk with very little emphasis on material that might be considered potentially threatening or harmful. However, it is anticipated that the interviews will be emotionally intensive for most participants. It will be important for the researcher to take cues from the participants and ensure the appropriate respect and empathy is accorded each individual. The researcher has had many years of experience dealing with individuals living with developmental disabilities and who are in crisis. She is very familiar with the topic area, as well as individual and family practice in this area. In the unlikely event that a participant is adversely affected by this interview, the researcher will direct the participant to the appropriate resource.

The research is potentially beneficial to participants both during the interview and as in the future. First, participants will have the benefit of talking through the issues that they are attempting to resolve. Second, in exploring the range of topics participants will have an opportunity to identify their strengths in addition to areas of challenge. Third, participants will have the benefit of self-exploration regarding possible sources of support and assistance. Fifth, this will be a consciousness raising experience for participants that may result in empowerment for some participants. Sixth, participants will have the satisfaction of knowing that they are contributing to research designed to ultimately improve the living conditions and enhance relationships on behalf of all persons living with developmental disabilities.

Procedures to be Followed to Obtain Informed Consent

All participants in the research will receive a letter from the researcher (Appendix 1) explaining the purpose and nature of the research as well as its potential use. The letter explains the confidential nature of the research and steps taken to safeguard data. Along with the letter, participants will receive a consent form (Appendix 2), which they will be asked to read and sign to indicate their willingness to participate in the research.

Incentive, Remuneration and Compensation

Participants will not be remunerated for their participation. For many participants it will be an opportunity to express their opinion with respect to important issues to be addressed when living with a developmental disability. Moreover, there is an opportunity to contribute to improving their own lives and the lives of other persons who live with developmental disabilities.

Information to be Collected and Data Collection Instrument to be Used

Basic demographic information will be collected at the onset of the interview outlining the participant's age, occupation and marital status. The interviews will be nonstandardized following the flow of the participant's conversation. However, the researcher will use an interview guide in the first interview to ensure that relevant and like topics are covered by each of the respondents. This guide will also serve to provide prompts for participants who require leads to discuss various areas pertaining to living with developmental disabilities (Appendix 4). The first interview will be tape-recorded and transcribed for all participants. The second interview will not be recorded.

Safeguards to Confidentiality

The information letter accompanying the consent form states that personal identity will be safeguarded. The interviews will take place in a private location. Tapes and transcripts will be stored in a locked cabinet in a locked office. Written reports and transcripts will contain basic demographic material but no identifying information. The data will be stored until the completion of the research and then destroyed. If for any reason the research is abandoned, the data will be destroyed.

Recording of Information

All first interviews will be tape-recorded, and transcribed. Analysis will be done manually by the researcher. Personal names will not be used. An individual, who has over ten year's experience working in a social work setting with confidential documents, will complete the transcription. The person completing the transcription will be required to sign a confidentiality agreement (Appendix 3). Any written notes that are taken as part of the first interview, the synopsis developed for the second interview, and any notes taken in the second interview will have no identifying information and will be stored in a locked cabinet in a locked office.

Consent Forms and Accompanying Letters

Appendix 1: Information Letter to Participants
Appendix 2: Consent Form to Participants
Appendix 3: Confidentiality Agreement for Persons Who Transcribe Interviews
Appendix 4: Interview Schedule

Memorial
University of Newfoundland

Office of Research

APPENDIX E

ETHICS APPROVAL LETTER

December 12, 2001

ICEHR No. 2001/02-019-SW

Ms. Karen Pollett
School of Social Work
Memorial University of Newfoundland

Dear Ms. Pollett:

The Interdisciplinary Committee on Ethics in Human Research (ICEHR) has examined the proposal for the research project entitled *"Social Work Knowledge, Skills and Values: Improving Services to Individuals and Families Who Live with Developmental Disabilities"* in which you were listed as the principal investigator.

The Committee has given its approval for the conduct of this research in accordance with the proposal submitted on the condition that the following minor modifications are incorporated:

1. You may allay any concern on the question of possible conflict of interest by adding to your letter for participants a statement to the effect that their decision whether or not to participate, or their withdrawal later on, will have no bearing on service delivery from Health and Community Services. Perhaps you may state that you will exclude yourself from any decisions relating to services for these clients.

2. Although you have included with your application only one version of the letter of information, consent form, and interview guide, you propose to use these documents with three quite distinct groups of people, who may be expected to have different levels of literacy and understanding. Specifically, the ICEHR has some concern that participants with developmental disabilities may have difficulty understanding the documents as they are presented in the proposal. The Committee recommends that you make appropriate modifications to these documents before beginning the recruitment process, so that each potential participant is presented with documents that he or she can understand.

St. John's, NF, Canada A1B 3X5 • Tel.: (709) 737-8251 • Fax: (709) 737-4612 • http://www.mun.ca/research

3. The final sentence of the letter of information to participants may be seen as somewhat peremptory. The voluntary nature of participation would be stressed if the present request to complete the consent form were to begin with the words "*If you wish to take part in this research ....* ".

4. Since the statements of participants may contain references to social workers within the agency in which you are an administrator, participants should be cautioned at the beginning of any interview not to identify any specific worker when commenting on such things as service delivery.

5. In the consent form, there are the words "*... privacy and confidentiality will be protected*". The Committee believes that this assurance may be interpreted in various ways, and that it is preferable to state clearly what steps will be taken to protect the confidences of participants. In this connection, you should also take account of the limits to confidentiality imposed by law.

6. The ICEHR now requests all researchers to include in their letter of information some version of the following: "The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research. If you have ethical concerns about the research that are not dealt with by the researcher, you may contact the Chairperson of ICEHR at icehr@mun.ca or by telephone at 737-8368".

If you have any questions regarding the requested modifications, you should contact Ms. Janice Parsons, School of Social Work representative on the ICEHR.

If you should make any other changes either in the planning or during the conduct of the research that may affect ethical relations with human participants, these should be reported to the ICEHR in writing for further review.

This approval is valid for one year from the date on this letter: if the research should carry on for a longer period, it will be necessary for you to present to the committee annual reports by the anniversaries of this date, describing the progress of the research and any changes that ma affect ethical relations with human participants.

Thank you for submitting your proposal. We wish you well with your research.

Yours sincerely,

Gordon Inglis
Chair, Interdisciplinary Committee on
Ethics in Human Research

GI/en

cc: Ms. Janice Parsons
School of Social Work

APPENDIX F

CONFIDENTIALITY AGREEMENT

Confidentiality Agreement for the Transcription of Data

Name of Transcriber (please print) ________________________

I understand that I will be transcribing confidential interview data conducted as part of a doctoral dissertation undertaken by Karen Pollett at Memorial University. The interviews will explore in an in-depth manner a number of topics related to the necessary knowledge, skills and values social workers need, from a consumer's perspective, to provide effective social work in the area of developmental disabilities.

As part of this research project, I will provide the transcription service and as such I understand that I am bound by policies that protect the privacy of the research participant information that I will be given access to. I agree to keep this information in the strictest confidence.

Signature: ________________ Date: ________________

Witness: ________________ Date: ________________

APPENDIX G

LETTER TO NLACL AND ATTACHMENT

School of Social Work
Memorial University of Newfoundland
St. John's, NF
A1C 5S7

February 15, 2002

Ms. Helen O'Rourke
President
Newfoundland and Labrador Association for Community Living
685 Water Street
St.John's, NF
A1E 1B5

Dear Ms O'Rourke,

My name is Karen Pollett. I am presently studying social work as a full-time PhD student at Memorial University of Newfoundland. I am conducting research on the knowledge, skills, and values social workers need to provide effective social work on behalf of individuals and families who live with developmental disabilities. I am hopeful that this information will be beneficial to the future education of social workers. This research is being used as part of my Social Work PhD dissertation.

I am writing to ask for the assistance of the Newfoundland and Labrador Association for Community Living in the recruitment of potential participants for this research. I have enclosed a document outlining the research and the role of NLACL in recruiting potential participants. If you are agreeable to assist with this research, I would like the opportunity to meet with association officials to further address the specific activities for NLACL.

Thank you in advance for your consideration of this request. I look forward to hearing from you concerning your response. If you have any further questions please call me at (709) 738-3470.

Sincerely Yours,

Karen Pollett

Newfoundland and Labrador Association for Community Living (NLACL)
Participation in Research Project
Researcher: Karen Pollett

Introduction

This research is being completed as part of Doctor of Philosophy studies the researcher is pursuing at the School of Social Work, Memorial University of Newfoundland. The research will be conducted to obtain information concerning the necessary knowledge, skills and values required for social workers to provide meaningful and effective services to persons who are living with developmental disabilities. The researcher will be gathering this information through talking with consumers to get their views and opinions. The objective of the research is to explore possibilities in social work education to enhance social work services on behalf of consumers living with developmental disabilities.

NLACL will be a partner in this research through identifying potential participants. NLACL will provide the researcher with a list of individuals who have indicated a willingness to be considered for participation in the research. The researcher will use the potential participant list to obtain necessary information for contact purposes. In addition, NLACL will provide the researcher with the names of three community advocates who are willing to participate in the research.

Requirements of Potential Participants

1. Three individuals will have developmental disabilities. These individuals will:
    - Have independent living skills to the level that s/he is able to take care of

personal self-care needs,

- Have the necessary skills to enable her/him to travel independently in the community,
- Be able to discuss supportive services and social work services from personal experience,
- Be recognized legally as an adult in her/his own right with the ability to provide an informed consent.

Individual consumer interviews will gather information based on the individual's memory of childhood, as well as, her/his adult experiences.

2. There will be nine individual parent interviews. Parents will belong to one of three parent groupings categorized as follows:
    - The first parent group will be three parents, each of whom will have a son or daughter who is able to comprehend and respond to interview questions. These parents, however, will not be the parents of the consumers with developmental disabilities who are interviewed.
    - The second parent group will be three parents who each have a child with greater developmental challenges than the first group, but less developmental challenges than the third group. Parents in the second group will have a daughter/son who needs help with personal care, and participating in community activities. In addition, parents of these children will have a daughter/son who is challenged with respect to being able to carry on a meaningful conversation concerning support services and social

work services.

- The third parent group will be three parents who each have a child with a high level of developmental challenges. Parents in the third group will have a daughter/son who requires total support to meet personal care needs, or participate in the community and, who is communication challenged to the level that s/he has no speech or other readily recognizable means of engaging in a conversation.

All parent interviews, as with other interviews, will be done on an individual basis. The groupings will ensure that individuals with varying needs of support services and social work service needs are heard.

Within each of the three-parent groupings, there will be one parent with a child up to eighteen years of age, one parent with a daughter/son between the ages of 19 and 25 years and one with a daughter/son over 25 years of age.

3. There will be three advocates interviewed. Advocates will:
   - Have had extensive experience working on behalf of individuals who are living with developmental disabilities,
   - Represent the views of individuals as described above in parent groups two and three,
   - Speak from one of three perspectives: a child up to 18 years of age, an adult between 19 and 25 years of age, and an adult older than 25 years of age.
4. Additional criteria for individuals who are living with developmental disabilities

(persons and parents) and who will participate in the research include the following:

- Participants will have had no prior professional or personal relationship with the researcher.
- All participants will be individuals who have a primary diagnosis of developmental disability or, be a parent with a child who has a primary diagnosis of developmental disability or, be an advocate for individuals who have a primary diagnosis of developmental disability.
- Participants will be able to discuss their personal situation without extreme emotional upset. The interviews will cover sensitive topics which participants may find emotionally challenging because they will be discussing personal life experiences.

General Information

A. The interviews will be scheduled to take place during the month of March 2002.

B. Interviews will take place at a time and location that is convenient for the participant and considered to be appropriate by the researcher.

C. There will be two interviews. The first will be up to two hours duration and will be audiotaped. The second will be up to one hour and will be conducted to provide an opportunity to confirm the information presented in the first interview. The second interview will not be audiotaped.

D. All information will be held in the strictest of confidence.

E. The research material will be kept in a locked office and destroyed upon completion of the research.

F. There will be no identifying information kept on any interviewing documentation or tapes.