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COPING AND SUPPORT NEEDS OF FAMILY CAREGIVERS OF OLDER ADULTS WITH A DEVELOPMENTAL DISABILITY

BY

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B.A./B.S.W., McMaster University, 1988

THESIS
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for the Master of Social Work degree
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ABSTRACT

Due to the policy of deinstitutionalization there is a population of adults with a developmental disability who are aging in the community and who are living with their aging parents as caregivers. This study used a phenomenological, qualitative approach to gain an in-depth understanding of the experiences of these aging family caregivers of aging adults with a developmental disability. A literature review indicated that some sources of support and service needs have been identified for this population of caregivers, and that planning for the future of their adult child with a developmental disability was important to these caregivers. Six caregivers, all of whom were mothers, were interviewed and asked to describe their experiences as caregivers and to identify any recent changes or any concerns that they might have for the future. Several themes emerged as important to the caregivers including: the importance of routines for both mother and adult child, faith, issues of service use, importance of family relationships and planning for and facing the future. Generally speaking, mothers identified a need for more respite and more recreational activities for their adult child but felt that they were coping well in their role as caregiver. Most mothers stated that they did not worry about the future but they made plans whenever possible. Many questions about caregiving issues for adults with a developmental disability who are aging remain.

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> *"I went to the doctor, I went to the mountains*
> *I looked to the children, I drank from the fountain*
> *There's more than one answer to these questions*
> *pointing me in a crooked line*
> *The less I seek my source for some definitive*
> *The closer I am to fine."*
> *Emily Saliers, 1988*

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CHAPTER ONE

Introduction

This thesis looks at the coping and support needs of family caregivers of aging adults who have a developmental disability. Typically, the caregivers of these adults are their parents, who are facing the challenges and difficulties of their own aging process as well as that of their adult dependent child.

As a backdrop to the research question, this chapter will begin by defining the population of adults who have a developmental disability and who are aging. Characteristics of this population will be outlined in an effort to better understand the caregivers' tasks. Finally, there will be a brief discussion on why aging family caregivers of aging adults with a developmental disability is a current concern.

With this base, the research question will be articulated.

1.1: The Population of Older Adults with a Developmental Disability

There is ample evidence in the literature that the population of older adults with a developmental disability is growing (Sison and Cotten, 1989). Some of the difficulty in defining this population arises from the idea that adults with developmental disabilities may age faster than the general population, thus making it difficult to pinpoint when the aging process begins (Walz, Harper, and Wilson, 1986). For the purposes of this thesis, developmental disability will be taken as below average intellectual functioning (which is usually defined as scoring two standard deviations or more below average on standardized intelligence tests) that is seen in the formative period (birth to nineteen years) and accompanied by difficulties with social behaviours (Dickerson, 1981). This definition focuses on the intellectual and behavioural aspects of the disability and not on the physical challenges that may also be present. This definition therefore, is directed largely to adults with what was previously called mental retardation.

An adult with a developmental disability may be considered to be aging when they are between the ages of 60-65, as with the general population (Hewitt, Fenner, and Torpy, 1985), or as early as age 40 (Panitch, 1983). However, most researchers seem to prefer the somewhat arbitrary age of 55 as the beginning of the aging process for adults with a developmental disability (Walz, Harper, and Wilson, 1986). There is conflicting evidence in the literature as to whether or not aging does begin earlier for adults with developmental disabilities (Seltzer and Seltzer, 1985; and Gibson, Rabkin, and Munson, 1992). In any event, when aging begins, physical, emotional and psychological changes occur, and new challenges arise.

Physically, adults with a developmental disability face possible losses in their sensory abilities of hearing and vision (Seltzer and Seltzer, 1985). This may make coping more difficult for both themselves and their caregivers. There is some evidence that adults with a developmental disability are at an increased risk to develop respiratory problems, seizure disorders, and Parkinson's disease (Walz et al., 1986; Seltzer and Seltzer, 1985). In general, health risks appear to be different for adults with a developmental disability living in the community than for those living in institutions; and different again for adults with a developmental disability in comparison to those in the general population, possibly due to the nature of their disability (Seltzer and Seltzer, 1985; Walz et al., 1986).

Cognitively and psychologically, there also are differences between adults who have a developmental disability and the general population. Specifically, it appears that adults with Down Syndrome may be at increased risk to develop Alzheimer's Disease at an earlier age than usual (Gibson, Rabkin, and Munson, 1992). Some literature indicates that there is a cognitive/intellectual decline at an earlier age, while other literature demonstrates no difference in onset of decline between adults with a developmental disability and those without (Walz et al., 1986). Psychologically, older adults with a developmental disability are possibly at a higher risk of developing mental illness and the accompanying behavioural disorders (Menolascino and Potter, 1989; Harper and Wadsworth, 1990).

There are two purposes in defining the population of adults with a developmental disability who are aging in such detail. The first is to demonstrate that the literature is not clear on how adults with a developmental disability age, and whether or not the aging process is any different from that of the general population. While some research indicates that these processes are parallel, other research indicates an acceleration in the aging process for adults with a developmental disability (Walz et al., 1986). This could mean that adults with a developmental disability and their caregivers could be going through the same, or similar, processes at the same time. Clearly, from the literature reviewed, the process of aging for adults with a developmental disability is not well known. Furthermore, there are many different types of developmental disability, and each may have its own aging process. Or, all developmental disabilities may have the same aging process. For the purposes of this thesis, all developmental disabilities will be considered to have the same aging process.

The aging process for adults with developmental disabilities impacts on their caregivers if, as previously mentioned, caregivers are experiencing their own aging process at the same time. Simultaneous aging can make caregiving much more difficult as the caregiver has to adapt to their own new challenges as well as help the care recipient adapt to new challenges. Caregivers will also have to cope with their own issues of aging with regards to their past, their relationships, their parenting, etc. as they try to reach integrity in Erikson's life stage of Integrity versus Despair (Brunn, 1985). What other challenges will these caregivers face? Will they be confronted with new, difficult behaviours or even aggression from their loved ones as a result of the aging process? Will they be confronted with an individual who has fewer functional abilities than before? Will they have to perform new care tasks with which they may not be comfortable? Will the aging process that caregivers and their care recipients go through make it easier or more difficult to provide care? Are these caregivers prepared to cope with these changes?

These questions all require further research. But these questions can also demonstrate the uncertainty caregivers may feel as they face the aging of their loved one as well as their own aging, in the context of providing care.

1.2: Current Trends

The brief review of literature has outlined some issues around individuals aging with a developmental disability. But what is the reality of caregiving for adults with a developmental disability who are aging today? It is estimated that there are 277 adults with a developmental disability over the age of 55 living in Hamilton-Wentworth (Houser, 1993). In a data base developed from 32 per cent of this estimated total, it was shown that 46 per cent require specialized health care, and 44 per cent have behavioural difficulties requiring intervention, and 16 per cent live with their own families or independently (Houser, 1993).

Other statistics indicate that there are approximately 176,725 persons with a mental (including developmental) disability between the ages of 15 and 64 residing in households in Ontario (Statistics Canada, 1985). This figure is broken down to approximately 11,125 in Hamilton (Statistics Canada, 1989). In Canada, approximately 19,000 people aged 35 to 54 have a mental handicap, and approximately 9,000 aged 55 to 64 have a mental handicap (Statistics Canada, 1985). These people or their caregivers reported that they require assistance with meal preparation, shopping, regular and heavy household chores, finances, personal care, and mobility (Statistics Canada, 1989). Many reported their income to be largely from sources such as Family Benefits Allowance (Statistics Canada, 1989).

It has already been well-documented that the seniors' population is growing in Canada (Norland, 1994), and that life expectancy is increasing while mortality rates are decreasing (Kerr and Ram, 1994). As previously noted, the life expectancy of persons with a developmental disability has also increased (Sison and Cotten, 1989). Deinstitutionalization has resulted in more of these adults with a developmental disability living in the family home, with aging parents as the main caregivers (Adams, 1990; Greenberg, Seltzer, and Greenley, 1993).

Thus, when all of the above issues are combined, the trend is to aging adults with a developmental disability living with their aging parents. This situation could have a large impact on support services and institutionalization rates for the elderly and for the adults with developmental disabilities. It is imperative that the needs of aging adults with developmental disabilities and their aging caregivers be identified, and that services be developed to meet those needs. Yet there has been little attention paid to these growing concerns.

As well, this writer has a personal concern in this matter as a sibling of an adult with a developmental disability. Many of the dilemmas that will be discussed in this paper are dilemmas which the writer's family will face in the near future.

1.3: Research Question Proposed

It has been established that the population of aging adults with a developmental disability is growing, that these adults tend to be cared for by their parents, and that the aging process they undergo may or may not be similar to that of the general population. As adults with developmental disabilities age, their caregivers also age, and both face an uncertain future. According to the literature, caregivers are often women with fewer financial resources than men (Laurence, 1992; Wood, 1991). Finally, it has been demonstrated that feelings of burden may be related to the social support networks of the caregivers.

This study proposes to examine the issues of: 1) coping strategies, and 2) support needs of caregivers of aging adults with a developmental disability. Specifically, how do they cope with their caregiving responsibilities? What social support do they have? What support do they need? Are there enough formal services for them? Can they find these services? Do they use these services? Or, should service intervention be directed towards helping them build informal support networks, as some literature suggests? As the population of developmentally disabled adults grows, the population of caregivers grows. Thus, the needs of caregivers of adults with developmental disabilities who are aging are likely to begin confronting service providers more frequently than ever before. It seems logical therefore, to ask these caregivers to define their needs, so that service planners may develop the appropriate services to meet those needs.

CHAPTER TWO

Literature Review

There is a growing body of literature on the needs of adults with a developmental disability who are aging. Accompanying this is a growing body of literature on the needs of caregivers of these individuals, which will now be reviewed.

First, general caregiver literature and theories of caregiving will be reviewed to gain some insight into issues for caregivers. Next, the sources of support for caregivers that have already been identified will be outlined. Following that, service needs that have been identified will be reviewed. Finally, permanency planning issues will be examined.

The focus of this research is on the support and coping needs of these caregivers. A review of some general caregiving literature follows to provide an understanding of the issues and theories involved in caring for another individual.

2.1: General Caregiving Issues

Women compose the majority of caregivers in our society, both formally (in institutions) and informally (in families, community homes) (Laurence, 1992; Wood, 1991). As well, the political trend towards care in the community is based on the assumption that women will continue to provide care (Laurence, 1992; Wood, 1991). Wood (1991) notes that although the trend towards community based care is in the name of cost containment, the end result will be increased costs as these caregivers will be dependent physically and financially in their old age, and the formal support services will either still be lacking or women will not be able to purchase these services.

It has also been noted that caregiving results in lost opportunities for those who are employed; for example, through, lost promotions and fewer responsibilities due to caregiving duties (Scharlach, Sobel, and Roberts, 1991; Wood, 1991). As women typically are paid less than men to begin with, these lost opportunities result in a large financial impact for female caregivers: they may never catch up to the earning power of men (Laurence, 1992, Wood, 1991). The end result of lower earning power is that female caregivers will have fewer assets and income to rely upon in old age (Wood, 1991). One suggestion to remedy this income disparity is to have employers look to the needs of their employees who are caregivers, and develop new ways to increase flexibility on the job for these employees (Scharlach et al., 1991). It is believed that increased flexibility at work would reduce the conflict between work and caregiving roles without reducing earning power for female caregivers (Scharlach et al., 1991).

Kaden and McDaniel (1990) have noted that women in Canada are more likely to be both caregivers and care receivers.

Their analysis of data from a 1982 survey of elderly people in the Waterloo, Ontario, region indicated that women live longer than men, tend to be poorer than men in their old age, and are the main caregivers for the elderly at all ages (Kaden and McDaniel, 1990). While women tend to be more economically dependent, which was associated with higher use of formal services, in all other areas of service use, men and women were the same (Kaden and McDaniel, 1990). Thus, for both men and women, increased service use was associated with increased age, decreased health and ability to function independently, and an increased need for help from family, friends and neighbours (Kaden and McDaniel, 1990). It was suggested that women's poverty in later life is an issue that needs to be addressed outside of the boundaries of service use and cost containment (Kaden and McDaniel, 1990). The authors pointed out that women are in a "double bind" of being both caregiver and care recipient and, thus, are vulnerable to many policy decisions regarding services (Kaden and McDaniel, 1990).

Kaden and McDaniel (1990) also noted that women caring for an elderly parent must juggle their responsibilities as wife, mother, and employee. Therefore, female caregivers are at increased risk for physical and mental health difficulties. They (Kaden and McDaniel, 1990) found that female caregivers tend to give up their free time and social/recreational contacts first when caregiving responsibilities become increasingly difficult to manage (Kaden and McDaniel, 1990).

They (Kaden and McDaniel, 1990) concluded that caregiving and care receiving are women's issues.

Ethnic and cultural issues also have been explored in research on caregiving. A study was conducted by Wood and Parham (1990) on caregivers of people with Alzheimer's Disease. Caregivers were assigned categories according to race (Black or White) and place of residence (urban or rural). Their results indicated that caregivers who were White or were urban residents were more likely than caregivers who were Black or rural residents to attend support groups and take an action-oriented, information-seeking approach to caregiving (Wood and Parham, 1990). The authors pointed out that urban caregivers view their situation more positively, perhaps because there are more services and less need in urban areas than in rural areas (Wood and Parham, 1990). Results of this study also indicated that Black caregivers tend to rely more on their informal support networks and to live in bigger households with their extended family; thus making respite and assistance more available (Wood and Parham, 1990). A final point is that Black caregivers feel a close relationship to, and support from, God (Wood and Parham, 1990). The authors suggest that churches may be utilized as alternative forms of support groups and information centres for caregivers who are Black or who live in rural areas (Wood and Parham, 1990).

Research such as the above points out some of the issues involved in caregiving and may give suggestions for service delivery. However, it is also important to understand how caregivers experience caregiving. Following is a review of some theories of caregiving.

2.2: General Caregiving Theories

Numerous studies have been done on feelings of stress and/or burden associated with caregiving, or the "stress-burden paradigm" of caregiving. One study found that feelings of burden were connected to a lack of social support for the caregiver and not to the characteristics of the caregiver or care recipient (Zarit, Reever, and Bach-Peterson, 1980). This finding resulted in a suggestion that services should be directed towards enhancing social support, both formal and informal, for the caregiver (Zarit et al., 1980). By increasing formal and informal social support, caregiver burden could be relieved, and caregivers could continue to provide care for their family, thus reducing the risk of institutionalization (Zarit et al., 1980).

Another study examined the concept of emotional strain in relation to caregiving by comparing sibling caregivers to spousal caregivers from a role theory perspective (Mui and Morrow-Howell, 1993). Results of the study showed a high incidence of role strain for both sibling and spousal caregivers (Mui and Morrow-Howell, 1993). Siblings tended to expect more assistance from their informal support networks; when this assistance was not forthcoming, role strain increased (Mui and Morrow-Howell, 1993). It was noted that siblings probably had more roles to fulfil which would contribute to their feeling of role strain (Mui and Morrow-Howell, 1993). The quality of their relationship with the care receiver also impacted on role strain for siblings (Mui and Morrow-Howell, 1993). For spouses, poor personal health and shorter caregiving duration tended to increase feelings of role strain (Mui and Morrow-Howell, 1993). Although there were several limitations of the study, it did conceptualize caregiving from a more theoretical perspective, that of role theory, while still offering suggestions for service delivery to caregivers.

A critique of recent caregiving literature noted that, as with the above mentioned study by Mui and Morrow-Howell (1993), much caregiver research to date has been quantitative, focusing on the tasks performed by caregivers and the stress that caregivers experience (Abel, 1990). However, this strategy is said to limit policy recommendations and to miss some aspects of caregiving, like the personal relationships in which caregiving occurs (Abel, 1990). For example, focusing on stress reduction as a goal of service misses other benefits programs may have such as educating caregivers (Abel, 1990). Focusing on stress also tends to make difficulties associated with caregiving appear to be individual issues when in fact these difficulties may reflect social or structural problems (Abel, 1990). The author advocated the promotion of caregiver well-being as a goal of service delivery in and of itself, not just in relation to prolonging caregiving in the family or decreasing societal costs of caregiving (Abel, 1990). It is suggested by Abel (1990) that researchers use qualitative as well as quantitative measures and a more holistic, interdisciplinary theoretical base, possibly from the area of women's studies.

A final article reviewed noted the difficulty of using the concept of "caregiver burden" due to "its lack of clear definition, the inconsistency between its conceptualization and operationalization, its inappropriate use within the stress paradigm, and its marginal policy relevance" (Braithwaite, 1992, p. 3). This article viewed burden as an inability for the caregiver to have their basic needs met as a result of several characteristics of caregiving for frail elderly people (Braithwaite, 1992). In other words, caregiving burden in this context is related to: the declining health of the care recipient; the lack of choice for the caregiver to be anything other than the caregiver; the unpredictability of the illness of the care recipient; the caregiver's awareness that the care recipient's health will deteriorate (not improve with care); and the caregiver's lack of time to fulfil other roles and responsibilities (Braithwaite, 1992).

Thus, caregiving can be placed in the context of many different theoretical perspectives. Role theory, stress/burden paradigm, and basic need frustration are just three examples. This study will approach caregiving from a qualitative perspective; data will be analyzed in part within the context of the stress-burden paradigm.

2.3: Sources of Support for Caregivers of an Adult Child with a Developmental Disability

As previously stated, caregivers of older adults with a developmental disability tend to be the parents and, in particular, the mothers of these individuals. Caregivers of older adults with a developmental disability who are also aging themselves are facing the physical, psychological, emotional, spiritual, and social challenges of their aging process. The challenges arising from the aging process may result in fewer resources being available to the caregiver to provide care for an adult with a developmental disability. It has been suggested that institutionalization of an adult with a developmental disability results when families are unable to cope with the care needs of their loved one (Black, Cohn, Smull, and Crites, 1985). Thus, services need to be directed to the needs of the family caregivers as well as to those of the aging adult with a developmental disability.

There is little information to indicate where caregivers of adults with developmental disabilities find support. One study, however, suggests that support for caregivers is found within the family itself (Seltzer and Krauss, 1989). Families of adults with developmental disabilities in which there is a strong sense of cohesion, an inclination to demonstrate their feelings, and an inclination to participate in activities together tend to be viewed as a source of support for caregivers (Seltzer and Krauss, 1989). It was also found that formal support services were not necessarily related to caregivers' well-being (Seltzer and Krauss, 1989). Families play a large role in the support of caregivers and in maintaining family members in the community while the role of formal support services is not as clear (Seltzer and Krauss, 1989).

Given that family support is so important, it is not surprising that siblings of the adult with a developmental disability have been seen as a source of support for both the adult care receiver and the caregiver (Seltzer, Begun, Seltzer, and Krauss, 1991). When siblings are involved in caregiving in some way the caregivers usually feel more satisfaction with life, less stress, and less burden associated with caregiving (Seltzer et al., 1991). It is not clear what in the nature of sibling involvement, which ranged from occasional visits to daily assistance with instrumental tasks, was found to be supportive for caregivers (Seltzer et al., 1991). It is also important to note that these caregivers, usually mothers, often expected siblings to assume caregiving responsibilities for the adult with developmental disability upon the death of the primary caregiver (Seltzer et al., 1991; Zetlin, 1986). As with caregivers in general, female siblings were seen to provide more support than male siblings and the mothers usually expected sisters to be involved more with caregiving for the adult with developmental disability than brothers (Zetlin, 1986). What has yet to be explored in the research is how well prepared and willing these siblings are to assume caregiving responsibilities for their brother or sister with a developmental disability (Seltzer et al., 1991).

A final source of support for caregivers is from the care recipient, the adult with a developmental disability. It has been noted that feelings of reciprocity (i.e. that the care recipient is contributing as much as the caregiver) are important in reducing feelings of burden and stress for the caregiver (Heller and Factor, 1993a). Adults with a developmental disability reciprocated care by reducing feelings of loneliness in their caregivers and by providing assistance with household chores and finances (Grant, 1986).

It should be noted that informal support networks for caregivers of adults with a developmental disability decrease with age as spouses and peers die (Heller and Factor, 1993a). As well, caregivers do not tend to turn to neighbours and friends for support (Grant, 1986). It appears that as long as neighbours and friends seem to accept the adult with a developmental disability, caregivers feel support from them (Grant, 1986). Thus, it becomes even more apparent that the main sources of support for these caregivers are found within their families.

2.4: Service Needs Identified

Many service needs have been identified to support caregivers in maintaining relatives in the community. These service needs will be outlined briefly here. It is interesting to note, however, that some of the studies quoted below are from the perspective of the formal service provider. These studies did not ask caregivers what their needs were to help them cope which would impact on the results.

In a study by Engelhardt, Brubaker, and Lutzer (1988), it was found that the amount of formal services used by caregivers of older adults with a developmental disability was related to the caregivers' perceptions of their ability to provide care for their loved one. In particular, caregivers who reported poor personal health felt less able to care for an adult with a developmental disability (Engelhardt, Brubaker, and Lutzer, 1988). As well, if the adult with a developmental disability was reported to be more dependent upon the caregiver then the caregiver reported less ability to provide care (Engelhardt, Brubaker, and Lutzer, 1988). The authors suggested that service providers should encourage caregivers to use the services that they need and that the caregivers' perceptions of their own health and feelings of burden played key roles in maintaining the caregiving role

(Engelhardt, Brubaker, and Lutzer, 1988).

Another study explored the need of parents of adults with a developmental disability for respite services (Lutzer and Brubaker, 1988). The results showed that older parents preferred out-of-home placements for respite while younger parents preferred respite that involved parents sitting each other's adult children and training for the caregiver (Lutzer and Brubaker, 1988). This study suggested that the age of the caregiver needs to be considered when making service provisions for caregivers of adults with a developmental disability (Lutzer and Brubaker, 1988).

Smith, Fullmer, and Tobin (1994) studied older caregivers of adults with a developmental disability who do not use services and found that these families will use assistance to make future plans for their loved one provided the assistance comes from outside the service system for people with a developmental disability. They noted that the difficulties reaching families who do not use formal services can be counteracted by comprehensive, extended outreach and provision of services on the caregiver's terms (i.e. in their own home, by phone only, etc.) (Smith, Fullmer, and Tobin, 1994). Again, these authors found a difference between the needs of older caregivers and those of younger caregivers of adults with a developmental disability (Smith, Fullmer, and Tobin, 1994). Finally, it was suggested that specialists who have combined the fields of gerontology and mental retardation are needed (Smith, Fullmer, and Tobin, 1994).

Another study noted that an increase in maladaptive or problematic behaviour of the adult with a developmental disability tended to increase feelings of burden and stress for caregivers (Kaufman, Campbell, and Adams, 1990). Services to assist in this area were then suggested: training for the adult with a developmental disability to correct their behaviour, if possible; training and support for the caregivers to help them manage the problematic behaviours of the adult with a developmental disability; and respite care to provide relief for the caregivers (Kaufman et al., 1990).

Still another focus for services that was identified in the literature was to help parents/caregivers resolve life and relationship issues (Brunn, 1985). This idea relates to Erikson's Developmental Life Cycle and the stage of Integrity versus Despair (Brunn, 1985). It was suggested that parents need to come to terms with their parenting, to accept that there were successes and failures, and to come to some kind of resolution in their relationships with their children (Brunn, 1985). These tasks are often interrupted or stopped completely when there is a developmentally disabled child in the family as the parenting role continues into adulthood (Brunn, 1985). Thus, it is believed that one of the service needs for these caregivers is to help them resolve these outstanding life/relationship issues as much as possible.

Financial assistance was identified as another service need. As previously stated, women tend to be the majority of caregivers and they also tend to have a lower income than men. Therefore, caregiving represents a real financial burden to women. As female caregivers age their income becomes fixed and limited due to retirement from any form of paid employment (Jennings, 1987). This limitation on income may be occurring at a time when the cost of caregiving may be increasing due to changing needs and abilities of the care recipient (Jennings, 1987). Assistance should be given in the form of increases to pensions of both the caregiver and the care recipient or through provision of needed medical services, supportive housing, supplies, clothing, etc. (Jennings, 1987).

By identifying social work roles for the population of caregivers for adults with a developmental disability, Kaufman, DeWeaver, and Glicken (1989) identified several formal service needs. One service need that was identified was assistance to access services for caregivers (Kaufman et al., 1989). Other service needs included assistance for caregivers to cope with their own aging, and assistance to the family as a whole to maintain the adult with a developmental handicap in the home (Kaufman et al., 1989).

Seltzer and Krauss (1994) reviewed the literature on the impacts of caring for an adult with a developmental disability throughout the life span and made several suggestions for future directions in policy, research and service provision to aging adults with developmental disabilities and their families. One suggestion was that service providers view the family from a broader perspective and include siblings of the adult with a developmental disability (Seltzer and Krauss, 1994). Another suggestion was to recognize that maintaining an adult with a developmental disability in the family home is becoming increasingly common and, in fact, caregiving for adults with physical disabilities, the elderly, etc. is occurring in the family home more often (Seltzer and Krauss, 1994). Therefore, long-term family care should be considered as a viable alternative for adults with a developmental disability (Seltzer and Krauss, 1994). Services should be designed to aid in a gradual move away from care by the parents to alternative forms of care when such a move becomes necessary (Seltzer and Krauss, 1994).

Kaufman, Adams Jr., and Campbell (1991) suggested that services should be directed towards assisting families of adults with a developmental disability to make future plans for their loved one. This idea is particularly important for people in rural areas where services may not be adequate for adults with developmental disabilities and their families (Kaufman, Adams Jr., and Campbell, 1991). If future plans are not made then adults with developmental disabilities and their families could find themselves in a crisis should the caregiver become unable to provide care (Kaufman, Adams Jr., and Campbell, 1991). The authors view planning for the future of a loved one as an on-going process that takes place across many dimensions including residential, financial and legal issues (Kaufman, Adams Jr., and Campbell, 1991).

A final service need identified also related to accessing services. Some researchers believe that families may need help in locating the services that are available to them (Caserta, Connelly, Lund, and Poulton, 1987). It was also questioned whether or not caregivers need to develop "competency" which includes the ability to identify needs and resources, assertiveness skills, etc. (Caserta et al., 1987). It was found that feelings of competence had an impact on the caregiving role (Caserta et al., 1987). Thus, it could be postulated that helping caregivers improve their competence skills could ease the stress of caregiving.

Most of the above literature reviewed for this section also identified what might be considered traditional service needs. Given that the caregivers' mobility and ability to perform some daily tasks may be decreasing services appropriate to the elderly population in general may be appropriate here. Meals-on-wheels, homemaker services, assistance with shopping, etc. can also be considered service needs of our older caregiving population.

One of the most important issues facing caregivers of adults with developmental disabilities is planning for the future of their loved one. This is also known as permanency planning and it is a major focus for literature regarding the caregivers of adults with a developmental disability.

2.5: Permanency Planning

One of the most pressing needs facing caregivers of adults with developmental disability who are aging is to plan for the future of their loved one. This appears to be a very difficult task for families of adults with developmental disabilities, who often state that although they worry about the future of their loved one they prefer to "take it one day at a time (Heller and Factor, 1991; Heller and Factor, 1993b). Grant (1990) found several different responses of families to the idea of planning for the future including indecision and ambivalence.

There are many factors that influence whether or not a family plans for the future of their adult with a developmental disability and the kinds of decisions the family makes about the future. For example, Grant (1990) found that planning was influenced by interdependence between the caregiver and care recipient (the more interdependence, the less planning), strong family traditions of commitment, and caregiver expectations of the formal service industry. Heller and Factor (1991) found that increased use of formal services was associated with an increased preference for placement outside the family home, perhaps because the use of services made the system of services for adults with developmental disabilities less threatening to their caregivers. As well, preference for placement outside of the family home if the caregiver was unable to continue providing care was also related to a high amount of need that was not met by formal services and a strong feeling of burden on the part of the caregiver (Heller and Factor, 1991). If placement was planned outside the family, then the majority of parent caregivers wanted it to happen after their death (Heller and Factor, 1991; Heller and Factor, 1993b). However, placing an adult with a developmental disability in a crisis means that the adult would not only have to cope with the death of a caregiver (most likely a parent) but they would also have to cope with a significant, perhaps inappropriate, change in their living environment (Heller and Factor, 1991; Heller and Factor, 1993b).

Some characteristics of caregivers of adults with a developmental disability were also likely have an impact on whether or not future plans were made. For example, it has been demonstrated that caregivers of adults with a developmental disability who are older and have high socioeconomic status are more likely to plan for the future of their loved one than caregivers who are younger and of lower socioeconomic status (Heller and Factor, 1991; Heller and Factor, 1993b). Race was likely to impact on where the adult with developmental disability would live in the future. An early study by Heller and Factor (1988) indicated that black families are more likely to make future residential plans within the family home for their loved one and less likely to make future financial plans than white families. However, in this study, the caregivers who were black were also younger, perceived themselves to be in poorer health, and were of lower socioeconomic status than white caregivers. Age of caregiver, perceived health of caregiver and socioeconomic status of the caregiver have all been associated with permanency planning so these factors may have contributed to the increased likelihood of placement within the home and the lack of financial plans for a relative with a developmental disability in black families (Heller and Factor, 1988).

Another aspect of permanency planning is making financial arrangements for the adult with a developmental disability. Families are more likely to make financial arrangements for the future of the adult with a developmental disability than they are to make residential arrangements for the future (Heller and Factor, 1991; Heller and Factor, 1993b). However, families need help in locating assistance for financial planning (i.e. help finding lawyers) and guidance in implementing these financial plans (Goodman, 1977).

The benefits to parent caregivers in making plans for the future would be to help them feel that their parenting is complete and that there is no unfinished business (Smith and Tobin, 1989). Yet there is still a call to treat families as a whole unit and to involve everybody in the family in permanency planning (Adams, 1990). The preferences of the adult with a developmental disability need to be considered along with the preferences of parents and siblings (Heller and

Factor, 1994). Assisting the whole family in this task is thought to decrease the risk of institutionalization and to improve support and service delivery to these families (Adams, 1990). Again, it is critical to have these caregivers, be they individuals or families, identify their needs so that appropriate services can be developed.

To summarize, it can be seen that the families, and siblings in particular, of adults with a developmental disability are the main source of support for caregivers of adults with a developmental disability. Many service needs for caregivers of adults with a developmental disability have been identified with the goal of helping the caregiver to continue in their caregiving role. The most pressing task facing these caregivers is to plan for the future of their loved one in terms of place of residence, finances, and guardianship. Yet, planning for the future is a task that often remains incomplete, placing the adult with developmental disability in danger of having to cope with the loss of their caregiver and a new, perhaps inappropriate, place to live at the same time.

This study proposes to explore the experiences of caregivers of adults with a developmental disability; to find out what they identify as their coping skills and sources of support; to find out what, if any, service needs they identify for themselves. Finally, it is hoped that characteristics of caregivers who tend to make future plans for their loved one can be identified and what helped or hindered these caregivers to make these plans. If no plans have been made, then this study hopes to explore the reasons why.

CHAPTER THREE

Methodology

3.1: Theoretical Perspective and Design

Phenomenology has been said to be the study of how a group of people structure and experience a phenomenon (Patton, 1990). It is a qualitative focus that seeks to understand "what people experience and how they interpret the world" (Patton, 1990, p. 69-70). In other words, the focus in a phenomenological method is to obtain descriptions from people of how they experience their world (Ray, 1985; Lynch-Sauer, 1985). This study proposes to explore the perceptions and experiences of family caregivers of adults with a developmental disability. It deals mainly with the caregivers' descriptions of caregiving, their daily tasks, and how they define their sources of support and coping strategies. The purpose is to achieve an in-depth understanding of the dilemmas and problems these caregivers face and what, if any, coping or support needs they identify for themselves. A phenomenological perspective is therefore well suited to this study, and is used in an effort to achieve an in-depth understanding of the caregivers' experiences.

3.2: Definitions

In today's society, the term family can be used in many ways. No longer does it refer to immediate or extended family only. Families of today are often reconstituted and include children from previous marriages, adopted children, etc. For the purposes of this paper, the term **family** referred to members of the immediate family: mother, father, brother, sister, step-children and adopted children. It did not refer to extended family such as aunts, uncles, cousins and grandparents.

Caregivers can be either formal (i.e. paid) or informal (i.e. not paid). Informal caregivers tend to be family members. Caregivers may perform a variety of tasks. These tasks may be instrumental (eg. bathing, hygiene, eating, dressing) or they may be more supplemental in nature (eg. help with financial or residential planning, emotional assistance). For the purposes of this study, **caregivers** were defined as informal (unpaid) family members who perform any of the previously mentioned activities or who assist their relative in performing them.

Coping may be considered to be any activities or strategies which assist caregivers in dealing with their tasks. This may include day programs, respite care, homemaker services, a healthy, active lifestyle, etc. **Coping** in this study was viewed as these more instrumental, action-oriented activities which help caregivers to continue providing care for their relative.

Support may be defined as a more emotional or social kind of assistance, which can reduce feelings of burden for caregivers and the stress which is often associated with caregiving. Support can come from many sources, like friends, neighbours, family, church members, club members, etc. For the purposes of this study, **support** was defined as any emotional assistance which a caregiver perceived to help reduce feelings of stress and burden.

3.3: Population Sample

Participants for this study were six caregivers of adults with developmental disabilities. They were obtained from an agency providing services to individuals with developmental disabilities in the Hamilton-Wentworth region. In addition, participants were obtained through the researcher's personal contacts. More detailed descriptions of the caregivers and care recipients appear in the next chapter (Findings).

3.4: Means of Data Collection

Letters of invitation (Appendix A) to participate in this study were sent out to caregivers in June and July, 1994, by an agency providing services to adults with developmental disabilities and their families. The letter explained the research protocol, and requested interested caregivers to contact the researcher directly. One caregiver contacted the researcher, the rest were recruited through the writer's personal contacts or through the contacts of one of the participants. Once contact had been made between the researcher and the participant an interview time and place was established and any questions caregivers had about the study at this point were answered. Signed letters of consent (Appendix B) were obtained during the scheduled visit prior to the beginning of the interview.

Each study participant was involved in a single one to one and a half hour interview which was conducted in their home or at another location of their choice. Five out of six interviews were audiotaped and transcribed at a later date by an experienced transcriber. One participant did not consent to be audiotaped but did permit the interviewer to take notes throughout the interview. This participant gave verbal consent for the content of her interview to be used for this study.

There was no deception or manipulation involved in this study. Participants could refuse to answer any questions or could withdraw their participation at any time. Every effort was be made to be sensitive to participants' vulnerabilities. Those participants who requested one will receive a copy of a summary of this thesis.

Interviews were held from July to September, 1994. Transcriptions were completed immediately following the interviews. Data analysis took place in January, 1995.

3.5: Instrumentation

An interview schedule consisting of two parts was used (Appendix C). Part A outlined demographic data for both the caregiver and care recipient including information on age, sex, ethnicity, income, religious affiliation, occupation, educational background and family composition.

Part B was a semi-structured interview schedule consisting of three main questions. The first question asked participants to describe their current experiences as a caregiver for an adult with a developmental disability. The second question asked participants to describe any changes that may have occurred associated with their aging process or that of their care recipient. The final question asked participants to think about the future and what changes they think may arise for them and their loved one and what plans they may have made for the future of their loved one.

Since the interview schedule was based upon a phenomenological approach the first question in particular was intended to obtain descriptions about the caregivers' experiences in their own words. The second question arose from the literature regarding aging with a developmental disability which indicated that the aging process is not clear for people with a developmental disability. Question Two attempted to discover the caregivers' perceptions of their own aging process as well as that of their loved one. The final question was a result of the literature review for caregivers of adults with a developmental disability which indicated that permanency planning was a major concern for aging family caregivers of adults with a developmental disability.

3.6: Ethical Considerations

There were several ethical considerations for this research: obtaining voluntary, informed consent, maintaining confidentiality of the data, sharing results with participants, and ensuring that there is no harm (especially psychological) to participants.

3.6.1: Plan for Obtaining Informed Consent

The following process was used in order to obtain informed consent of the participants:

1. Initial contact by letter or telephone was made by the researcher or another participant or an agency that provides service to individuals with developmental disabilities to explain the researcher's role and to give a brief overview of the proposed research.
2. A phone call between the researcher and interested caregivers followed during which the purpose of the study, what would be involved in participating, issues of confidentiality and consent and the right to withdraw at any time was explained. If the caregiver chose to participate an interview time and place were established. If they chose not to participate they were thanked verbally for their time.
3. A letter of consent was discussed by the interviewer and the participants and signed by the participants prior to beginning the interview.

3.6.2: Procedures to Ensure Confidentiality of Data

The following procedures were used to ensure confidentiality of data:

1. Audiotapes, disc copies and hard copies of the interviews were kept in a locked environment.

2. Audiotapes were transcribed by a person experienced with interview transcription who was aware of issues of confidentiality.
3. Initials only were used in the transcriptions.
4. Audiotapes and all copies of transcriptions were destroyed upon completion of the study.
5. Neither real names nor initials were used in the final research report.
6. Permission was obtained to use direct quotes.
7. Demographic data was reported in aggregate terms only.
8. Content of interviews was analyzed for themes, categories, and reflections on the overall study questions.

3.6.3: Nature of Feedback to Participants

Feedback was given to participants as follows:

1. Any questions were answered as promptly as possible and in writing if requested.
2. A summary of the study results will be given to participants at their request, upon completion of the study.

3.6.4: No Harm to Participants

A study of this nature has the potential to be harmful in that some questions may cause discomfort, particularly around sensitive issues like permanency planning. Participants were informed of their right to refuse to answer any questions with which they were not comfortable. If the interview was too upsetting then participants could stop it altogether. Interview questions were framed with consideration to participant vulnerability.

3.7: Data Management and Analysis

Interviews were tape recorded and transcribed. When using the phenomenological approach, data in the form of key concepts or ideas is sorted according to themes or categories that appear to emerge (Lynch-Sauer, 1985; Patton, 1990). Therefore, in this study key phrases, concepts or ideas were obtained from the transcriptions and written on index cards. The index cards were then sorted according to various themes such as: current service use, gaps in current services, changes related to aging for both caregivers and care recipients, and concerns and plans for the future. The index cards were sorted several times in an attempt to ensure that as many themes as possible emerged. The themes that emerged are reported in the following chapter.

CHAPTER FOUR

FINDINGS

Interviews from five out of six caregivers were taped and transcribed; one caregiver refused to be taped but did consent to have the interviewer keep a written record at the time of her interview. Data from Mrs. I., therefore, should be viewed in light of the fact that the interview was not taped verbatim and reflects the memory and the significance which the interviewer gave it. Key phrases from these records were written on index cards which were then sorted according to themes. The cards were organized and re-organized, to ensure that all possible themes were explored. As a phenomenological approach was used, the goal was to find out how the caregivers experience caregiving, what their world consists of, and how they interpret it. The themes identified by this process were: routines, faith, government, services used, dealing with professionals, service needs for the future, acceptance of their child, respite, information, family relationships, reactions to being a caregiver, how the caregivers cope, tasks of caregiving, arrangements for the future (permanency planning) and facing the future. In the next chapter, the themes presented here will be related back to the research question. In this chapter, the themes of the caregivers' experiences are presented as they were expressed by the caregivers.

4.1: DEMOGRAPHICS

4.1.1: CAREGIVERS

Six caregivers were interviewed for this study. All six were women; one was married; four were widowed; one separated prior to her second husband's death; one was divorced. The interviewees were all mothers; their ages ranged from 66 years to 77 years old. Four of the mothers were born in Canada, two immigrated prior to their marriage. Most of the mothers were on fixed, limited incomes in the form of the Old Age Security pension. Some were fairly well set up financially with savings and/or pensions and/or inheritances from their husbands. Some relied on the income of their adult child to help maintain their homes. Four mothers were Roman Catholic, one was Protestant, and one United. Most mothers who were Roman Catholic were still practising their faith or involved in the Church in some way. Mothers who were not actively practising their faith still spoke of having faith, of believing in God, and using their faith as a coping mechanism. Faith will be discussed further in the next section of this chapter.

Occupations of these mothers ranged from home maker "motherhood is all I wanted" to "stripper" (prepared film for the presses in a printing plant), to nurse. Some mothers completed high school, some went beyond high school for specialized training (eg. the nurses). Five of the six mothers were living in homes they owned in middle class neighbourhoods. The other mother was renting an apartment, also in a middle class section of the city. Four caregivers had more than one child; Mrs. H. had only one child; and Mrs. I. had another child with a mental health problem (schizophrenia). Mrs. Y. had one son die and one daughter develop multiple sclerosis and subsequently alienate herself from the rest of the family. Cultural/ethnic backgrounds of the mothers were English, Italian, Canadian and German.

These mothers were all fairly healthy, the most common complaint being arthritis. They reported an array of health problems which modified but did not prohibit their function. Mrs. H. stated that some days her knees were so sore that she could not really walk. Cold days and days when she was fairly busy were hard days for her to cope with her arthritis; getting up and down the stairs was a problem on those days. Mrs. E. had a bad arm as a result of a break that occurred when she was born and was set improperly. This arm was shorter than the other, was a bit twisted and she could not raise it as high as her other arm. She stated that her bad arm slowed her down a bit but she has developed her own way of doing things: "Give me an extra half hour that you'd give a 'normal' person, I'll find my niche." However, she also had some nerve problems in this shoulder for which she was receiving treatment. Mrs. E. also had arthritis and osteoporosis: "My health is not too bad from the waist up."

Mrs. E. was taking an anti-inflammatory for her arthritis and a stomach pill for her ulcer. She has had a couple of falls and landed on her tailbone which she said was damaged as a result of the falls. She was not concerned about her difficulty walking; the doctor has told her that she is lucky she is walking at all. Mrs. H. spoke of how hard she tried to stay healthy, through diet and exercise, in order to take care of her son. Mrs. Y. had a heart attack in 1988 and found it difficult to care for her son while she was recovering. At that time, it was all she could do to get him out the door each morning so that she could have a rest. These difficulties went away with her recovery.

The mothers had a variety of interests which included recreational activities, volunteer work, advocacy, and physical fitness. Mrs. I. had been a foster parent. Several mothers attended a religious group called Faith and Light which also appeared to provide support and information to them as parents of children with developmental disabilities. Mrs. O. enjoyed babysitting her grandchildren:

> "I love my grandkids, I love to see them come and I love to see them go..."

Mrs. H. enjoyed gardening with her son. Mrs. O. volunteered at the Good Shepherd Centre serving meals to people. She was also a member of the Women's Auxiliary of the Association for Community Living (hereafter referred to as the

Association) and participated in several activities through this group which also provided support to her. She enjoyed going to plays with H., her daughter with a developmental disability. Mrs. E. was a member of a board of directors of an organization. Her involvement included assisting with garage sales and bake sales. Mrs. O. went to night school with her daughter. Mrs. L. volunteered with the Trillium Awards, visiting people's homes to judge their flower gardens. She stated that she found a great deal of pleasure in looking at flowers: "I get so much delight going around and seeing the flowers and the colour combinations."

Mrs. Y. was involved with a bereavement group trying to develop information for parents to assist their child with a developmental disability in dealing with the loss of a loved one. Mrs. Y. felt that this was an important thing to do but she said that she did not understand the process, why information had to be changed so often, why people could not accept the way it was written the first time. This group was not offering a lot of satisfaction for her and she was considering leaving the group.

4.1.2: CARE RECIPIENTS

The six care recipients ranged in age from 25 years to 42 years. Four out of six worked, three in sheltered workshops and one, A., worked in a local hospital although he did not receive a pay cheque for this work. H. attended adult education classes daily and Z. had no daily program to attend. All adult children received Family Benefits Allowance (FBA). All had been through the education system for children with developmental disabilities. There were four males and two females in this group. Five of the six adult children had Down Syndrome; one had an undiagnosed developmental disability with a mental health problem (schizophrenia). The care recipients were very healthy, none had a heart condition or health ailment beyond being overweight.

According to their mothers, the adult children were all functioning at a fairly independent level with the exception of Z. who had been tested to have an intelligence level of two years. Most of the care recipients were able to dress, bathe, feed and shave themselves and make simple meals like sandwiches. Even though these adult children were fairly independent, the mothers all reported that they were "slow, slow, slow" in completing any task. Often, then, the mothers would assist their adult child with bathing, dressing, shaving, etc. in order to have the individual ready on time in the mornings. All mothers wondered if this was the right way to cope but most felt that even if it was not the right way they would continue to do so in the interest of saving time and sanity. Most of the mothers described their adult child as easy going, not too hard to manage and a joy to be with.

Most of the adult children had few behavioral issues. Mrs. E. said her son, A., would stamp his feet or grumble when he became angry. Mrs. L. said her son, T., appeared frightened of stairs and if he did not want to go out he would "scream and bellow" to go home. Another son was deathly afraid of falling in the tub. One daughter, however, had many behaviour problems. Mrs. I. said that Z. spent most of her day standing and looking at her hands. Z. has cried while she is on the toilet and has pounded her head or hand on the tub. Z. was not able to dress or bathe herself. She has sworn when she has been upset and she needed a lot of encouragement to eat. Z. has been aggressive towards her mother, slapping and scratching her. She was not cooperative, cried and ran away from "baby sitters" that Mrs. I. tried to use for respite. Mrs. I. described two attempts to place Z. in a group home; one time her daughter ran away, another time she was aggressive upon her arrival and the home would not keep her. Mrs. I. also had a son, M., who had schizophrenia and epilepsy. He apparently has attempted suicide a couple of times and ran away from home as well. Mrs. I. felt that her daughter "wanted to win," was hard to discipline and she worried what people think when they hear Z. yelling.

The mothers described the personality of their adult child in detail and often said that their adult child was a special, happy person. Mrs. O. stated that her daughter, H.'s, biggest fault was that she will not clean up her room. She also described H. as sociable, someone who enjoys having company and going to parties and someone who does not spend her money freely. Mrs. E. said her son's biggest problem was that he does not listen but he was good with his hands and his biggest handicap was that he could not read or write. Mrs. L. said her son, T., liked to watch T.V. and listen to the radio but he did not share well because he does not understand why he has to share. Mrs. Y. said her son, V., was basically lazy, not very ambitious, stubborn, strong-willed. Mrs. L. described T. as a loner, a very good eater and not much of a socializer. She said:

> "His radio, his T.V. and his food are the three prime objects in his life, outside that he couldn't care about anything."

The adult children were all fairly healthy. Z. had some physical problems including not menstruating for five months and problems with her bowels. R. was a bit overweight but otherwise healthy. H.'s health was good. When she was young she was a bit colicky and after the age of two she could no longer cry. The doctor told Mrs. O. this is a quirk of someone with Down Syndrome. A. was healthy, although he too was overweight. There was some concern that A. could be diabetic. He had flat feet and was almost blind in one eye; this was a "wobbly" eye that Mrs. E. thought was part of having Down Syndrome. T. had a serious health problem; for several years his blood platelets have been very low. He has been taking Prednisone to control this problem. He has been on Prednisone for twenty years and Mrs. L. said that "sooner or later it will catch up with him." T. has the potential to bleed internally because of these low blood platelets and he must avoid strenuous activities. Although he ate well, T. was thin. Mrs. Y. has noticed that V. has been forgetting things lately and the staff at the sheltered workshop have noticed it too. Although they wondered if he has been forgetting on purpose, the thought that he might have Alzheimer's Disease has crossed everyone's mind.

> "It's not a serious forgetness, I don't think, like
> I don't think it's Alzheimer's forgetfulness..."

Mrs. Y. was not worried about V.'s forgetfulness at the present time. As with most of the other care recipients, V. was very overweight.

4.2: ANALYSIS OF INTERVIEWS

The following are the themes that emerged after a content analysis was completed on the transcriptions of the interviews; they are descriptive of the experiences of the caregivers.

4.2.1: Routines

These caregivers were very familiar with the daily activities of their adult children. In fact, many of their own routines and activities centered around their adult child's schedule. These mothers could recite their adult child's day from the moment they awoke until the moment they went to bed. Furthermore, their own day was just as structured as that of their adult child. Here are some examples of daily routines:

> "...he takes a pill in the morning and a vitamin pill and juice and he has coffee...as soon as he comes home at 4:30 his supper's ready. After supper he has an hour and a half sleep...Then he sits down and if we're not going anywhere he has the programs that he watches on the T.V....and I either sit and watch or read...At 11 o'clock we go to bed..."

And another example of a daily routine:

> "Every day is very simple because she's so very easy going...she gets up in the morning, gets herself ready for school...she goes out the door by herself because I'm already gone...she's at school until noon...she gets home at 1:30; it takes her one and a half hours to get home...she makes herself lunch, a sandwich or something...after lunch is vacuuming and straightening up her room, which she does not do very willingly...after supper she does her homework...at about 8 o'clock she watches T.V....at 9:30 she has a bath and gets her clothes ready for school..."

The caregiver's daily routine was just as structured:

> "...every morning I go out for a walk for one half hour...I end up at St.Peter and Paul's Church for morning mass...at 9 a.m.I come out and my girl friend meets me and we walk for one half hour more. Then we go to the plaza and have a coffee..."

> "I have to have a routine. I couldn't be without it...he has to have a routine, even when he's on holidays..."

The caregiver's daily routine centered around the activities of their adult child:

> "He's gone for the day and I do my chores and I enjoy my free time because I need that. I have to have a rest in the afternoon and I'm happy when I see him come home at 4:15..."

Mrs. I., whose daughter Z. did not have a day program, was unable to leave the home unless there was some kind of relief worker. Unfortunately, Z. would run away from any relief worker, thus Mrs. I.'s entire day revolved around her adult child.

These caregivers also spoke of sharing activities and chores with their adult children, such as yard work, swimming, computer classes:

> "...we read the paper and at 9 o'clock we turn the T.V. on again...and watch T.V. together..."

Particularly for the widowed caregivers, the adult child with a developmental disability often became a companion as well, someone with whom they could take trips, share interests.

These caregivers also spoke of the need of their adult child to have as much structure as possible:

> "...routine works for him..."

> "He's one of these routine children...and he doesn't like the [change in routine] at all..."

> "They're [adults with developmental disabilities] creatures of habit...if she's setting the table and I put something on it, she'll take it off..if I'm making the bed, she'll put it the way she wants it and start over...every 10 minutes make a difference to her..."

Most mothers felt their adult child was very happy in his or her daily routines. They said their adult child did not cope well with change. For example, on holidays the adult child could cope as long as s/he knew they would be going back to work at the end of the week or two weeks. The common difficulty these adults with a developmental disability experienced in coping with change raises the issue of how they will cope with retirement. How will they cope with the loss of an activity which their mothers feel is key to their well being and happiness?

There were also some routines around banking. Although the adult child may not understand finances, banking procedures, or even the value of money, a couple of them enjoyed going to the bank to deposit their pay cheques or to take out some spending money.

In summary then, the adults with a developmental disability were very dependent on their daily routines as a way of coping. Their mothers were very familiar with these routines and could recite them in detail. The mothers also had elaborate routines of their own. The routines of the caregivers were often dependent on those of the care recipient. The mothers also used their own routines as a way of coping with their responsibilities as caregivers.

4.2.2: Faith

Many of the caregivers spoke of receiving assistance from God, church groups or their faith in coping with their role as caregiver:

> "The Lord tells me to cheer up when I get sad...The Lord gives you energy to help yourself."

> "I say a prayer every day and thank the Lord for my strength and my health."

> "...I don't go very often [to Church], but I think it's my upbringing because I was brought up in the Church, and I have faith, and I don't know what it is [that helps me to cope]."

> "The Lord will come around and do something [to help me and my child] I feel that in my heart."

> "I come home and count my blessings..."

> "...you feel like you're getting hope, getting help from God,...it gives you peace of mind."

Several of these mothers were members of a church group called Faith and Light, in fact many of them knew each other through this group. They described the Faith and Light group as an opportunity to get together with other parents while their children received Bible study and extra assistance to make their First Communion and Confirmation. These ladies began attending the group years ago; some have dropped out because they had no transportation, others have stopped going because they felt the group could not offer them any more assistance. Some of the adult children stopped going while the mothers continued to go. It was a chance for the mothers to find support from other parents, to get information, to plan trips, and to honour faith all at the same time.

> "[Faith and Light] is kind of nice because the parents get together and they kind of discuss [things]..I enjoy it and T. likes to go, that's a day for him to get out once a month."

> "[Faith and Light] discuss trips, activities, and guest speakers...discussed the new laws about power of attorney..."

Unfortunately, members of the group are aging and the composition of it is changing. Thus, a source of support for some of the mothers may end:

> "We've been together for 29 years, and developed lots of friendships...it's sad because lots of people have died, at least 15 mothers and father since we started..."

> "The woman running Faith and Light is getting older...they thought it would fold up...no one wants the job..."

The Faith and Light group was helpful for these mothers in coping with their role as caregiver. Besides providing support and friendship, it also provided information and comfort.

4.2.3: Government

Many caregivers mentioned the government, appeared to be suspicious of the government and its intentions, and were actively trying to avoid any involvement with the government.

> "It's all taken care of [son's financial future]...I did it several months after my husband passed away....it must be done because you can't trust the government..."

These caregivers wanted the government to leave them and their adult children alone.

> "I want the government to leave us alone...don't take away things, rearrange things [pensions]...leave us alone the way it is now...lots of widows rely on money for their kids..."

> "I don't think the government wants to hear people...I marched on Toronto, it halted things a bit, they're back full tilt now [referring to new legislation that proposes to close sheltered workshops]...I wish this government would step out of this workshop bit and let it run itself the way it has been running for years"

Many mothers were aware of the new legislation regarding powers of attorney for property and had consulted with a lawyer to arrange for powers of attorney for their adult child, especially in the event that they were no longer living or able to make decisions for their adult child. Many mothers had also consulted with a lawyer to set up their will and to establish a trust fund for their adult child with a developmental disability. Most mothers chose to have another adult child administer the trust fund for their adult child with a developmental disability.

> "That's what lots of parents do...have another child they can ask to be trustee...leave the money to that person so the government doesn't get it and the FBA doesn't go down..."

When the mother had more than one child, she often chose as trustee the child who would be providing care to the adult with a developmental disability once the mother died. Where there were no other children, trusted friends or extended family members (eg. nieces) were named. In this way, the adult child's financial future was more secure and their Family Benefits Allowance (FBA) would not be affected by any inheritance they may receive.

Two mothers viewed the government as extremely unhelpful:

> "Politicians don't see suffering, don't take care of people, so they don't know...They [the Ministry of Community and Social Services] offered some in-home help, but I refused because we'd been hurt by them..."

> "I've been screwed and tattooed every time we turn around."

Some mothers pointed out that they had saved the government money by caring for their child at home. Many mothers were told to institutionalize their child when s/he was born. They recognize that caring at home has saved the government some money. Now, when their finances are dependent on their pensions, these mothers feel they are not getting any kind of compensation for saving the government some money:

> "...you don't get any satisfaction, you don't..." Some mothers were concerned that pensions and tax breaks would be cut:

> "They're cutting hospitals, they'll cut for the mentally retarded too."

> "They say the government is going to take away our pensions..."

Other mothers spoke of red tape when dealing with the government. Another felt that computerization was good as it allowed the government to know how many people are needing services: "...so the government knows we're out there..."

Thus, these mothers did not trust the government and often felt the government was trying to take benefits away from them. They felt no reward for having been caregivers. Most mothers were actively trying to avoid government intervention into their adult child's finances and inheritance.

As these mothers relate the story of being a caregiver for their child with a developmental disability, a theme runs throughout their stories of having to fight for the services they used. These mothers told people what they needed, then had to fight to get it. Let us now look at their experiences with services and with professionals.

4.2.4: Services Used

Many of the mothers had some experience dealing with the local Association for Community Living. These mothers had strong feelings about the Association and had plenty of experience dealing with the Association while putting their child through the specialized education system and later having their child placed in a sheltered workshop. Mrs. Y. had this to say about the Association:

> "The Association has never been much help...it's been a fight with them and they don't tell you anything..."

The idea that the Association does not provide sufficient explanations or keep parents well informed was a common thread for a few mothers. They also felt that information sharing was a role that the Association should play.

Mrs. E. said:

> "[the Association] don't listen to parents...treats everybody the same--all have to be normal..."

Along the same lines, Mrs. Y. had this to say:

> "[the Association] is not listening to what the parents identify as their kids' needs...every kid's an individual, no two are the same..."

Mrs. Y also said:

> "...The Association talks about stupid stuff that's not real..didn't fit with anything in my life...Annual meetings don't do it...I don't want to know about what they made, how much money they lost..."

When asked if she felt any support from the Association, Mrs. Y. replied:

> "None. None. And like, maybe I didn't support it either, eh? Because a few things turned me off...It was just fight, fight, fight all the time..."

Mrs. Y. was also speaking to the difficulties of obtaining services in a rural area. She felt that applications for leisure "buddies" for her son and for transportation were ignored if the address on the applications indicated a rural route. In particular, Mrs. Y. had to fight for transportation for her child into the city; she advocated for the Disabled and Aged Regional Transit System (DARTS).

In speaking about the idea of closing sheltered workshops, Mrs. Y. said:

> "I'm almost ready to blame whoever is in the hierarchy at the workshop for letting it happen and not calling parents in and saying 'hey, look this is serious'...I've never been this angry before,

> for so long...I feel like I'm being put upon or taken away from or something..."

Most of the mothers whose adult child worked in the sheltered workshop wanted the workshop to remain open; they did not want their adult child in a new, different program. Mrs. Y. pointed out that for her son it would mean changing jobs after 20 years and he does not cope well with change:

> "He isn't [able to move to the community to work] because he's been so many years trained this way and I don't think he's capable of making that whole change...It's [the workshop] safety in numbers and supervision..."

The mothers did not feel the workshops segregated their adult child, they felt the workshop was a safe, protected place to be, somewhere their adult child enjoyed going each day. These mothers were supportive for younger parents with younger children who wanted to be integrated into the community but for their own children they wanted things to stay the same. And they pointed out that many current services would not be available except for their efforts and advocacy:

> "...kids 21 now wouldn't have the opportunities to go to school if we hadn't fought and learned that maybe some of them are capable of doing otherwise...they wouldn't have it better if we hadn't gone through what we did and learned what we did."

These mothers were pioneers in identifying needs and fighting for services for children with a developmental disability. They feel a certain amount of pride in what they have accomplished and do not agree with a lot of the changes which are proposed to a system they fought so hard to establish;

> "...workshop changes are terrible...I heard there'd be no more jobs..."

Some mothers raised the concern that there was still a fight for services. Yet, they felt the funds available for services were not being distributed properly. The mothers were also concerned about services being cancelled like the sheltered workshops and the residential programs. Nor did they want to see favourite staff leave the programs.

Some mothers had very positive experiences with the Association and did not hesitate to express their satisfaction with the services:

> "I felt H. was protected in the special schools...she was happy...I've had good experiences with the Association..."

> "The workshop is everything to T., he loves it."

Most mothers and their children were involved with the Association; for some, this was the only service they used. Other mothers used many services; Mrs. I. and her daughter appeared to have used the most services, including group homes, institutions, day programs, advocates, special needs workers, psychiatrists, specialists in behaviour management. Mrs. I. talked about the problems she had in leaving her daughter with strangers. She also related an incidence of abuse her daughter had suffered from another resident in a group home. Mrs. I. felt that this experience made it impossible for Z. to develop trust. Mrs. I. also mentioned another incident where Z. was physically harmed and for this incident it was not clear if Z. had hurt herself or if another resident had hurt her. Mrs. I. did not trust the service system nor the professionals in it, yet she continued to seek help from them. Mrs. I. also had another child at home with a mental health problem and was having difficulty finding help for him too. Mrs. I. was adamant that more group homes were needed, and more support for parents. She was unsuccessful in placing her daughter who had many behavioral difficulties. Sadly, Mrs. I. died approximately one month after her interview. After her death, both of her adult children were placed immediately.

Mrs. Y. spoke of when her son, V., was placed when he was five years old. She placed him in an institution because professionals had told her she should. She did not visit him for 6 weeks because professionals told her not to. Then, when she did go to see him she found him no longer able to walk, no longer continent, in restraints and with many skin problems. After that experience, she and her husband agreed to never place their son again. She said that she thought doctors and other professionals would know more than she did about how to care for her son. She related this story of talking to her doctor about inoculating her son:

> "He said he didn't know what the reaction would be. And I didn't insist because I thought he must know something more than I do...And the decision really turned out to be mine all the time..."

Mrs. Y. was referring to the fact that these mothers had no one to turn to who knew more about children with a developmental disability than they did. In the beginning, these mothers could not rely on the knowledge and judgement of professionals, they had to rely on themselves and other parents in the same situation.

Some mothers only went on holidays with their adult child, others were comfortable leaving their adult child with a sibling or friend. These mothers could not just go on a trip whenever they wanted; plans had to be made. Mrs. E., herself a member of a seniors group, stated that she would like to be able to just pick up and go somewhere if she wanted to and not have to plan so much. Having their adult child involved in more recreation activities and trips could free up more time for these mothers. Mothers like Mrs. E. wanted services that could allow them to have more flexibility to do the things that they wanted to do, like travel.

Mrs. O. was very pleased to have H. attending adult education classes. She felt it provided more intellectual stimulation for H. than a sheltered workshop could. H. was also a member of a group called People First. This group is composed of adults with a developmental disability, it is chaired by an adult with Down Syndrome and its main goal is to advocate for the needs of adults with developmental disabilities. Mrs. O. was very proud that H. is a member of this group.

Mrs. E. spoke of her son A., who is working in the community. She related a meeting that took place between the various workers involved with her son and herself. Apparently, these workers had some kind of disagreement and the end result was that her son's work hours were cut back. She was upset about this, did not understand why the hours were changed but felt unable to do anything about this:

> "...He [the supervisor] wasn't mad at the kid, but the kid's getting the brunt of it and so am I..."

In describing the situation, Mrs. E. referred to the education levels of the various workers and said that she couldn't compete, that she did not understand most of what they were talking about:

> "...I'm only the mother, I don't hear about these conversations. I didn't know for the longest time they were meeting every Friday... he's [the supervisor] well educated, can sit in a think tank, brainstorm, that's way beyond me, I can't think like that..."

Mrs. E. was hoping that the worker in question would change his mind about her son's work hours when he has had a chance to cool down. This seems to be an example of how dependent and sometimes helpless these mothers can be with the service providers and the day programs which their adult children attend.

Another issue for the mothers was transportation. Most adult children used DARTS or its equivalent in their communities. Some difficulties with transportation services that were identified by the mothers included a lack of flexibility in scheduling trips and a lack of reliability in vehicles arriving when they should. These mothers would like a more flexible, reliable system of transportation for their children.

In summary, the Association was a common service provider for many of the mothers and/or their adult child. Some mothers were pleased with the services from the Association, others were not. The sheltered workshop was very important for those adults with a developmental disability who attended one. It was important for the mothers that the sheltered workshops not be closed, especially after they worked so hard to establish the sheltered workshops for their children. Day programs were a key for respite for these caregivers. It is interesting to note that high service use coincided with behavioural difficulties and mental health issues in the adult child, in the case of Mrs. I. and her daughter Z.. Trust in the service provider was particularly important for these caregivers.

4.2.5: Dealing With Professionals

These mothers spoke of having close relationships to the service providers with whom they were involved. If they liked a worker then they did not want to see that person leave the agency. According to the mothers, service providers had to have the following qualities or abilities: knowledge, kindness and the ability to be firm. Mrs. I. felt that she did not meet anyone with knowledge and compassion. She felt disappointed when Z.'s behaviour did not change after professionals had promised that it would. She also said that she felt Z. was betrayed by professionals and that was one of the reasons why Z. had behavioural difficulties.

Service providers whom the mothers liked became their friends. Everyone was on a first name basis and there was a real sense of loss if the person left:

> "Lots of people were disappointed when Anne left, she was a real go-getter..."

> "Mary and Jane are like friends to us..."

Some mothers felt that service providers could get a little pushy in what they felt the adult child needed:

> "I've always felt they did a little too much

> pushing...the more they try to hold me back, the more determined I become..."

Mrs. Y. did not agree with the philosophy of normalization which many professionals in this field promote:

> "...this one dame came in...and...everybody was normal, normalization, normalization...you can take that too far too...I know V. will never be normal. You can treat them as normal, get them to do things as normal as possible, but they'll never be normal...Anybody that tries to tell that, shove that down my throat, I won't buy it."

She had this to say about theory:

> "...when you hear theory stuff all the time when you've gone through it yourself, and lived it, this theory is bunk. But I guess there has to be theory too..."

Mrs. Y. sometimes felt as if professionals were questioning how she cared for her son. She said:

> "...I wouldn't take blame from anybody. No, I don't think they even blame me, they just think 'have you done everything you can about this?'"

With the exception of Mrs. I., most mothers felt their relationships with service providers were positive. Again, how these mothers viewed their relationships with service providers often reflected whether or not they felt these people were listening to them.

In summary, then, the mothers identified compassion and firmness as important qualities for service providers to have. In terms of theory and knowledge, some mothers felt it was difficult for them to understand what service providers were doing and they had difficulty relating to the providers. Theory was seen as not reflective of their real life experiences and so was not really accepted. These mothers developed a high degree of trust with providers whom they liked, often viewing them as friends. The mothers had difficulties saying goodbye to their favourite service providers.

4.2.6: Service Needs for the Future

When the mothers spoke of the future for their adult child, they would often mention living accommodations. Several mothers suggested the idea of leaving their home to the adult with a developmental disability. The idea was that the adult child could remain in the home after the mother had died, thus maintaining a stable environment. These mothers saw this as a way to have supervision and support for their adult child within their current home. This is an interesting idea and one that could be developed in the future by Associations since the emphasis is on living in the community.

Mrs. I. identified a need for more group homes for adults with developmental disabilities. She suggested that these group homes be based on sex (i.e. women only). Mrs. L. felt that any group home should be like a home, with someone there to make sure that everyone is dressed, looks nice and gets a good meal:

> "It [a group home] should be like home...[with] someone that's interested in him, and that would guide him...Does there exist a home like this? I don't know..."

Mrs. L. also said that since people with developmental disabilities are living longer there will be more adults in need of living accommodations as their caregivers now die before them:

> "So now they're living longer...what are they going to do with these children?...I think lots of people will need group homes in the future...because I know a whole lot of old people now that aren't looking after their kids."

Mothers also identified the need for more recreational programs for the their adult child: dances, bowling, buddies to do things with, etc. Many of the recreational activities run by the Association were viewed positively; the dances, in particular, were a favourite for both mothers and children. These mothers felt comfortable having activities segregated from activities with "normal" adults and felt that their children would not enjoy an activity if it was not segregated. Most mothers said that while the current activities were wonderful, more were needed.

Some mothers identified a need for more respite for caregivers and said their first choice is to have the respite take place in the person's home. Having the person go into a group home or family member's home were choices only if the respite could not take place in the home. Mrs. E. said she would like more time, more hours to herself. She stated that she did not think it was fair that after all her years of work she still had to work as a caregiver. She felt disheartened and hoped that her involvement with a community group would help in obtaining more respite for caregivers in her community:

> "It's disheartening. I've worked for 40 years and I feel that it's my time and I had to work, I had no alternative...I'm not working outside the home, but I'm still working..."

She would like to have the freedom to be able to sign up for trips with her seniors' group and not have to worry about what to do with her son.

Another mother identified that there should be work programs for everyone. Everyone should have something to do that is stimulating. If there was any criticism of the workshop, it was that it wasn't stimulating enough intellectually for their child.

Many of the mothers felt that they had everything they needed at present and these suggestions for future services were more for people who did not have as much support and help as they did.

Mrs. E. was a member of a group similar to the

Association. She was very active in developing service initiatives, applying for funding, etc.. She was pleased with her involvement with this group and felt hopeful that through the group some gaps in the services currently being provided could be filled. A couple of mothers felt that there should be services for adults with developmental disabilities who are aging. They recognized that this is a group that is growing and felt that there were not very many services for them.

The most commonly identified service needs for the future were for more recreational or stimulating activities for the adult child and more in-home respite for the mother.

4.2.7: Acceptance of Their Child

For many of the mothers, it was important that their child be accepted both within the family and in the larger community. Any group that the mother was involved in had to be accepting of the child with developmental disability, particularly since these women often brought their children to group meetings:

> "I belong to the Senior Benevolent Society...they enjoy R. because he's well behaved and friendly.."

> "Oh they've accepted him great...they make an awful lot of him...they have accepted him that way and all of my friends have accepted him, they're very good to him."

> "...the first time I took him up there, there was a lot of... "she's bringing him"...But nobody does

> that now. It's just an accepted thing."
>
> "And I think that was the main thing in all of these kids that he was accepted and well they just took him because I didn't see any reason they wouldn't take him. He was ours and he was one of us."

Of having others accept her son, Mrs. Y. said:

> "Oh yeah [acceptance is important] and especially with people that haven't had the opportunity to rub shoulders with these people. I said there's no way they're going to hurt you and they're just as safe and I said: 'If you don't like him he knows it right away.'"

Mrs. O. talked about how her sisters-in-law never offered to take H. for the week-end or for a visit. She felt that they did not feel comfortable being alone with H., perhaps because H. was "just not their family" (i.e. H. was an in-law). Mrs. O. said that she would not attend parties where H. was not welcome as well.

These mothers spoke of how some people might think their "normal" children are better than those with a developmental disability. These mothers disagree. One mother said:

> "We don't think they're that unusual [children with a developmental disability] and yet they [other people] seem to find it - they seem to sense it right away..."

Many mothers spoke of not liking it when people stare at their child:

> "It's impolite to stare..."

> "What I hate more is when you get on the bus and people stare something dreadful...So I just got mad and I said: 'You got eye problems?'...I don't know what's the matter with these people...Is it that they've never seen mentally retarded? What is it?"

Another thing that bothered these mothers is when people talk to or treat their adult like s/he is still a child.

> "It's strange how people who haven't been involved with handicapped act...the dentist gave my daughter a picture of her with her tooth for the Tooth Fairy. How do you tell intelligent people about this kind of thing? H. says 'I don't want it, I'm not a baby.'"

Friends were important to these women. Mrs. Y. spoke of having had a friend for several years, both of them getting older, but still getting along well. Mrs. E. said that she never had time to make friends because she was always working. Some had friends who also had children with a developmental disability. Groups like the Faith and Light group were very important:

> "...it's what keeps us going with our kids and what's going for the kids..."

> "I know a lot [of people] from going to the Faith and Light because they're all handicapped kids down there..."

Mrs. I. stated that her neighbours were harassing her family and cited several incidents including an altercation with a neighbour over a tree that needed pruning and another where neighbourhood children threw a rock and broke her living room window. She had consulted with a lawyer over these incidents. Mrs. I. said that she did not have any friends nor did she feel support from anyone else. As one of her other children had schizophrenia and she was estranged from her oldest child, Mrs. I. truly did not have anyone to support or accept her or her children.

In summary, these mothers felt strongly that friends should accept their child with a developmental disability. Many mothers mentioned not liking it when people stared at their child. Furthermore, these mothers wanted and needed the support of friends and neighbours; family were not enough.

4.2.8: Respite

> "Z. has run away from one group home, refused to stay and was aggressive...another refused to take her because she hit me and was aggressive...she ran away from her baby sitter, fell, hit her head and hurt her back..."

Here are the words of Mrs. I. who would have liked to have some respite, but was not able to get any. Mrs. E. said that caring for her son is very time consuming. She stated:

> "You're very tied...you definitely do need respite."

Mrs. H. tried respite because she thought "it wouldn't be a bad idea" when a social worker recommended it and she was pleased when the reports from staff indicated that her son functioned well without her. Mrs. E. said:

> "I'd like to see respite for anybody with a handicapped kid, not just for me...or even for older people..."

Mrs. E. wanted to go on a trip to England but felt that she could not if she could not find someone to look after her son.

> "I have a friend, an RN, she worked with kids; but I don't like to leave her alone with A. for too long because she has a bad heart...I get a little panicky....I'd worry what would happen..."

Another mother felt respite: "...gives you a breather for him to be away..."

The mothers who did use respite services either formally or through their families had varying levels of success. On one occasion when Mrs. L. went on a vacation and left T. with her daughter B., T. ended up getting sick and spent some time in the hospital. Fortunately, this experience did not prevent Mrs. L. from going away again.

Many of the mothers said that no matter where their adult child went for respite, be it to a sibling's home or to a group home, the adult child was always glad to return to his/her own home in the long run:

> "It doesn't matter whether it's with [my daughter] or whoever it is, he likes his home."

The mothers also said that using respite services did not necessarily make them more comfortable with the idea of placing their adult child in a group home. Mrs. L. pointed out that it would be hard to tell from a few days of respite how T. would manage if he was placed in a group home for an indefinite period of time.

Mrs. Y. felt that she did not need respite:

> "But I don't even feel like I need it [a holiday]...No, there's nowhere I want to go. Because I'm quite satisfied here now."

To summarize, the mothers identified varying levels of need for respite services. While some mothers felt a strong need for respite, other mothers had no need. Using respite services did not necessarily make these mothers feel more comfortable with the idea of placing their adult child permanently in a group home although it did increase their awareness of the group homes in their area.

4.2.9: Information

Information was fairly important to these caregivers. Often the information these mothers received was not what they wanted or was about something they already knew:

> "...they [the Association] sent me lots of information and I threw it out...it was things I was already familiar with..."

Mrs. Y. said it was important to her to receive information in print so that she can read it and think about it before she does anything. She also wanted to have some input in what was happening in the Association:

> "I wanted the opportunity to get the information straight and the chance to say I don't like it, the chance for input..."

Another mother found the Faith and Light group to be a source of information. One mother said she was getting her information from another mother and that none of it was good. None of the mothers could think of what information they might want or need that they did not currently have.

Many mothers had recently been to meetings where guest speakers talked about the new legislation regarding substitute decision making and powers of attorney. This information appeared to be very relevant and important to all the mothers.

These mothers had an excellent informal network to pass along information. Not only did they know about each other, these women were also familiar with stories of caregivers in other communities. The mothers realized that other people were fighting for the same things that they were: more services, more group homes, more money, more control regarding how funds are spent. The successes and victories that other caregivers experienced were celebrated by all caregivers.

In summary, these mothers wanted information with sufficient time to give their input. Some of the information they received was not useful. Other information, for example anything related to the new powers of attorney legislation, was so important to these mothers that they actively sought out as much as they could on the subject. Perhaps the informal groups which they attend would be an excellent way to get information to these caregivers.

4.2.10: Family Relationships

Family relationships appeared to be of importance to these mothers. They talked about the relationships between their children at length. Mrs. I. spoke about the relationship between her two adult children, Z. and M. She said that M. would become very upset whenever Z. started to scream and bang. Z. would yell: "M., M., help me, help me!" This would upset M. and it was often after such an episode that M. would run away. M. running away would then upset Z.. Unfortunately, M. could not manage on his own and the police would have to bring him back. His running away would increase the stress and pressure on Mrs. I.. M. has attempted suicide on a couple of occasions as well. Thus, Mrs. I. also had to keep a close eye on him and was always looking for pills that he might hide. She also had to make sure all the pharmacies in the city know him so that they would not give him pills he should not have. Mrs. I.'s oldest child was married with three children and was estranged from the family.

Thus, Mrs. I. received no support from her family and, in fact, the family relationships often created more stress for everyone. Mrs. I. spoke quite a bit about her need for a break and for more places to go. However, some of the other mothers who participated in this study knew of her circumstances and felt that Mrs. I. often alienated people who were trying to help her.

In any event, this family needed a lot of support and assistance which Mrs. I. felt was not available. Mrs. I. said that her husband remarried after their divorce and he did not maintain involvement with his children. Mrs. I. did not like his second wife, she felt that this woman neither understood nor liked Z.. The only people from whom Mrs. I. received support were her parents. She spoke highly of her parents, said they were wonderful people. She said that she lived with them after she and her husband split up, not leaving them until they became sick. She never said how or why Z., who had been living in a group home, ended up living with her again; nor did she say where M. lived while she was living with her parents.

Mrs. H. spoke of her husband and her son, R.. Her husband did not want to have children at all so he did not support her when she became pregnant. After her son R. was born and they found out he had Down Syndrome, her husband would have nothing to do with him. R. was also very colicky but she received no help from her husband in managing him. It was not until R. grew up a bit and began to speak and be more independent that his father began to pay attention to him.

They began to do things together like going to the park or shopping at Canadian Tire.

Mrs. O. described with delight the similarities between herself and another daughter, coincidentally the one who would be caring for her adult child with a developmental disability upon her death. She spoke of her family as being very close, happy and accepting:

> "We're one big happy family...the grandkids fit in like dirty shirts...There's never a party where the [other] three [children] don't invite each other..."

Mrs. O. and her family have spaghetti together every Tuesday, and have done so for the past 14 years. Mrs. O. said that when she can no longer cook then one of her children will take over. She felt that her children are all very close. They all invite H. for over night visits. Mrs. O. felt that H. liked to go to one sister's house because there are children there and H. likes to have children around.

Mrs. O. said that she realizes how hard it is for some people to "warm up" to people like H.. That is why she was thrilled to see her son-in-law accept H.; he is comfortable enough to tease her but is also firm. It is especially important for Mrs. O. that this son-in-law get along well with H., since he is married to the daughter who will be looking after H. if anything happens to her: "This would be the happiest place for H.". The grandchildren are also good with

H.:

> "I'm surprised how well they [the grandchildren] understand what their mom and dads told them about her [H.]...I wonder what will happen when they're smarter than her..."

Thus, Mrs. O. described her family as loving and close. She appeared very comfortable with her children's relationships with each other. It seemed that Mrs. O. received a great deal of comfort and support from her family.

Mrs. E. talked about her family and said that one daughter is fairly close to both her and her son. Although this daughter did not live close by, she maintained more contact than the other children and paid attention to A. when she comes to visit. However, this daughter was also very busy and contact was not as regular as Mrs. E. would like it to be. Mrs. E. was very proud of this daughter and stated that she loves her. Of her other daughter, Mrs. E. said:

> "She never takes the time to be bothered, sometimes she'll speak to me and sometimes not... we talk but we have nothing in common..."

Mrs. E. was also fairly close to one of her sons; although she did not see him often (he lived far away) she stated they were close. What was important to Mrs. E. about the children with whom she felt a close connection was that they were both "good with A., affectionate with him, pay attention to him..."

Mrs. E. said that she does not see her other son and does not care if she ever sees him again; "He and I don't see eye to eye." She did not say much about her husband except to talk about how he died. Apparently, he was an alcoholic and did not provide much support or assistance while they were together. They separated:

> "...because I was close to a nervous breakdown...I had to look after A., work, and come home to a drunk all week-end..."

Mrs. E. and her husband remained friendly. He lived in the same building and she used to check on him to see if he was well. He was fairly close to A. and provided some financial support.

Thus, Mrs. E. received some financial support from her husband and some emotional support from two of her other children. However, Mrs. E. received little practical assistance from her family in terms of help in caring for A . For example, none of her other children had A. over for visits to give Mrs. E. respite.

Mrs. L. said that her family was fairly close; her son and her husband had a good relationship. Mr. L. had a stroke and was forced to retire at a young age. This enabled him to spend a lot of time with his son. And T. used to look after his father, reminding him of when to take medication, etc. They enjoyed watching sports programs together and T. would listen if his father reprimanded him. T. and his sister were fairly close and he has stayed with her when Mrs. L. has gone on a vacation. T.'s brother-in-law and his two nieces get along well with him. The only concern is that his sister and her husband have had marital difficulties which may make it difficult for her to care for T. after Mrs. L. dies.

Mrs. Y.'s family were fairly close, especially when the children were growing up. She stated that the children used to play together frequently. They also played with neighbourhood children and V. was always included. If V. was sick and the other children could not do something they wanted to, they did not resent V., they just accepted the situation. One daughter has V. visit her home every Saturday and Sunday, giving Mrs. Y. a chance for some time alone. Mrs. Y described this daughter and her husband as being capable of caring for V..

One of Mrs. Y's sons died in an airplane accident. Another daughter has Multiple Sclerosis and has cut off all contact with everyone in the family. One child has had difficulty accepting the plans that Mrs. Y. has made for V.'s future. This daughter may create problems for the others. Mrs. Y. felt that her daughter who will be caring for V. can handle any difficulties that may arise from her other daughter.

Mrs. Y. said that her husband had a very difficult time accepting that D. was born with Down Syndrome. She said that he "went wild" in the hospital and the police had to escort him home. She felt that he never accepted V.'s disability and that he always felt guilt or blame for it. She said that money became an obsession for her husband and he was always worried that they would not have enough. V. and his dad used to go out for lunch every Saturday.

Thus, Mrs. Y. had some support from her family. Mrs. Y.'s husband was of minimal support while he was alive, after his initial reaction to V.'s birth. Fortunately, Mrs. Y. has one daughter who provides respite every week-end. Mrs. Y. is aware that there are some difficulties in the relationships of her children but appears confident that her children can work out their differences and it will not jeopardize V.'s future.

In summary, these mothers discussed the relationships within their families in some detail. Some families were very supportive, harmonious, and provided comfort to their mothers. These mothers were confident of the future for their adult child. Other mothers had very little support and appeared to have a few more concerns about the future. The mother who had the most difficulty with family relationships was also the mother who had the most concern for the future and who expressed the greatest need for respite.

4.2.11: Reactions to Being a Caregiver

These mothers had various reactions to being a caregiver, ranging from very positive to fairly negative. Almost all mothers talked about activities they enjoyed doing with their adult child. Some of the relationships appeared to be fairly reciprocal, with the adult with a developmental disability contributing as much as the mother did. Other relationships between the mother and the adult child sounded fairly one-sided.

Mrs. I talked about how she and her daughter would work together sometimes during the day but she said that Z. would not always cooperate. She felt that she had her hands full and that society was not always kind to people like her and Z.. Mrs. I. felt that most of Z.'s behaviour was the result of not being busy enough. Mrs. I. wanted a group home for Z. and for M.. At the same time, she said that she accepted her responsibility as a caregiver and that group homes are not like homes and staff cannot take care of people like their mothers can. Mrs. I. said that she wanted to look after her daughter, it was her responsibility. She cried several times throughout the interview, often when talking about her feelings as a caregiver and the stress she was experiencing with both of her adult children. As a caregiver, Mrs. I. felt that she could not get any kind of support or assistance to relieve her burden.

Mrs. H. was more positive in describing her experiences as a caregiver. She said that she and her son R. "...do everything together...It's all a harmonious way of living...we work together..." She said that she was glad to have him but that it was also a responsibility. Mrs. H. listed the chores that R. helps her with: gardening, laundry, making the beds, washing dishes, vacuuming, dusting. She said that R. is a good companion for her:

> "He's a friend, he's my son, I love him...He's a good helper, it's good for me to have him, I don't resent that he is what he is, I love him the way that he is...I'm not ashamed of him."

Mrs. O. said that she enjoyed her daughter H. and she does not want people to think that she is putting up with H. Mrs. O. equated her enjoyment of H. with her enjoyment of her grandchildren. Mrs. C. said that when she found out H. had Down Syndrome she had some idea what that meant because a child in her neighbourhood growing up had it. Mrs. O. said that her mother was very supportive, loved H. and offered to look after her. Mrs. O. believed her prior knowledge of Down Syndrome was good, it helped her to accept what H. would be capable of: "I knew what she could and could not do."

Mrs. E. said that she felt grateful that A. is not sickly, that he can get around and do things. Mrs. E. acknowledged that sometimes she takes out her anger and frustration on her son but, she said, he sometimes aggravates her, especially when she is already aggravated. However, once they have had an argument it is over, there are no hard feelings or resentments after.

Mrs. E. said that her parents were not very supportive when A. was born. She was closest to her father and felt that he was more supportive than her mother. She said that she and her mother never really got along. Her mother said that she should put A. "away" when he was born. Mrs. E.'s response was:

> "...he's mine, I brought him into the world, I'll look after him."

Mrs. E. said that she gets depressed when she is trying to help the Association and then doesn't know if they are listening to her. Also, the difficulty she has had recently with her son's work hours being cut back has left her feeling angry at everyone.

Although Mrs. E. felt comfortable leaving A. alone, she did not like to go too far away, so she said that she felt "tied to the neighbourhood." She described caregiving as:

> "...a time consuming job...you learn as you go along what you can and what you can't do...one thing I have learned is that you can't give in to them, you have to be determined and stay with what you have said..."

Mrs. L. felt that only having one other child was difficult. She would like her son T. to die before she does:

> "Lots of Moms feel that way....my friends say that...then I know I've done everything and it's in the Lord's hands...when you get to my age, you don't know how long you're going to live..."

Mrs. L. felt that her husband may have favoured T. a bit over their daughter because "he [her husband] felt he [T.] had a disability and needed more attention." But Mrs. L. felt that her daughter never resented T. for the extra attention he may have had. Mrs. L. felt that her husband was a very good caregiver, when he disciplined T., T. listened. Mrs. L. said that she is not as successful as her husband was in disciplining T.. She said that one of the main tasks she has had as a caregiver was to be firm with T. and to set consistent limits for him.

Mrs. L. said the following about being a caregiver for T.:

> "When he [T.] was first born, I think I was a little depressed. I couldn't believe what was happening...I haven't had any remorse."

Mrs. L. said that she would look after T. as long as she can, while she's here:

> "...why should I put him in a home while I'm still able to look after him, it's crazy."

Mrs. L. has used respite services from a group home when she went on vacations. Although she worried initially about whether or not T. would fit in with the other residents, she has gone away many times since and is quite comfortable leaving him now.

Mrs. L. stated that she enjoys being a caregiver and that she would not be able to keep her home were it not for T.'s financial assistance. She also feels that he is company for her.

Mrs. Y. said the following about being V.'s mother:

> "Well I have felt since day one that I must be the person that was supposed to get him and look after him."

For Mrs. Y., acceptance of her role as a caregiver came right after her son's birth, when she knew immediately that he had a developmental disability. She said that her husband had a hard time accepting V.'s disability; the police had to remove him from the hospital on the day V. was born because he was so upset. She said:

> "I think his dad was a little afraid...or...he didn't know how to handle a lot of stuff with him [V.]...It [caring for V.] is part of my living. It's just part of what happened."

4.2.12: How The Caregivers Cope

Mrs. I. found physical exercise helped her to cope; she used to ride an exercise bicycle and work out with weights daily. However, she had occasions when she felt discouraged about caring for her son and her daughter, which in turn made it harder for her to actually provide care for them. Mrs. I. said that her situation was considerably more difficult than that of other parents given the number of behaviour problems her daughter has. Whenever Mrs. I. feels discouraged she wants to place Z. in a group home.

Mrs. H. coped by finding enjoyment in daily activities: writing letters, reading geography books, resting, doing housework, appreciating nature. She said:

> "I do a lot of planning, that's for sure. Planning and thinking...I just pray to God that He keeps me well for a while."

Mrs. H. said that she coped by taking good care of herself so that she can stay healthy to look after her son. She enjoyed redecorating her house and said that she felt complaining did not help at all, while counting your blessings did. Mrs. H. said that caring for R. has been a very positive experience for her.

Mrs. O. felt that her outgoing nature has helped her to cope and she felt pleased that H. has the same outgoing nature. She said that she is lucky that H. is easygoing and not too stubborn. Mrs. O. liked to keep busy socially and she takes H. along wherever she goes. Social activities and H.'s personality have helped her to cope with her role as a caregiver.

Mrs. E. said that she coped by trying to keep up her current activities, especially sewing and making crafts. Crocheting helped her to calm down more than anything else. But Mrs. E. would like to have more independence and freedom. When asked how she coped, Mrs. E. replied:

> "I don't know, I think I'm nuts...I think it's just

> determination...I'm a fairly strong person anyway...I've had a lot to bear with the 'stupid arm' and being held back in a lot of ways..."

Mrs. L. felt that she is coping well as a caregiver and does not need anything for herself to help her cope. She said that her daughter will help occasionally but she does not like to ask her for too much help because she has her own family to look after. Mrs. L. said that hearing other people's stories about being a caregiver usually makes her feel grateful that her situation is not as bad as that of others. Mrs. L. has found that being a volunteer judge for the Trillium Awards helps her to get her out of the house and provides a lot of enjoyment for her. Mrs. L. said she has always been a strong person; her strength has helped her to cope not only with having a child with Down Syndrome but also with her husband after his stroke left him with permanent disabilities. This strength also helped her to cope with her husband's death. Mrs. L. stated that she has never felt as though she could not cope. She said that if her health ever changed (i.e. deteriorated) then she would have much more difficulty coping with her responsibilities as a caregiver.

Mrs. Y. coped because, she said,:

> "...this is what I'm here for. And if I do a good job, why that's fine. If I don't do a good job, well I better try a little harder. That's all."

Mrs. Y. did not know what helped her to cope, although

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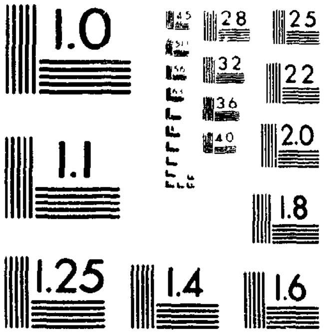

she believed that she has "some kind of protection inside..." She also joked that perhaps she was "nuts" and that is how she coped. She said:

"I just have accepted life to be this way."

In summary then, many of the mothers spoke of simply accepting their role as a caregiver. They believed that this acceptance which came immediately after the birth of their child helped them to cope with their responsibilities as a caregiver. A couple of mothers joked that they were nuts or crazy and that was how they coped. Some mothers coped by using other interests such as flowers or crocheting to take their mind off of their troubles. Other mothers really could not say what helped them to cope. Many mothers mentioned having inner strength and being grateful that their situation was not as bad as that of other caregivers.

4.2.13: Tasks of Caregiving

One of the main tasks these mothers spoke of, and perhaps the most difficult for them, was assisting their adult child in coping with their grief after their father died. Mrs. H. stated that R. needed comfort and support when his father died and periodically still needs comfort and support regarding his father's death. She said that R. does not like to hear her say that his father has passed away and he does not want to go to the cemetery to see his father's grave. She has tried to comfort him by reminding him that his father was a good man who worked hard so that they would be well looked after. Mrs. H. said that she thought R. sees and hears his father (i.e has audio and visual hallucinations) and talks back to him. She said these hallucinations were more frequent immediately following her husband's death and that R. only experiences them occasionally now. She did not appear to be concerned about these hallucinations.

While she was helping R. deal with his grief, she was also trying to deal with her own. Mrs. H. said that she needed time to recover from her husband's death. She gave herself three months to grieve for her husband, to be sad and to think about him. Then, she made herself stop because:

> "I noticed that I was getting sick and I said it's no good for me to get sick. I still have to look after my son."

Mrs. H. said that she felt the need to move on, to make some changes to help her get over her husband' death. For example, she could not look after her husband's garden so she covered it over, even though it "almost broke my heart to do that." Mrs. Y. also made some changes when her husband passed away and she made them to suit her, believing it was the right thing to do to help her and her son get over her husband's death.

Mrs. E. found that she had to help her son understand the deaths of his grandparents:

> "I explained to him that they were old, tired of living, had gone to sleep and gone to live with Jesus."

It was not as simple with the death of his father. Mrs. E. stated that she had a closed casket for his funeral and is not sure if that was the right thing to do as A. still talks about his father's death. However, he also talks about the death of his grandparents even though their caskets were open.

Mrs. L. stated that T. has had a very difficult time accepting his father's death. He misses his company and says:

> "I wish I had my dad. I wish I had my dad."

Mr. L. was very close to T. and as previously stated, T. used to look after Mr. L.. Mr. L. always used to greet T. when he came home and they would spend a lot of time watching T.V. together. Mrs. L. said that her husband's death:

> "...was terrible, just terrible...You don't know if they really take it in or not...T. misses his father dearly. He still talks about him, still talks about him."

Mrs. Y. found it difficult to reassure V. when he gets upset about his father's death. She said that V. gets "good mileage" and lots of attention out of getting upset over his father's death. Mrs. Y. has found it exhausting to explain to V. about his father's death repeatedly and sometimes ends up being frustrated with V.:

> "[I say to him] This isn't doing you any good and I am tired and it doesn't do me any good having to chew this up again with you, so let's get to sleep."

Mrs. Y. believed that when V. goes to the cemetery to put flowers on his father's grave it triggers him to start asking what happened to his father. However, she also felt that V. enjoys the attention that he gets when he asks about his father.

There are many other tasks that these caregivers performed in the daily course of their lives. Mrs. I. bathed and dressed Z., assisted her in the bathroom and helped her to exercise. Mrs. I. has slept with Z. in a single bed for several years. Mrs. I. felt that sleeping in the same bed as Z. was the only way to get Z. to sleep. If Mrs. I. did not stay with Z., then Z. would wet the bed. Mrs. I. even tried restraining Z. in the bed alone only to have Z. injure herself trying to get out of bed. This is one task that Mrs. I. did not enjoy doing.

Mrs. I. was not the only caregiver who had difficulty at night. Mrs. Y. has slept in the same room as V. since he was a young child. Initially she did it because he was sickly:

> "I think I kept him in our room too, at first. I can't remember any of this stuff now. It seems like 5,000 years ago. But that was what I had to do."

Later, V. developed sleep apnea. Ever since, she has slept in the same room with him and she reminds him to take a breath when she hears him stop breathing in his sleep. Mrs. Y. said that she believes that the daughter who has agreed to take V. after she dies will also sleep in the same room as V. and monitor his breathing. Mrs. H. felt one of her tasks as a caregiver was to ensure that her son watched only appropriate programs on T.V.. Mrs. H. also said that travelling with R. is exhausting, she worries about him and whether or not he will behave.

Mrs. H. listed the daily tasks she fulfills as a mother: ensuring R. brushes his teeth and combs his hair, monitoring his bowel movements, taking him to the dentist, ensuring he gets a proper diet and exercises. She also said that they have many conversations together about whatever is interesting to R. and that she helps him complete exercises in reading and math books and that they do puzzles together.

Mrs. O.'s tasks as a caregiver included driving H. to activities and programs in the evening because she does not like H. being out alone. She also does not like to leave H. alone at home in the evening so she usually stays home for H.. Mrs. O. also tries to help H. understand why she is different from other people:

> "I tell her that part of the brain that tells you to read and write didn't all come out too full, didn't develop when you were small...I'll tell her she's handicapped--that means not stupid, but handicapped, like someone who can't walk or talk properly...I don't want to hear her say retarded

because that would label her."

Mrs. O. wondered if she and her husband should encourage H. to be more independent but she said that H.'s independence would conflict with their need to be informed about H.. Mrs. O. also said that a main task for her is to ensure that H. is on time for appointments, school, etc..

Mrs. E. said that she always made sure A. had a good diet and she tried to keep his weight down. She said that if A. woke up in the night she would tell him to go back to sleep. She also said that one of her caregiving tasks is to be very firm with him, to set limits. Mrs. E. drives A. only at night or when he is going a long distance. Many of the caregiving tasks that Mrs. E. performs are in the interest of "quickness." In other words, even though A. can do things for himself like shaving and choosing his clothes, Mrs. E. will do them for him because he is too slow otherwise. She felt that A. needs supervision and would not trust him to be able to use the stove or regulate the temperature of water for his bath by himself.

Mrs. L. felt that T. could have done more for himself but she and her husband were always protecting him. Her husband never wanted T. to take the bus by himself, he felt it was too dangerous for T.. Mrs. L. listed a variety of caregiving tasks that she performed for T.: deciding when it is time to see the doctor, getting his meals, brushing his teeth, washing his face, putting the water in the tub and washing his hair.

Mrs. Y. also said that she did things for V., not because he could not do them but because he is too slow, takes too long. Mrs. Y. wondered if this was the right way to handle things:

> "...I guess I done this wrong...Because maybe I've made him too dependent on me..."

Mrs. Y. included advocacy in her list of tasks as a caregiver. She advocated for transportation for people like V. who live in rural areas. She is also advocating to ensure V. will be able to return to the workshop if he does not like the new job the Association has planned for him.

A common task that these mothers were faced with was to help their child cope with change and they have had varying levels of success. Mrs. H. stated that R. has no problem coping with change, he adjusts well. Mrs. O. said that H. will not change her patterns at all. Mrs. E. felt that A.'s independence is increasing; a positive change for him but a difficult one for her as she found herself worrying about him more. Mrs. L. was worried that everyone in her peer group is getting older, there is only her daughter to rely on as a potential caregiver for T.. She also stated that T. does not cope well with change. Mrs. Y. felt that she has less pressure on her to do housework now that her husband has died. Her attitude has changed as well and she no longer worries about getting all the chores done. Mrs. Y. felt that this was a positive change for her.

Thus, these mothers listed a variety of tasks that they performed in their role as caregiver. These tasks ranged from instrumental assistance like helping with activities of daily living, to emotional support like helping their adult child cope with grief. One mother mentioned that she tried to help her daughter understand her disability. The mothers were not always sure if they were doing the right thing but they did what they felt to be in the best interests of their adult child. Several mothers were concerned that they were making their adult child too dependent but also acknowledged that sometimes they gave extra assistance for their own sake.

4.2.14: Arrangements for the Future: Permanency Planning

These caregivers were most concerned with the future in the sense of wondering what would happen to their adult child when they die. Mrs. O. said that her daughter offered to take H. Mrs. O. said that both she and her daughter agree that is where H. would be happiest since H. and her other daughter are very close. Mrs. O. felt that her oldest daughter would not be a suitable caregiver for H. because of her "single lifestyle." Mrs. O. also talked about her son taking H. and said that things are different with daughters-in-law and sisters-in-law: you are not their family, they are not yours. She felt that her daughter-in-law is not as close to H. and so is not as willing to take her. Oddly, this does not apply to her son-in-law who, Mrs. O. stated, would be the first to offer to look after H.. Mrs. O. felt that H. would not disrupt her other daughter's family life.

As a result of her daughter's offer to care for H., Mrs. O. has not put H.'s name on a waiting list for a group home. She said that when her daughter offered to take care of H. she insisted that Mrs. O. and her husband sign a paper giving her authority to look after H.: "It's been done by a lawyer." Mrs. O. has not told her other children of these plans, stating that they have neither asked what plans she has made nor have they offered to look after H.: "Their lives are too involved to even think about it." Mrs. O. thought that her oldest daughter may be upset when she hears of the plans for H. but did not think it would bother her son. She has not told the other children about the plans because she says she does not wish to open a can of worms.

Mrs. O. did not ask H. where she would like to live if anything happened to Mrs. O. Mrs. O. said that she has tried to find out where H. would like to live. Occasionally, Mrs. O. has told H. that she could go to a group home if she did not help out around the house. H. has responded by saying that she likes her home now.

In terms of finances, Mrs. O. did not put money aside for H.. She felt that H. will have enough money as long as she receives her FBA: "You don't need much of a pension when you've got family". Mrs. O. has chosen her other daughter to look after H.'s finances since she will be the one to provide care for her. Mrs. O. would like to split her estate three ways but she said: "If I had my way, whoever has H. would take the house."

Mrs. H. has no other children to ask to look after R. so she has asked a couple of friends to look after him. They are long standing friends who would care for R. until he could move to a group home. Mrs. H. put R.'s name on a waiting list for a group home, picking it on the basis of an open house. Mrs. H. said that she liked the people she met at the group home and knew some of the people living there. She liked the fact that they only had one T.V. so everyone had to watch the same thing. Her husband only wanted to be sure R. would get his own room. Mrs. H. also liked the fact that everyone at this group home had an assigned chore to do, something R. is already used to doing.

Although Mrs. H. placed R.'s name on the waiting list and appeared comfortable with her choice, she did not stay in touch with the home. She said that while she used to know the staff at the group home, she had not been there for a while. She said that she did not know how long the waiting list was for the group home, that R. had been on the list for two years and that her contact with the home had been on a yearly basis. If he has moved on the list, she is unaware of it. Furthermore, if an opening came up for R. tomorrow Mrs. H. was not sure if she would accept it, even if it meant R. would go to the bottom of the list or off the list entirely.

What Mrs. H. would really prefer is to have her niece, who lives in Australia, immigrate to Canada, live in the house and look after R.. Mrs. H. said this niece is the only family member who could look after R., as she is young and single. Mrs. H. felt this niece would be a good caregiver for R. because she is a social worker and has worked with children with developmental disabilities. Mrs. H. said that she has discussed moving to Canada with her niece and they agreed that she would visit, get acquainted with the country and then get a work permit. If she liked it here and if Mrs. H. felt comfortable having her look after R., then she could stay in Canada permanently. However, this niece apparently is not ready to move to Canada yet. As well, this niece has never met R.; they have only talked on the phone. Despite this, Mrs. H. still felt hopeful that her niece will come to Canada to look after R. after she has died.

Mrs. H. has not discussed future plans for her son with him. She has also threatened R. that he would go to a group home if he did not behave. He has replied that he likes his home.

Mrs. H. has designated the couple mentioned previously and her lawyer the trustees for R.'s estate, which he would inherit upon her death. If her niece were to be R.'s caregiver then she would also become guardian to his estate.

So the house would be left to the niece if she came, to R. if she did not come or did not stay. Mrs. H. was hopeful that caring for R. could generate income for her niece if she was unsuccessful in her search for a job. Making arrangements to transfer control of R.'s estate to her niece requires that Mrs. H. trust her niece to care for R. and not abscond with his money. The previously mentioned couple have promised to ensure that this niece treats R. well. Mrs. H. has also set money aside to pay for R.'s burial. Mrs. H. said that she and her husband made out their will when R. was 2 years old and that she found this very helpful when her husband died.

Mrs. L. has not asked her daughter if she will look after T.. Her daughter has never said that she would take care of T. after Mrs. L's death, although she has acknowledged that she is aware that is her mother's wish. Mrs. L. wondered if it would be fair to her daughter's children if T. went to live with them. Mrs. L. said that she would be happy if T. lived in a group home with a housekeeper, as long as her daughter would have him visit on week-ends. But Mrs. L. felt that it would be hard for her to see T. in a group home. She thought that hiring help might encourage her daughter to provide care for T. and would also allow her to stay at home with her children. Generally, Mrs. L. said her approach to the future is: "I'm leaving everything down the road and I'm not worrying about it." Mrs. L. would prefer that T. stay in his own home or live with her daughter or have someone look after him in a small environment after her death.

In terms of finances, Mrs. L. has left her estate equally to T. and her daughter. It has been arranged so that the government will not be able to take any of the estate away from T.; so her daughter and a niece of Mrs. L. will be the decision makers for T.. Mrs. L. wanted to ensure that T. has enough money to enjoy his life (i.e. enough money to travel, have decent clothes, etc.). She also said that T.'s burial arrangements were paid for three years ago when her husband died.

Mrs. E. has made her funeral arrangements but has not paid for them. There is also money set aside for A.'s funeral arrangements although the details have not been worked out yet. She has not made out her will as she feels that most lawyers do not understand the legal issues for a parent of an adult with a developmental disability.

Mrs. E. has made provisions for A.'s future. She has made investments for him, set aside RRSP's and purchased life insurance. Although Mrs. E. said that she has not made out a will she has made arrangements that if anything happens to her, her money will automatically go to her daughter. All of A.'s inheritance will be in her daughter's control as well and this daughter is aware of these arrangements and the fact that she will be managing A.'s finances. Mrs. E. said:

> "I told her you don't have to take him in...let him know he has a sister and you'd be there for him as

a friend if he needed anything."

Mrs. E. would prefer it if A. could stay with his own family after she dies. However, she is trying to get the community group with which she is involved to look after him.

Mrs. Y. found out that her husband made arrangements for their daughter to look after their son, V.; she only found out about these arrangements after his death. The arrangements surprised Mrs. Y. as her husband did not choose his favourite child to be V.'s caregiver. However, Mrs. Y. said that she believed her husband chose the daughter whom he trusted the most and whose husband he trusted the most to care for V.. Mrs. Y. felt confident this daughter would be a good caregiver for V. because she takes him to her house every Saturday and Sunday and she is the closest to him of the siblings. Mrs. Y. said that this daughter will care for V. the same way that she does, their thinking is the same. Mrs. Y. said the following about her daughter caring for V.:

> "Oh, she understands [about caring for V.] but she just hasn't taken that into her stride yet. She'll take it the same as I have...I don't think she realizes that she's got herself into a big job..."

When asked what will happen when V. retires, Mrs. Y. replied that she doesn't think about things like that. She stated that her job is to get him as far as she can, that when she has died someone else will have to worry about V. and that she felt confident that her daughter will do what is best for him.

Mrs. Y. set up her will so that her daughter will be V.'s powers of attorney and if anything should happen to her daughter then her daughter's husband will take over. V.'s father also left some money to pay this daughter and her husband for looking after V.. This daughter's husband has already made some investments for V.. Thus, these arrangements appear to be working well already and Mrs. Y. was very comfortable with them.

Mrs. Y. said that her other children have never talked about the future and she has never talked about it either. She always assumed that one of them would step forward to look after V. when she could not any longer. Mrs. Y. said that one of her other daughters did not like the arrangements that her husband made for V.'s future. Apparently this daughter felt that she should be the one to look after him. This daughter was the favourite of Mr. Y. and perhaps she was hurt that he did not choose her. Mrs. Y. thought that her husband did not choose this daughter because of whom she married. Mrs. Y. stated that this daughter "...will always be the little snag in everything..." but that she felt confident her daughters could work out their differences and that V. will not suffer from any disagreement the two sisters may have.

Sadly, Mrs. I. died shortly after her interview, and her plans for the future had not been established. She said that arrangements had been made with her brother and her oldest son. At the time of her death, she was estranged from both of them, stating they had a disagreement and that both men were too selfish to be trustees. She wanted to change her will after Z. was placed in a group home but this did not happen before her death. Z. did go to a group home right after Mrs. I.'s death, as did her son, M.. It is a shame that places could not be found for Z. and M. before Mrs. I. died.

In summary, these mothers talked in detail about the financial arrangements they had made for their adult child with a developmental disability. These arrangements often included a trustee so that the pension of the adult child would not be affected by their inheritance. The residential plans for the adults with a developmental disability were not as straightforward as the financial plans. Some mothers were fortunate enough to have another child whom they could ask to care for their adult child with a developmental disability. These other children were described as being the closest to the care recipient and the closest to the mother. Mothers who did not have another child to rely upon as a caregiver turned to extended family members and trusted friends. It seemed that group homes were chosen when there was no one else upon whom the mother could call to care for her adult child and be comfortable with the decision.

4.2.15: Facing the Future

The mothers had different perspectives about facing the future and different thoughts about what would happen to their adult child if they should die first or become unable to look after their adult child any longer. Mrs. H. felt that the future had to be faced, that it could not be ignored:

> "You can't go around with your head between your knees and not think about what's going to happen."

Mrs. Y., on the other hand, did not worry about the future:

> "Like I don't worry about the future in my own thoughts for myself even."

Mrs. Y. stated that she wakes up every morning grateful for another day ahead of her. She believed that worrying about the future will only make you sick. It is interesting that she does not worry about the future but she also has fairly secure plans for V. if anything should happen to her.

Mrs. L. hoped that T. will die before she does as she does not feel comfortable with the responsibility her daughter would have in taking care of T. While Mrs. L. felt comfortable placing T. while she takes vacations, she also said that she coped by trying not to worry too much about how he is doing. She said that if she did worry she would never take another holiday. Mrs. L. stated that she takes life one day at a time:

> "I live every day to the fullest...One day at a time...because you can go crazy if you think about the future..."

Mrs. L. agreed with Mrs. Y. that thinking about the future too much is futile and will only make you sick. Again, even though Mrs. L. said that she is not comfortable with her daughter caring for T., she seemed to believe or hope that her daughter would take him if need be. Her main concern was that T. be comfortable. Although she knows that she should probably put T.'s name on a waiting list for a group home, she said that she would not even know where to begin. Mrs. L. was aware that T. could develop Alzheimer's and that the day could come when she could no longer look after him but she does not worry about it. She said that worrying about it wouldn't change anything and that it may never happen. She said that people may think that she is crazy but she never worries about the future.

Mrs. E. was quite comfortable with the thought of A. going into a group home in the future. She recognized that she will not live forever and that he will need somewhere to go. She had made arrangements for him to be on a waiting list for a group home but the funding for the home fell through. She said that she would like to see him in an apartment with, perhaps, one other person with a developmental disability and someone to supervise them. Mrs. E. said that she sometimes gets "despondent" thinking about the future. She would like to have more freedom to travel than she does. However, Mrs. E.

stated that she does not worry about the future, she tries not to think about the future too much and she takes life one day at a time. She said that she knows someone else will have to look after A. in the future and that she will not settle his financial future until she can settle his living accommodations.

Mrs. O. asked at a meeting at the Association what would happen if she died and her child's name was not on a waiting list for a group home. She said the answer was that her child would still be placed in a group home if necessary. Mrs. O. has never put H.'s name on a waiting list for a group home. She would like to see H. in an apartment or a house but not in a group home as she feels there would be too much distraction for H. in a group home. Mrs. O. did not think H. could manage on her own. Mrs. O. was pleased that her arrangements have been made so that H. will be cared for when she dies. The fact that one of her other daughters has offered to take care of H. if she cannot is reassuring to Mrs. O.:

> "It gives us such a nice feeling to know that you don't have to worry about the future..."

Mrs. O. stated that she does not worry about the future and that she also takes life one day at a time. She said that she had not thought about the future for H. before her other daughter raised the issue with her. Mrs. O. believed that parents who are scared about the future, especially given the long waiting lists for group homes, will often say that they hope their child dies first. However, Mrs. O. does not want H. to die first and if H. were in a home, she said she would go to visit H. daily.

Mrs. I. hoped that her children Z. and M. would both die before her. She said the Lord had given her "this cross to bear", to be a caregiver for Z. and M., and that she must bear this cross all her life. Mrs. I. also said that she coped by taking life one day at a time. Mrs. I. had no plans for the future but was trying to find homes for Z. and M. Although it was sad that Mrs. I. died so suddenly and unexpectedly it is somewhat reassuring to know that places were found for Z. and M. when they really needed it. What is sad is that the places could not be found when Mrs. I. really needed them.

CHAPTER FIVE: DISCUSSION AND CONCLUSIONS LIMITATIONS AND RECOMMENDATIONS

This chapter will connect the themes outlined in the previous chapter to the research questions posed in chapter one. Specifically, these themes will now be connected to the initial questions of how caregivers of adults with a developmental disability cope, what support they have and what, if any, more support do they need.

5.1: Discussion

5.1.1: Characteristics of the Caregivers

As previously stated, women compose the majority of caregivers in our society (Laurence, 1992; Wood, 1991). In this study, all of the caregivers interviewed were women. Even though one caregiver was married it was still the woman who was identified as the primary caregiver and who participated in the study. Furthermore, these mothers made arrangements for another daughter, if they had one, to be the caregiver for the adult with a developmental disability when they no longer could. Daughters often offered to be the caregiver for their sibling. This follows from literature which states that daughters are often expected to provide more support and be more involved in caregiving than their brothers (Zetlin, 1986).

As well, all of the caregivers were the mothers of the adult with a developmental disability. This also fits with the trend that began with deinstitutionalization and resulted in more adults with a developmental disability living in the community with their aging parents as caregivers (Adams, 1990; Greenberg, Seltzer, and Greenley, 1993).

The women who participated in this study fit well into Kaden and McDaniel's (1990) profile of female caregivers in Canada; they noted that women live longer than men (five out of six caregivers were widowed), tend to be poorer than men in their old age and tend to be the main caregivers. In Kaden and Mc Daniel's study (1990) increased service use was associated with increased age, decreased health and ability to function independently and increased need for assistance from others (family, friends, neighbours). In this study, increased service use appeared to be associated with the behaviour of the care recipient; Mrs. I. had used the most services and Z. had the most behavioural issues. Mrs. I. reported the least number of health concerns of the caregivers and she was the youngest.

All of the caregivers in this study were Caucasian women who lived in the city. As mentioned in a previous chapter, urban dwellers tend to view caregiving more positively, perhaps because there are more services (Wood and Parham, 1990). In this study, most mothers viewed caregiving positively except for Mrs. I. who viewed it as a burden. Although she was an urban dweller, Mrs. I. had the most behavioural issues to deal with regarding her adult child with a developmental disability and in her son with a mental health issue. Comparisons in this study cannot be made on the basis of race but it is interesting to note that in their study, Wood and Parham (1990) found that Black caregivers received a great deal of support from their faith and that they utilized Churches as a form of support group and an information centre. In this study, although the caregivers were all Caucasian, they all said that they found support in their faith. Mothers who attended the Faith and Light group found it to be a source of support and information.

These caregivers were all fairly healthy, according to their own reports. The caregiver who reported the least health problems died shortly after her interview. She also reported the highest level of stress and burden.

As is typical of their age group, all of the caregivers were retired, most were widowed and many were facing the physical challenges of the aging process (arthritis, decreased mobility).

5.1.2: Characteristics of the Care Recipients

The majority of the care recipients had Down Syndrome and appeared to be relatively independent, high functioning and pleasant. The notable exception was the adult who also had a mental health problem and who appeared to be functioning at a much lower level than the others. While most mothers spoke very positively about their adult children, Z.'s mother did not. She also had difficulty describing Z.'s brother in positive terms.

Most of the care recipients attended day programs which filled a part or all of their day and provided their caregivers with respite. The mother with the least amount of free time was Mrs. I., who expressed needing more free time away from her daughter than any of the other caregivers. While most of the other adults had some kind of recreational program, Z. did not. In most of the families with more than one child there was usually another sibling who would have the handicapped child over for a visit. This provided support to both the adult with a developmental disability and his/her mother.

The five adult children who had Down Syndrome were overweight. In terms of their behaviour, most of the adult children had no difficulty. Occasionally, one would have problems with his/her temper but these instances were rare. Again, the notable exception was Z. who had many behavioral difficulties. Mrs. I. had gone to many service providers for assistance in dealing with Z.'s behaviour, yet her behaviour has only worsened over the years. It seems that services for people with a mental health issue and a developmental disability need to be developed or expanded.

5.1.3: Sources of Support for Caregivers

It has been noted that institutionalization of an adult with a developmental disability often occurs when the caregiver is unable to cope with the care needs of their loved one (Black, Cohn, Smull, and Crites, 1985). All of the mothers in this study identified that they would place their adult child in a group home only if they could no longer care for that child themselves. Arrangements for another family member to care for the adult were often preferred to placement in a group home.

Seltzer and Krauss (1989) noted that caregivers of adults with a developmental disability often find support from family members. They identified the following characteristics of a supportive family: a strong sense of cohesion, an inclination to demonstrate their feelings and an inclination to participate in activities together. This description would fit very nicely for Mrs. O.'s family: they invited each other to their parties and they enjoyed a weekly spaghetti dinner together. Given the fact that all of the mothers spoke about their family (either immediate or extended) in detail, it appeared that they mainly sought support from their families. Even families that were not supportive were discussed at length. Perhaps it was because the family relationships will determine the future of their adult with a developmental disability. Or perhaps it was because these women were so immersed as caregivers that they did not look outside of their family for support.

Husbands often were not viewed as supportive with one exception (Mr. L.). A couple of them had substance abuse problems. If the husbands offered any support it was in the form of being the firm disciplinarian, a common role for husband to play. It would be interesting for future research to focus on the perspective of the husband/father and then to compare the differences between the mothers and the fathers.

Siblings of the adult with developmental disability were found to be a source of support for both the caregiver and the care recipient (Seltzer, Begun, Seltzer, and Krauss, 1991). Many of the care recipients who had siblings had a special relationship with one sibling. A rare form of assistance for the adult with a developmental disability from a sibling was help in dealing with grief. More commonly, the sibling of the adult with a developmental disability would provide respite by taking their brother or sister to their home for visits. This sibling usually was the sibling designated to be the caregiver if the mother was no longer able to and this was the sibling designated to be the trustee for the estate of the adult with a developmental disability. Mothers expressed satisfaction with the arrangements they had made. These arrangements also provided them with a sense of comfort, the future was not threatening to them.

It is well known that informal support networks decrease with age as friends and relatives in the peer group die

(Heller and Factor, 1993a). Certainly, this has been the experience of members of the Faith and Light group. This group has been in place for years but members are seeing their friends from this group pass away or cease attending.

One area of support not really explored in the literature review for this study is the faith of the caregivers. Many of the caregivers talked about how their faith gave them comfort and support. The Faith and Light group developed out of the Roman Catholic church. This group provided a forum for social support, a place to go to for information and recreation. Faith provided these mothers with justification for keeping their child-- caregiving is what God wanted them to do--when everyone else told them to institutionalize their child. Belief in God helped some of these women to cope, gave them hope and helped them to accept their handicapped child. Many of the mothers talked about their experiences when their child was first born, what they felt, how their husbands reacted. Although some of the reactions of their husbands were fairly extreme, the mothers discussed them in a matter-or-fact manner as yet another thing with which they had to cope. Many used words such as destiny or just being "the one who should do this" as reasons for why they were chosen to be caregivers.

A final source of support for caregivers is from the adult child with the developmental disability. Heller and Factor (1993a) noted that feelings of reciprocity reduce feelings of burden. For most of the mothers in this study, the relationship with their adult child was a reciprocal one. Most of the mothers described their adult child as a companion, as someone with whom they travelled and completed chores together. Grant (1986) also noted that adults with a developmental disability helped their caregivers by reducing feelings of loneliness and by providing assistance with finances. A couple of the mothers acknowledged that they could not stay in their homes were it not for the financial assistance of their adult child. Thus, for most of the mothers who participated in this study, their relationship with their adult child was perceived to be reciprocal. The exception to this was Mrs. I., who did not mention anything that she might be receiving from either Z. or M.. If they were helping her financially, she did not acknowledge it. Certainly Z. was unable to provide any kind of emotional support to her mother.

One of the most striking points in analyzing this data is the insular life which these mothers and their children led in the sense that the children were very emotionally dependent upon the mothers, and any activity the mothers engaged in outside the home usually centered around developmental disabilities. Some research has indicated mothers do not tend to look to neighbours and friends for support but that acceptance of their child by these people is important (Grant, 1986). This was true for the mothers who participated in this study, who joined groups and made friends according to who would accept their children. Furthermore, many of them knew each other, or knew of each other. They were all familiar with each other's stories, triumphs and trials. It seems to be a fairly close community for caregivers of people with a developmental disability.

Another point related to acceptance of their child is that most of these women mentioned their strong reaction to people staring at their child. They also spoke of having to tell people how to interact with their adult child and not treat them as though they were still children. Perhaps normalization to them meant that their child should be treated as an adult even though they will never be a "normal" adult.

5.1.4: Coping Strategies of the Caregivers

These mothers spoke at length about the daily routines of their adult child. They also spoke about having their own routines. Although they said that their adult child needed the routines to help them cope, some acknowledged that they needed the routines as well. One idea that was not explored in this study was how these routines helped them cope. Why did it not bother the mothers to face the same activities day in and day out without a conceivable end in sight?

Related to this is the idea of "taking it one day at a time". All of the mothers talked about "taking it one day at a time". Most of the mothers said that they did not worry about the future, they preferred to "take each day as it came". This is consistent with findings from Heller and Factor (1991 and 1993b). Grant (1990) found some families are ambivalent and indecisive regarding the future. While most of these mothers had made plans for the future they preferred not to think about it. Even the mothers that were pleased with their plans did not think about the future. There could be two explanations for this. One possibility, as one mother said, is that people don't worry about the future for themselves so why would these mothers worry about the future of their adult child. Mrs. L. pointed out that she will have taken her son as far as she can, the rest of the trip down the road of his life will be up to someone else. The other possible reason for not thinking about the future is that it is too frightening to face. For these mothers, "taking it one day at a time" could mean that they do not have to face an uncertain and possibly unhappy future. Or, as Mrs. L. said, why worry about things that may never happen. These mothers have also had to narrow their perspective because their child will never develop beyond a certain point. Mrs. Y. said her son would never be normal and that she did not like people trying to treat him as though he would be. Perhaps for these mothers, part of coping was accepting their child for who s/he is and not developing too many expectations for who they might become. In this way, they could cope with the daily trials and tribulations of life as well as their responsibilities as caregivers.

Some literature indicated factors which influenced whether or not a family made plans for the future. Some of the factors included interdependence between the caregiver and care recipient and family traditions of commitment (Grant, 1990). Many of the caregivers in this study were financially dependent on the adult child. This certainly would impact on placement of the individual outside the family home. Even if a mother could not cope with the care of her adult child she may be reluctant to place him/her if the loss of income could result in the loss of her home.

Another study found increased service use was linked to increased likelihood of placement of the adult with a developmental disability outside the family home (Heller and Factor, 1991). For Mrs. I., this certainly was true. Z. had been living in group homes for several years before returning to live with Mrs. I.; perhaps she was comfortable with placement because she knew what kind of care Z. would receive. Perhaps her experiences with services had demystified them for her, so that she knew what to expect and did not fear group homes. Or perhaps Z.'s behavioural difficulties were so onerous for her to manage that she felt she had no other choice but to place Z. in a group home. Mrs. I. certainly fit with Heller and Factor's (1991) finding that service needs that were not met and high feelings of burden increased the caregiver's preference for care outside the family home. Mrs. I. did not want to wait until she died to place Z.; she wanted

Z. to be placed as soon as possible. This was contrary to previously mentioned research which indicated that caregivers prefer placement to occur after their death (Heller and Factor, 1991; Heller and Factor, 1993b). Certainly her assessment of burden was high and she had more difficulty coping with caregiving than the other mothers. However, her caregiving was also more demanding of her, requiring more intervention. She was the only mother whose adult child had been physically aggressive towards her and perhaps this aggression would increase likelihood of placement. At present, she could manage Z.'s behaviour but what would happen if she became more frail, if Z. became stronger than her? How could she cope then? However she assessed her situation, these were considerations she would have that the other mothers did not. Also, she was the mother most anxious to have plans implemented immediately; placement for Z. was in the future only in the sense that there was nothing available immediately; had there been a space for Z. somewhere she would have been placed immediately. This is unlike the other mothers, who even if they had plans would say that they would look after their adult child for as long as they possibly could.

There are other characteristics of the caregiver that were cited as increasing the likelihood of placement for an adult with a developmental disability. These included age (older caregivers more likely to place) and socioeconomic status (higher socioeconomic status tended to increase likelihood of placement) (Heller and Factor, 1991; Heller and Factor, 1993b). This was difficult to assess in this study as all the caregivers appeared to be of the same socioeconomic status. Their age range was fairly close as well being 68 to 77 years. Again, for this study, the factor that appeared most relevant seemed to be the behaviour of the adult with a developmental disability and the availability of another family member to care for the adult when the mother no longer could. Thus, Mrs. I. wanted immediate placement and mothers like Mrs. E. were considering placement as there was no one else who could look after her son. Race was another characteristic of the caregiver that was likely to impact on placement. Again, in this study the caregivers were all white and so comparisons based on colour cannot be made. Perceived health of caregiver has been found to impact on likelihood of placement of the adult with a developmental disability (Heller and Factor, 1988) but this was not the case for this study. Mrs. E. and Mrs. Y. and Mrs. H. appeared to have the most health concerns but Mrs. I. was still the mother pressing for placement ahead of the others. Again, one could question how much significance this has in light of the fact that Z. had been living in group homes previously and Mrs. I. could simply be more familiar and aware of the system.

Heller and Factor (1993b) found that families are more likely to make future financial arrangements than they are to make residential arrangements for their adult child with a developmental disability. In this study, most of the mothers had made future residential plans for their adult child but some plans were more secure than others. Mrs. H., for example, had plans that did not sound likely to work out with her niece in Australia. And she had not maintained contact with the group home which she chose for her son in over a year. She also acknowledged that she would turn a spot down if she was not ready for R. to be placed even if it meant he would go off the waiting list. Either Mrs. H. had a remarkable trust in the system (that she knew he would ultimately be placed if necessary) or she had a remarkable fear of the system (do not place him unless all else fails). These mothers all acknowledged that they would have a hard time seeing their adult child in a group home. In this sense they are like the people in Heller and Factor's (1991 and 1993b) studies which showed that caregivers only want their adult child placed after their death. However, most of these mothers had made solid financial plans for their adult child and had even used legal services to ensure that these plans would be carried out. Fear of the government seemed to motivate these plans. Many of the mothers felt that the lawyers they spoke to did not have a good understanding of legal issues related to long term care of an adult with a developmental disability, suggesting an area for expertise for lawyers to develop.

Parents who make future living arrangements for their adult child with a developmental disability would have the benefit of feeling that their parenting is complete (Smith and Tobin, 1989). Some studies have indicated that perhaps parents need assistance in resolving any outstanding life or relationship issues related to prolonged caregiving and their stage of life (Brunn, 1985). Yet, these mothers did not express feelings that their caregiving was incomplete. On the contrary, with the exception of Mrs. I., the rest of mothers said that they would look after their child for as long as they could. Caregiving had become a part of who they are and what they do, they are not ready to relinquish this role until they have to. Adams (1990) suggested that the whole family needs to be involved in future planning and Heller and Factor (1994) suggest that the wishes of the adult with a developmental disability need to be considered. It is interesting to note that the mothers interviewed in this study had made future plans without consulting their adult child at all. In fact, they had not informed the adult child of whatever plans had been made. Any mention of placement outside the home was often made in the context of a threat; the adult would be going to a group home if they did not behave. This kind of threat would make placement more difficult for the adult since they may consider going there to be a punishment.

Another striking point from the interview data is that these women are fighters. They began fighting from the day their child was born, when they disagreed with the professionals who told them to put their children away in institutions. It continued with this group of mothers in particular as they fought to start up services when there were none. This is the group of caregivers who saw the beginning of the Associations for Community Living, the beginning of DARTS and similar transit systems, the beginning of sheltered workshops and specialized schools. Their children would not have gone to school, would not have had work to go to, except for their efforts. Now, they are faced with many changes in the service system including professionals who say that segregation is not a good thing. Is this a criticism of all of their efforts? Is it a negation of what they thought would be good for their children? Is it a negation of all their hard work?

In talking to these mothers, it is striking to note how difficult it has been for the children to accept the death of their father. Since most of these children are heavily dependent on their mothers physically, emotionally and socially, one can imagine how much more difficulty they will have coping should their mothers die before them. Coping with grief and helping their adult child to cope with grief was a big task for these women. It is something which they have faced over and over again. The bereavement group mentioned by one mother is perhaps a recognition that this is a caregiver issue. One thing that may be useful to explore is finding out the mothers' thoughts on how their adult child will cope with their death. These mothers are so connected to their children and their children are so dependent on them emotionally, and sometimes socially, that there must be a lot of concern for the mothers about this topic.

Many caregivers coped by performing unusual tasks for their adult child. For example, a couple of mothers mentioned sleeping in the same room or bed as their adult child. The sacrifice of privacy involved for the mothers who did this is astounding. So too is the fact that they are willing to do such things for their children, perhaps to the detriment of their marriages. Many mothers questioned if they should not have helped their adult child to be more independent but the mothers acknowledged that in the daily grind it is sometimes easier to do things for their child than to have their child do things on their own.

The women who had families who were willing to look after their child were very relieved. For the others without family or whose family were not willing, the future held a lot of unknowns. Wanting to get these issues settled was important, but not knowing what to do or not wanting to do what needed to be done presented some problems.

5.1.5: Service Needs and Service Use

All of the mothers were highly suspicious and mistrustful of the government. They perceived that the government was trying to take away the following from them: the sheltered workshop, pensions, tax benefits. These mothers felt anger towards the government and a certain amount of betrayal. After all, as one mother pointed out, they saved the government a lot of money by keeping their children at home. Now they feel that they are being penalized for having a handicapped child.

There was also a certain amount of mystery and misinformation regarding the new legislation on substitute decision making and powers of attorney. Most women appeared to have the same information and framed the legislation as the government trying to take over their money. Most seemed pleased to have circumvented that.

Mothers looked to professionals for direction on how to care for their child with a developmental disability, what to expect. What they found was that they knew their adult child best and were the best ones to identify their children's needs. Thus, these mothers became the experts as well as the advocates for their children and some of the mothers were disappointed in the service providers' lack of knowledge and understanding.

One study cited previously stated that the caregiver's perceptions of their ability to provide care were related to the care recipient's dependence on them and that caregivers needed to be encouraged to seek out the services they need to maintain their caregiving role (Engelhardt, Brubaker, and Lutzer, 1988). Most of the mothers in this study reported that their adult child was fairly independent and their expressed need for service was low. As always, Mrs. I. was the exception; not only did she relate high service use and need but she also felt that she could not care for Z. any longer, there were days when she just wanted to place her.

In terms of respite, research has shown that older parents prefer out-of-home respite while younger parents preferred in-home (Lutzer and Brubaker, 1988). While the mothers who participated in this study were all relatively young (the oldest was 77) they all said that they preferred in-home respite or in-home care if they were no longer able to care for their adult child. Their preference was first that a family member care for or provide respite. If a family member could not or if there were no family members, then an in-home solution was preferred. When all else failed, then the mother would accept out-of-home respite or placement. Some mothers were comfortable using respite for vacations but respite use did not necessarily increase their comfort level regarding placement. Almost all of the mothers expressed a need for respite.

A study by Kaufman, Campbell and Adams (1990) suggested that caregiver burden and stress increases with the number of maladaptive behaviours of the care recipients and that solutions to relieve caregiver burden should include education and training for the caregiver and more respite to help them cope. Mrs. I. certainly expressed feelings of burden and a need for respite. However, it would have been helpful to find out if Mrs. I. would view training on how to cope with her daughter's behavioural problems as assistance.

Financial assistance for caregivers of adults with a developmental disability was suggested by Jennings (1987). Many of the mothers reported that they relied upon the income of their adult child to maintain their home. Furthermore, many financial plans that had been made were in the interests of providing financially for their adult child after their death. It would stand to reason then that these women would have appreciated some form of financial assistance.

Another service need identified in the literature is to help parents access services (Kaufman, DeWeaver, and Glicken, 1989). However, most of these mothers did not express a need for assistance in accessing services. In fact, many of them seemed to be aware of the services available and felt that their service needs were being met. Even Mrs. I., whose service needs were not being met, was aware of the services available. Furthermore, one could question whether or not Mrs. I. was turning down services since she mentioned at one point doing so because she had been hurt by service providers and did not trust them. Thus, these women did not need help accessing services.

It is interesting to note how close a relationship these mothers developed with professionals. The mothers said that the service providers that were particularly helpful ended up being like one of the family. Service providers that were not helpful were seen as powerful and became a source for anger and frustration. A common comment was that professionals do not use common sense and do not listen to what the parents say are their adult children's needs. It would be interesting to explore how these parents would like to be involved in decision making and planning processes. The mothers also seemed to want a better integration of theory with their own experiences. Normalization, for example, did not match their experiences at all - they still have their child living at home, they are still providing care, their experiences are not "normal" and never will be. Thoughts of their adult child moving out were intolerable as long as the mother could care for her child, even though this is part of the "normal" life cycle.

One service need identified in the literature was to assist families in moving away from parent care gradually and including the whole family in the planning process (Seltzer and Krauss, 1994). This was very relevant to these mothers, many of whom have made future plans for their adult child without the input of the adult child. Fortunately, all have discussed their future plans with the designated future caregiver and sometimes this person has even initiated discussions. As previously mentioned, the daughters who were to be the future caregivers often had their sibling over for visits. Gradually moving care away from the parent could begin with the respite that is already taking place. One can recognize the importance of a gradual transition when one considers the response of these adults to the loss of their father. The grief remains outstanding for years and the adult child has difficulty understanding what has happened. Imagine then how much more difficult it will be for them to lose their primary caregiver upon whom they are far more reliant, and always have been, than their father. Facing this loss will be difficult, and one way to ease the adjustment to the loss of their mothers might be to prepare them for a change in living environment.

Kaufman, Adams, Jr. and Campbell (1991) suggested that families need to be assisted in making future plans. The mothers in this study did not need this type of assistance for the most part. Where they did need assistance was in dealing with legal issues, making out wills, setting up estates and powers of attorney. Since the families were involved in the future planning, especially the daughters who would be the future caregivers, it does make sense to include the whole family as several studies suggest.

These mothers did not identify many service needs for the future except for respite and more recreational activities for their children. It would be beneficial to these parents if the idea of leaving the family home to the adult child and making provisions for someone to come live with them could be further explored. It would certainly address the dilemma these mothers have about not wanting their child to leave their home, wanting to help maintain the routine and not wanting to burden other children with the care of an adult with a developmental disability.

These women needed information and only wanted what they did not already have. It would be important when examining communication with these caregivers to ensure that the information they receive is relevant, clear and accessible. Often, mothers said that they threw out information because they thought they already had it or it was too long to read. Informal networks appear to be the mothers' greatest source of information so these networks could be utilized to disseminate important information.

One of the mothers identified a need for developing services, especially group homes, for adults with a developmental disability who are aging. Smith, Fullmer and Tobin (1994) suggested the need to develop specialists in the combined fields of gerontology and mental retardation. After speaking with Mrs. I., one might add mental health issues to that list of expertise. Particularly as the adults age, it will become increasingly difficult to sort out issues related to the aging process from issues related to the developmental disability from issues related to mental health concerns.

5.2: Biases and Limitations

One bias in this study is that all of the mothers have had some connection to services. Therefore, these mothers are all receiving some kind of formal support. It would be useful for future studies to explore the support needs and coping strategies of mothers who are not connected with any formal services. Perhaps caregivers who are not receiving formal support have different needs. Only through further research could this issue be explored.

Another limitation of the study is how this sample was obtained through informal snowballing. Letters were sent to families through the Association requesting their participation but only one mother responded. The other mothers who participated were friends or acquaintances of Mrs. L., through the Faith and Light group. Mrs. L. actually suggested the names of these women as participants and she approached them initially. When asked if they had received letters inviting them to participate in the study, a lot of mothers responded that they had not received a letter or if they did they threw it out without reading it. Due to this snowballing, the participants' comments are biased towards white, female, Roman Catholic caregivers. Perhaps caregivers of other religious, cultural or ethnic backgrounds would have responded differently and different themes would have emerged.

A final limitation in this study is the small number of caregivers interviewed. This group is a very small representation of the caregivers of adults who are aging with a developmental disability. It is possible that they do not represent the views of most caregivers. It is also possible that because they were of similar age, race, religious affiliation and socioeconomic status their responses only represent that very small group of caregivers. Only through repeating the study with a larger, more diverse sample could one determine how representative of caregivers the responses in this study were.

5.3: Future Study Ideas

There are several questions that remain, questions that could be answered through other studies. For example, the perspective of the adult child with a developmental disability who is aging has not been explored in depth. It would be beneficial for future service planning to know what services these adults would like to have and how they feel about the services they are currently receiving. It would also be useful to know where these adults would like to live should their mothers be unable to look after them.

The women in this study, unlike most people in their peer group, were still caregivers for adult children living with them. A future study could explore the effect of this prolonged parenting on both the adult child and the parent.

The issue of the connection between dependence and behavioural difficulties in the adult child and stress and burden in the caregiver may become more significant as adults with a developmental disability age. Since most of the care recipients had Down Syndrome and there is a tentative link between Alzheimer's Disease and Down Syndrome, it is possible that these adults will deteriorate in their functional abilities and behaviour if they develop Alzheimer's Disease. How will these mothers cope with this type of age-related change in their adult child? Will this type of scenario alter the future residential plans that these mothers have made for their adult child? In other words, would it cause their sibling to reconsider taking them? Or would it become impossible to maintain them in the community? If this were the case, are the long term care institutions prepared to handle someone with a developmental disability and Alzheimer's Disease? Questions such as these need to be answered, as they have significant implications for planning for future services.

Another future study could focus on the perspective of the siblings of the adult with developmental disability: are they aware of their parents' plans and expectations regarding the care of their sibling? Are they willing to assume the caregiving role? Are they willing to continue doing some of the things that their mothers do (eg. sleeping in the same room or the same bed with their brother or sister)? Are the spouses of these siblings willing to assume the caregiving role? How would caregiving impact on their family?

It would also be interesting to further explore faith as a source of support. What is it about faith that is so supportive? Is it the external locus of control that helps these mothers? Is it being with people of similar belief and value systems? Is it a combination of the two? Does belief in fate, and external control help these mothers by providing an explanation for why they ended up being caregivers for life?

Another topic to explore further is how a lack of reciprocity could affect some of the more positive relationships between an aging parent caregiver and an adult child with a developmental disability. Again, what if the adult child developed Alzheimer's Disease, would that change the feelings of reciprocity? Does a lack of reciprocity lead to an increased desire to place the adult child in a group home? Would reciprocity be as important to sibling caregivers?

Another question is the idea that the needs of older caregivers are different from those of younger caregivers. It would be interesting to repeat this study with older caregivers, perhaps in their eighties, to see if their issues or needs are different. This would also provide a different perspective as the care recipients would be older as well. It may also be useful to repeat a study such as this with caregivers of adults with a developmental disability who are less independent or who have more behavioural issues. Mrs. I.'s responses were often quite different from those of the other mothers. Replication of this study with caregivers in similar circumstances to hers might elucidate possible reasons why her responses were different.

Many of these women appeared to have accepted their ongoing role as caregiver. It would be interesting to do a longitudinal study to explore this acceptance further. When did the acceptance begin? How did it begin? How does it fit with the idea of taking life one day at a time? How does being a caregiver over the majority of the lifespan affect people as they age? With the changes in legislation putting the onus for care back on the family the issue of long term caregiving is becoming more important to service providers as well as to caregivers themselves.

5.4: Conclusion

It appears that most of the caregivers interviewed were coping well, with sufficient support for their caregiving role. They identified respite and recreation for their adult child as future service needs. They coped by taking life one day at a time and some of them had family or friends to help them cope. Faith was important to all of these mothers as a source of support and as a coping strategy. Generally, the mothers viewed their experiences as caregivers positively.

Suggestions for future service planning would include building on the informal networks of these caregivers as a means of passing information and as a means for support. Furthermore, it would be important to include the input of the caregivers when developing services. The idea of providing care in the home of the adult child after the parent has died could be explore further. Finally, it would be important to consider the needs and perspectives of the whole family when planning for the future including those of the adult with a developmental disability and of their siblings.

This study was intended to provide an in-depth look at the experience of aging caregivers of adults with a developmental disability who are aging. As both of these populations grow and their needs become more prevalent, the services that develop should be geared to their specific needs related to their developmental stage, health and circumstances. The world of these caregivers is focused on their adult child. Any future initiative for services should be built upon the caregivers' current coping mechanisms.

Finally, the experience exemplified by Mrs. I. should be explored further. As previously stated, there may be a need for expertise in the area of aging with a pre-existing developmental disability and/or mental health issue. While the other mothers did not express much need for assistance, Mrs. I. did. She demonstrated how inadequate the current system could be. Perhaps coping and support needs are different for caregivers of adults who are more dependent upon their caregiver and who have more behavioural problems. Perhaps this is a direction for service providers to pursue further. Persons with developmental disabilities are living longer, and may develop more disabilities related to their aging process. Family caregivers who are mostly parents of these individuals are also living longer and facing difficulties related to their own aging process. With so much emphasis on caring in the community and placing the onus on families, this study attempted to explore the support needs and coping strategies of these aging caregivers. There are still gaps to fill in our knowledge and questions to answer for these caregivers. This study presented the perspectives of the caregivers interviewed and provided some information for thought and future action.

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APPENDIX A: LETTER OF INVITATION TO PARTICIPATE

Dear Family Member,

I would appreciate it if you would consider participating in a study I am conducting on the experiences of family caregivers of adults with a developmental disability. I am conducting this study because there is little information on this topic. One of the benefits you might enjoy by participating in this study is to become more aware of your experiences as a caregiver, and how you manage to care for someone on a day to day basis.

I will be interviewing interested caregivers for one to one and a half hours, in their homes or in the place of their choice. I will be audiotaping these interviews to ensure that all the information provided will be considered in the final report. The audiotape will be transcribed to a type-written copy. All responses will be kept confidential and specific identifying information will be changed or left out of the final report. All tapes and written materials will be kept in a locked place, and destroyed once the report is complete. People being interviewed may refuse to answer any questions, stop the interview at any time, or withdraw their participation at any time.

This study will help to complete the requirements for the Master of Social Work program at Wilfrid Laurier University in

Waterloo, Ontario. My research advisor's name is Dr. M. Laurence. I would appreciate it if you would call me if you are interested in participating in this study. I can be reached at (905)648-8549. At that time, I can answer any further questions you may have, and we can arrange a time for our interview. You may reach Dr. Laurence at (519)886-1970 if you have any other questions.

Thank you for your consideration.

Sincerely,

Caroline Cochrane

APPENDIX B: LETTER OF CONSENT

I agree to participate in the study being conducted by Caroline Cochrane on the experiences of caregivers of adults with developmental disabilities. I understand that my participation will involve a personal interview of one to one and a half hours duration, which will take place in my home or the place of my choice. I am aware that this interview will be audiotaped, and that these tapes will be transcribed by a person who is experienced in transcription and is aware of issues of confidentiality. I am aware that all personal information will be kept confidential, and all identifying information will remain anonymous. I understand the tape and written transcription of my interview will be destroyed once the report is complete, and will be kept in a locked place until then. I am aware that I may withdraw my participation at any time, and that I may refuse to answer any question.

Signed,____

Date: ____

I would________, would not_______, like a summary of the study results.

APPENDIX C: INTERVIEW SCHEDULE

PART A: DEMOGRAPHICS

Caregiver Demographics

Name:

Age:

Sex:

Cultural/Ethnic Background:

Income:

Religious Affiliation:

Occupation: Retired: Yes No

Relationship to Care Recipient:

Family Composition:

Education:

Care Recipient Demographics

Name:

Age:

Sex:

Cultural/Ethnic Background:

Income:

Occupation: Retired: Yes No

Religious Affiliation:

Education:

PART B: SEMI-STRUCTURED SCHEDULE

1. **What is it like to be a caregiver for an adult with a developmental disability? Tell me your experiences.**

   Ideas to probe for in this question are:

   - patterns of service use
   - service accessibility
   - service characteristics (i.e. what is helpful and what is not helpful)
   - current methods of coping
   - current sources of support
   - tasks involved in caregiving
   - positive aspects of the caregiver role

2. **How is caregiving different now that both you, and the person you are caring for, are getting older?**

   Ideas to probe for in this question are:

   - changes in the caregiver's health, or ability to provide care
   - changes in the care recipient's health, or ability to receive care
   - gaps in services for the caregiver or the care recipient that are a result of aging

3. **What do you think will change as you both age?**

   Ideas to probe for in this question are:

   - concerns for the future of both the caregiver and care recipient
   - plans for the future of both the caregiver and the care recipient