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1 INTRODUCTION

This review examines the literature pertaining to aging parents who are the primary caregivers to their adult sons/daughters with lifelong disabilities, focusing on the experiences of parents and their changing needs as they age. Literature searches were conducted using several databases available through Ebsco Academic Search Elite, including Academic Search Elite, PsychINFO, Sociological Abstracts, ERIC, Ebsco Online Citation, as well as Medline and Ageline. Further searches were conducted at the Mount Saint Vincent University Library and in the specialized collection at Caregivers Resource Library at the Nova Scotia Centre on Aging, Mount Saint Vincent University. Keywords used singly and in combination included: caregiving; disabled persons; mental retardation; developmental disabilities; intellectual disabilities; resiliency; reciprocity; social support; adult offspring; mental disorders; mental illness; deinstitutionalization; planning.

In the context of this literature review, the terms *mental retardation*, *developmental disabilities, psychiatric disorders* and *mental illness* are subsumed under the broad category of *disabilities.* For purposes of clarity or comparison, or where direct quotes from original sources are use, specific disabilities may be named.   The authors considered in this paper typically use either mental retardation or developmental disabilities to describe conditions that result in various levels of cognitive and physical impairment. The former term is used most often in literature originating in the United States, whereas developmental disabilities and more recently, intellectual disabilities, are the most commonly used terms in Canada. For the purposes of this review, the term *intellectual disabilities* refers to a range of conditions that results in significant impairment, is acquired before the age of 22, and will continue indefinitely (Salvatori, Tremblay, Sandys & Maraccio, 1998).

None of the authors reviewed in this paper define mental illness per se, but list the specific diagnoses of the offspring of the participants in their research, the majority of whom have been diagnosed with schizophrenia. This broad category of psychiatric disorders is referred to as *mental illness*. Consistent with current standards, the terminology used herein puts people before the disability, e.g., - adult with intellectual disabilities rather than an intellectually disabled adult.

This literature review focuses on parents' experiences caring for adult offspring with lifelong disabilities, and therefore the issues raised are considered vis-`a-vis parents' perspectives and based on the assumption that caregiving parents have been vested with the ultimate decision-making responsibilities for offspring with disabilities. While it is recognized that the assumption that parents should make choices for offspring with disabilities has been challenged and debated, and supportive decision-making models for persons with disabilities exist, issues surrounding the right of offspring with disabilities to self-determination are beyond the scope of this paper.

2 OLDER PARENTS CARING FOR ADULT SONS/DAUGHTERS WITH LIFELONG DISABILITIES

There are no firm data available on the number of persons with disabilities in Canada. Salvatori et al. (1998) report current estimates regarding the size of the population of adults over the age of 60 with intellectual disabilities vary from 17,000 to 45,000, and the prevalence rate is estimated to be less than one percent of the population. Based on 1991 census data, Mahon and Goatcher (1999) estimate approximately 12,500 (0.4%) people over the age of 65 have an intellectual disability, but caution this estimate could be low. Data drawn from the Health and Activity Limitation Survey of 1991 on all types of disabilities indicate 4.2 million (16%) Canadians have some level of disability. The rate of disability increases with age, with 50% of those over 65 years reporting a disability. The rate of disabilities for Aboriginal adults is almost twice the national average. Thirty-two percent of all those with disabilities indicated their disability as "mental" (Federal/Provincial/Territorial Ministers Responsible for Social Services, 1998). In Canada, 98% of persons with disabilities between the ages of 15-64 years live in the community (Disabled Persons Commission, 1995).

Although the majority of adults with lifelong disabilities live at home with their families (Seltzer & Krauss, 1994), these family caregivers have been largely overlooked. It has only been in the past two decades that researchers have turned their attention to the experiences of older parents who provide care for their adult sons/daughters with disabilities (Roberto, 1993a).

Several demographic and social trends have had an impact on this group of caregivers. First, the life expectancy of people with lifelong disabilities has increased. Prior to the current cohort, few people with disabilities lived into adulthood. Improvements in medical technology, health care and nutrition and the movement away from institutionalization to community care has increased the longevity of adults with disabilities (McDermott, Tirrito, Valentine, Anderson, Gallup and Thomspon,1996; Salvatori et al.,1998).

Most adults with mild to moderate intellectual disabilities, other than those with Down syndrome, will likely experience similar life expectancies as the general population (McDermott et al.,1996; Heller,1999). However, persons with moderate to profound intellectual disabilities are likely to have a shorter lifespan than the general population (Eyman & Borthwick-Duffy, 1994). The increased lifespan of adults with lifelong disabilities translates into a longer period of family caregiving. These adults are now outliving their parents, thus parents have the additional concern of planning for the future care of their offspring with disabilities when they are no longer able to provide that care.

Secondly, the population of North America is aging, resulting in an increase in the ratio of older to younger caregiving families (Seltzer & Krauss, 1994). The leading edge of the baby boom cohort, which accounts for one third of the Canadian population, are now in their fifties, and will reach retirement age in the next 11 years. Their parents

will be approaching their late 70s and early 80s during this same period (Foot, 1996). Estimates suggest that in the next 25 years the majority of individuals with schizophrenia will be elderly (Lebowitz & Light, 1996). As well, there appears to be a higher incidence of mental illness among baby boomers than the current cohort of older adults (Rice, as cited in Lebowitz & Light, 1996).

As adults with lifelong disabilities and their parents age, their needs change, necessitating a change in support services provided to these families. Whereas younger families require support in areas of education and socialization, the needs of older families tend to be in the area of health care services and long-term care (Seltzer & Krauss, 1994).

Thirdly, the shift in the service delivery paradigm from institutionalization to community living has contributed to the increase in the numbers of aging parents caring for their adult sons/daughters with lifelong disabilities. Changes in the formal care system resulted in adults with mental illness who were previously hospitalized returning to their family's care (Kaufman, 1998). The deinstitutionalization movement of the 1970s and 1980s in Canada and the accompanying increase in community-based services also saw the return of some individuals with disabilities to their family home (Salvatori et al., 1998).

3 AGING WITH A LIFELONG DISABILITY

There is great heterogeneity among individuals with lifelong disabilities. While some conditions associated with disabilities cause no deleterious effect on the aging process, other older adults with disabilities have special needs because of age-related declines associated with their disabilities (Janicki, 1999). Adults with Down syndrome, for example, have a known genetic predisposition to precocious aging (Zigman, Seltzer & Silverman, 1994) and a compromised life expectancy (Janicki, 1999). Many individuals with Down syndrome experience age-related declines in biological, psychological and social functioning, beginning in their 40s for females and in their 50s for males (Hawkins, Eklund & Martz, 1993). As well, there is evidence of an elevated risk of Alzheimer disease, which may occur precociously, in this population (Zigman et al., 1994)

There is no consensus as to the chronological age at which a person with disabilities is considered "aged." In Canadian society old age is generally defined in terms of chronological aging, and is typically considered to be reached during the sixth decade of life, with the ages 60 and 65 most commonly used as markers (Viswanathan,1995). However a lower age may be more appropriate for adults with disabilities (Zigman et al., 1994). Janicki, Otis, Puccio, Rettig & Jacobson (1985) suggest that the mid 50s typically mark a period when physical and psychological adjustments are made in response to aging, but a lower age may be more appropriate for some individuals with certain conditions such as Down syndrome. Concerns

regarding the aging of persons with disabilities emanate from the need to identify and assess service requirements as the individual ages. Age is frequently a criterion for eligibility for services. Service plans should be re-evaluated in response to physiological and physical changes as opposed to chronological age (Janicki et al., 1985).

Several factors, including chronological age, should be assessed in understanding the effects of aging on adults with disabilities: increasing physical debility and weakening of physical reserves related to age and not disease or injury; diminishing levels of functional skills for daily living, not related to injury or illness; and when appropriate, self-perception of aging (Janicki et al., 1985).

The parents of adult offspring with disabilities experience their own age-related changes which may create new challenges for them in their role as caregiver. Age-related declines in energy levels, sensory loss and increased vulnerability for illness, which may cause further restrictions in mobility and activities, may result in additional stresses for older parents (Kropf, 1997). As well, older parents are more likely to experience losses in their social networks and often live on fixed incomes (Janicki, 1996). Awareness that their own aging may force them to seek alternative care for their adult sons/daughters with disabilities is yet another source of stress (Brubaker & Brubaker, 1993). Older parents may also face the unique challenge of having to deal with their own aging issues as well as contend with the premature aging of their offspring.

These age-related changes may compromise parents' ability to continue to provide care and support for their adult offspring with disabilities. As both parent and offspring with disabilities move into their later years, they are more likely to experience increasing declines that will require additional support at a time when fewer supports are available to them (Kropf & Greene, 1993; Smith, Fullmer & Tobin,1994).

4 EXPERIENCES OF OLDER PARENTS CARING FOR THEIR ADULT OFFSPRING WITH LIFELONG DISABILITIES

Although much of the research on the experiences of older parents of adult offspring with disabilities adopts a micro-level perspective, parents' experiences are influenced by normative forces operating at the macro level. The philosophy that drives policy and program development and service provision, as well as societal attitudes regarding people with disabilities powerfully influence parents' experiences, both past and present (Gubman & Tessler, 1987; Stehlik, 2000).

4.1 Shifting Paradigms
While the shifts in policy and service provision of the last several decades have been viewed as positive overall, integration and inclusion of persons with disabilities has

not been achieved. Impediments such as discriminatory societal attitudes, the paucity of government funding and limited accessibility to individualized services remain (Salvatori, 1998). In addition, service delivery in Canada is disjointed. A mixture of benefits and services are offered by various levels of government, various governmental departments, as well as community groups and the private sector (Federal/Provincial/Territorial Ministers Responsible for Social Services, 1998).

The Federal, Provincial and Territorial Ministers responsible for social services have launched a joint effort to ensure full citizenship for persons with disabilities by enacting policies that will engage all sectors in the goal of promoting access to generic programs and services for all Canadians (Federal/Provincial/Territorial Ministers Responsible for Social Services, 1998). The *In Unison* documents (1998, 2000) address the impediments people with disabilities face that result in personal, social and economic disadvantages and prevent them from achieving full citizenship.

The initiative identifies income, employment and disability supports as key in supporting full citizenship. In terms of disability supports, issues of accessibility and portability of supports have been identified as central. Portability, or continuity, refers to benefits and services being linked to the person with disabilities, as opposed to being tied to the agencies or services the person uses in a particular region. As people age, supports for persons with disabilities and their families become increasingly important, as needs tend to increase with age (Federal/Provincial/Territorial Ministers Responsible for Social Services, 2000). Family members are central in the provision of disability supports, particularly in rural and remote areas where there is limited availability of services, and in some cultures, such as the Aboriginal culture (Federal/Provincial/Territorial Ministers Responsible for Social Services, 2000). This initiative also targets barriers to education and training programs and income programs that act as disincentives to employment.

The new approach to disability issues represents a shift from a program centred approach with multiple access requirements to a person centred approach with integrated access requirements. Persons with disabilities will be viewed as independent participants rather than dependent recipients. The government will no longer be wholly responsible for achieving full citizenship of persons with disabilities, but will enlist the commitment of all segments of society in realizing this goal. This new paradigm recognizes the importance of supports to increase employability as opposed to the assumption that persons with disabilities are unemployable (Federal/Provincial/Territorial Ministers Responsible for Social Services, 1998).

The *In Unison* (1998, 2000) documents focus little attention on the unique needs of aging parents and their adult offspring with lifelong disabilities. The minsters' initiative has been criticised by persons with disabilities and disability advocates as too narrow in scope. Whereas the ministers focus on issues regarding disability supports, employment and income, disability community members argue all activities of government must assume an access and inclusion perspective. They also criticize the initiative as focusing solely on working-age adults, excluding children and seniors with disabilities, and overlooking the importance of families. Persons with disabilities and

disability advocates call for legislative, regulatory and policy reforms; improved research and data; and increased accessibility overall (Federal/Provincial/Territorial Ministers Responsible for Social Services, 2000).

4.2 Conceptual Frameworks that Guide Research

A large portion of the research on parents caring for adult sons/daughters with disabilities adopts one of two opposing hypotheses, family caregiving burden models or the adaptational framework (Hayden and Heller, 1997). As well, the life course perspective, family development theory, and the strengths and resilience approach to family caregiving are represented in the literature (Allen, Blieszner and Roberto, 2000).

4.3.1 Family Caregiving Burden

The family caregiving burden framework adopts the single viewpoint that caregiving is a burdensome activity and seeks to identify factors that are related to, or predictors of, burden (Rungreangkulkij & Gilliss, 2000). Gubman and Tessler (1987) cogently argue that *burden* is a value-laden term when used in the context of caregiving to a family member with disabilities, specifically mental illness. They contend it ignores the possibility of positive family relationships and gratifications from the caregiving situation and blames the care recipient for creating the stressful situation. They suggest *impact* is a more appropriate term. Nonetheless, burden is the term typically used to describe disruptions in family life and social relationships and the accompanying feelings of loss, worry and stigma, as well as the financial strains that are a consequence of providing care to a member with disabilities (Gubman & Tessler, 1987).

One commonly used model is the wear-and-tear hypothesis which contends stress has a cumulative effect, and long-term exposure will deplete physical and psychological resources (Hayden & Heller, 1997). Most research on family caregiving focuses on the perceived psychological, social and economic costs (Seltzer & Krauss, 1994).

4.3.2 Adaptational Models of Family Stress and Coping

Hayden and Goldman (1996) describe the adaptation model of long-term caregiving as based on the assumption that better adjustment to the caregiving role occurs over time. This framework hypothesizes stress can be mediated through coping resources, positive appraisals by caregivers and aspects of the family's ecological environment, which allows caregivers to assimilate and accommodate the family member with disabilities and to ultimately cope and thrive (Hayden & Goldman, 1996). Heller and Factor (1993b) assert the double ABCX model of adjustment and adaptation, which hypothesizes stress can be mediated by internal and external resources, is the most prominent framework used to study family caregiver stress. Other models of this nature include the stress-buffer hypothesis, which assumes that social support may mediate the effects of stress (Kaufman, 1998), and the framework developed by Pruchno, Patrick and Burant (1996a) that predicts caregiving appraisals and

psychological well-being of aging parents by determining the intricate relationships between stressors, resources, caregiving appraisals and outcomes.

4.3.3 Resiliency Models

A strengths and resilience approach is appearing in the literature in contrast to the previously much used deficit approach to aging and caregiving relationships (Allen et al, 2000). The resiliency approach adopts the premise that caregivers are competent and able to provide care without jeopardizing their well-being (Valentine, McDermott & Anderson, 1996). This approach describes family functions within stressful circumstances, and assumes families adapt to challenges in ways that enrich and strengthen them (Singer & Powers, 1993). The model focuses on acquiring new meanings, flexible coping and flexible interdependence (Singer & Powers, 1993). Rungreangkulkij & Gilliss (2000) argue the resiliency model is the most appropriate for studying family caregivers of adults with mental illness, as it provides a systems framework which permits family level analysis, and when applied to clinical practice promotes resilience and limits dysfunction in families caring for individuals with schizophrenia.

4.3.4 Family Development Models and The Life Course Perspective

Allen et al. (2000) suggest the advancement of the life-course perspective, with its focus on historical process, social process and individual time is the most important development in family research of the 1990s. This perspective addresses how individuals change over time and how their changes are interlinked with those of other family members. This framework may be particularly useful for studying families with members who have intellectual disabilities, as little is known about the impact of having a family member with lifelong disabilities over the life course (Seltzer & Krauss, 1994). The life course perspective has also been used in combination with other theories such as family development framework, which describes the stages of the family life course and how typical stages such as child launching may not be experienced in families with adult offspring with disabilities (Seltzer, Krauss, Choi & Hong, 1996).

4.4 Stress and Burden

Characteristics of both the caregivers and the adult with disabilities as well as contextual factors have been found to influence caregiver stress and burden.

4.4.1 Caregivers' Demographic Characteristics Related to Burden and Stress

Gender, marital status, race and age are associated with caregiver burden in parents of adult sons/daughters with disabilities. With respect to gender, mothers

typically assume caregiving responsibilities for their adult offspring with disabilities (Seltzer & Krauss, 1989). The majority of research on aging parents of adult offspring with intellectual disabilities is conducted primarily with mothers. Fathers' caregiving experiences have been to a large extent ignored (Pruchno & Patrick, 1999a).

Overall, caregiving has a greater impact on females than males. Female caregivers experience more psychiatric symptoms resulting from their role than do males (Yee & Schulz, 2000). Heller, Hsieh and Rowitz (1997) found mothers spent more time providing care, were more affected by the behaviours and health of their adult offspring with intellectual disabilities, provided more types of support and perceived more burden than did fathers. Similarly, mothers of adults with mental illness reported higher levels of anxiety, depression, fear and emotional drain than did fathers (Cook, 1988). Pruchno and Patrick (1999a) found fathers of adults with disabilities reported more disruptive and violent behaviours on the part of their offspring, and poorer relationships with their offspring than do mothers. Predictors of burden, depression and satisfaction were similar for both fathers and mothers. However, overall, women derived more satisfaction from their relationships with their offspring than men, regardless of the presence of disability (Pickett, Cook, Cohler & Solomon, 1997). Valentine et al. (1996) argue the gender differences in stress and needs may reflect variations in the type and level of care given as well as cultural expectations that women assume the role of primary caregiver.

In terms of marital status, single female parents of adults with intellectual disabilities experienced more stress than married parents (Hayden & Goldman, 1996).

In a comparison of burdens and gratifications of African American caregivers and non-minority Caucasian mothers of adult offspring with intellectual disabilities, African American mothers perceived less burden and reported fewer conflicts than non-minority Caucasian mothers (Valentine, McDermott & Anderson, 1998; Pruchno, Patrick and Burant,1997). Pruchno et al. argue that, rather than race, factors related to race, such as socioeconomic status, explain the difference in perceived burden and gratifications.

Does burden increase with age? Several studies have addressed this question with mixed results. Heller (1993) contends that families differ across their lifespan with respect to perceived caregiving burden. She found parents of younger children (under six years) and adult offspring (over 30 years) with disabilities reported the lowest levels of burden. Other studies have found older parents of adults with intellectual disabilities reported less burden than younger parents (Hayden & Heller, 1997; Seltzer et al., 1996), as did older parents of adult offspring with mental illness (Bulger, Wandersman & Goldman, 1993; Reinhard & Horwitz, 1995). On the other hand, McDermott et al. (1996) found no significant difference in caregiver burden in younger (under age 60) and older (age 60 and over) parents caring for adult offspring.

Heller (1993) argues that as offspring and parents age, families experience less burden because of increasing reciprocity in the relationship, better adaptation and increasing emotional bonds. Seltzer et al. (1996) suggest the onset and completion of active parenting are distressful periods for parents of offspring with disabilities. They argue parents' stress levels may follow a U-shaped pattern, with higher levels of stress

following the original diagnosis of the offsprings' disability and then again when the offspring is leaving the parents' care.

Other studies have found a relationship between age, stress and burden. The perception of negative age related changes was associated with feelings of burden in older mothers of adults with intellectual disabilities (Smith, Tobin and Fullmer, 1995a). In a study of perceived role changes in caregivers (85% parents, the remainder siblings) of adults with disabilities, 58% of caregivers reported no age-related changes in their roles, but of those that did, caregivers perceived age-related increases in physical (39.6%), emotional (37.5%) and financial (20.8) burdens (Roberto, 1993b).

McDermott et al. (1996) conclude isolating caregiver characteristics such as age from the caregiving context yields simplistic and misleading results.

In their study of parents of adults with severe mental illness, Cook, Lefley, Pickett & Cohler (1994) found the content of burden changes over time. Younger parents reported more burden related to family conflict and older parents are more burdened by issues related to the ongoing and future care of the offspring with mental illness. Cook et al. conclude some aspects of burden are related to the stage or length of the illness, regardless of the parents' age.

4.4.2 Characteristics of Adult Sons/Daughters with Lifelong Disabilities Related to Burden

Characteristics of the adult with intellectual disabilities are also related to burden. Specifically, higher levels of intellectual disability, greater degree of physical limitation, and higher frequency of maladaptive behaviours resulted in higher levels of caregiver stress (Hayden & Goldman, 1996; Heller, 1993). Greater care and supervision needs of the adult with intellectual disabilities are also related to caregiver stress (Hayden & Goldman, 1996).

Mothers of daughters with intellectual disabilities were more vigilant, provided more caregiving assistance for them and perceived higher levels of burden than mothers of sons (Fullmer, Tobin & Smith, 1997). Increased vigilance may stem from maternal fears of sexual exploitation of their daughters and may explain increased burden.

4.4.4 Service Use and Unmet Needs

Both service use and unmet needs are related to perceived burden. Families needing three or more services had significantly higher stress than families requiring less than three services (Hayden & Goldman, 1996). Heller and Factor (1993b) found high levels of unmet needs resulted in higher perceived caregiver burden.

4.4.5 Place of Residence

Findings regarding the impact of the place of residence on stress and burden are mixed. McDermott, Valentine, Anderson, Gallup & Thompson (1997) found social, emotional and objective burden did not differ for parents whose adult offspring with intellectual disabilities lived at home compared to those whose offspring were in out-of-home placements. On the other hand, Seltzer, Greenberg, Krauss and Hong (1997) found the end of co-residence predicted significantly lower levels of maternal subjective burden in families with adult offspring with both mental illness and intellectual disabilities. One possible explanation for the differences in the findings is that Seltzer et al. examined factors that led to the end of co-residence, whereas McDermott et al. studied caregiver burdens and gratifications based on place of residence of adult offspring with disabilities. As well, McDermott et al. note it is possible that offspring who had been placed in residential facilities previously may have been perceived to be more burdensome prior to placement than those in the co-residing group.

4.4.6 Summary

In summary, while it appears that caregiving can be a stressful and burdensome experience, and some factors that are related to or predictive of perceived burden have been identified, the level of burden experienced by older parents caring for adult offspring with disabilities may not be markedly higher than that experienced by other caregivers or the general population (Seltzer et al., 1996). Though long-term parental caregiving for adult offspring with disabilities is not a normative role, it does not necessarily constitute a crisis. Age may be a less telling predictor of burden than assumed (McDermott et al.,1996).

4.5 Coping, Adapting and Social Support

There is a limited pool of research available on how parents cope and adapt to caring for offspring with disabilities. Hayden and Heller (1997) found both younger and older parents of offspring with intellectual disabilities typically used two strategies, acquiring social support and re-framing stressful events, to problem-solve and cope. Older parents (over age 55) were more likely than younger parents to seek spiritual support. Both sets of parents had similar size social support networks and received, on average, the same number of formal supports.

Informal support resources have been found to reduce perceived caregiving burden in older parents of adult offspring with intellectual disabilities (Heller & Factor, 1993a, 1993b). The family social climate, specifically family values, relationships among family members and organization of the family is a strong predictor of the well-being of mothers caring for their adult sons/daughters with intellectual disabilities (Seltzer & Krauss, 1989). Formal support does not affect levels of satisfaction, burden or stress (Seltzer & Krauss, 1989; Smith, Fullmer & Tobin, 1994).   Seltzer & Krauss argue this finding contradicts the widely held assumption that formal services improve

the well-being of the caregiver, and suggest further research is required on the relationship between caregiver well-being, formal supports and the caregiver's ability to continue to provide care.

Kaufman (1998), in a study of older parents caring for adult offspring with mental illness, asserts the most important finding of his study is how well parents managed caregiver stress and burdens. He suggests high levels of social support and the many years of experience in providing care to their offspring contribute to the coping abilities of these parents. Similarly, Greenberg et al., (1997) conclude social support reduces the negative effects of caregiving stress in parents of adult sons/daughters with mental illness. In contrast to the findings of Black, Cohn, Smull & Crites (1985), which suggest older parents are socially isolated, Kaufman found high levels of contact with family and friends.

Seltzer et al. (1996) found mothers who provide long-term care to their adult sons/daughters with intellectual disabilities are resilient, optimistic, function well in multiple roles and are substantially healthier than a sample of non-caregiving women their age and a sample of caregivers for elderly people. The mothers reported about an average level of perceived burden and stress relative to the comparison groups and less stress than younger parents of children with intellectual disabilities. Seltzer et al. conclude nonnormative parenting roles do not result in nonnormative outcomes and offer two likely explanations. First, these findings support the adaptational hypothesis, in that it appears mothers coped and thrived in their caregiving role over time. Additionally, the mothers in this study viewed caregiving as being a reciprocal relationship, and reported receiving a number of benefits from their caregiving role.

4.6 Gratifications

Few studies have examined the positive aspects of caregiving. Seltzer and Krauss (1989) found parents of adults with intellectual disabilities generally evaluated their experiences positively. Bulger et al. (1993), in a study of the burden and gratification experienced by parents of adult offspring with schizophrenia, found a low level of burden and a high level of gratification, with even the lowest scores of gratification quite high and no participants reported an absence of gratification. Bulger et al. argue that earlier researchers considered even a single report of burden by a respondent as representing significant burden, and while this approach is sensitive to challenges of caregiving, it may indicate higher levels of burden than are actually present. They contend that earlier studies found little burden, considering the demands of caregiving.

Bulger et al. (1993) found the majority of the parents, when asked what personal rewards they received from caregiving, listed strength, patience, assertiveness, greater capacity for understanding and caring and fewer judgmental attitudes. Similarly, in a study of older mothers caring for adult offspring with intellectual disabilities, the majority

reported personal rewards from their experience as including patience, empathy, sensitivity, strength and changed values (Valentine et al., 1996).

Smith and Tobin (1993) argue a lifetime of successful caregiving for offspring with disabilities can engender feelings of control over everyday life and the ability to cope with new challenges, such as those presented by age-related declines in themselves or their offspring. Not only is the relationship between parent and offspring with disabilities a source of satisfaction, but caregiving reciprocity is a factor in predicting the well-being of both parents and offspring (Heller & Factor, 1993b).

5 RECIPROCITY

Caregiving reciprocity, in the context of older parents caring for their offspring with lifelong disabilities, refers to the exchange of instrumental and affective supports between parents and their offspring (Heller & Factor, 1993b). Historically, researchers have viewed caring for offspring with lifelong disabilities to be unidirectional, with support provided to the dependent care recipient, rather than a process of mutual exchange (Horwitz, Reinhard & Howell-White, 1996).   The reciprocal nature of caregiving in families with adult offspring with disabilities has been largely overlooked (Heller & Factor, 1993b; Horwitz et al.,1996).

Although it is widely recognized that individuals with disabilities receive support, it is important to acknowledge the support they give, in whatever form it takes (Jacobson & Kropf, 1993). Acknowledging the contributions adults with mental illness make to their families can help build and maintain self-esteem, reduce stigma, expand their opportunities and overall, improve the quality of their lives (Greenberg, 1995; Greenberg, Greenley & Benedict, 1994).

The level of support adults with mental illness give to their families is strongly related to the amount of support they receive (Horwitz et al.,1996). However, Horwitz et al. argue reciprocity in families is generalized and does not necessarily involve equivalent exchanges, rather it takes into consideration the different needs and capabilities of each member. Whereas parents may provide substantial amounts of instrumental assistance, adult sons/daughters with mental illness offer symbolic rather than instrumental exchanges. Zetlin's (1986) findings from her study of sibling relationships in families with offspring with intellectual disabilities support this argument. She determined that while the concept of reciprocity is important to the adult with intellectual disabilities, the exchanges are generally not equivalent.

Grant (1986) acknowledges the importance of mutual aid in the relationship between parents and offspring with disabilities. He argues reciprocity represents a reward to parents for their extended caregiving commitment and helps sustain them in their caregiving role. Stehlik (2000) characterizes the mother/daughter relationships of the participants in her study as being based on trust, reciprocity and love, with an evident bi-directional flow of support.

Caregiving reciprocity is an important factor in predicting the well-being of both parents and their offspring with disabilities (Heller & Factor, 1993b). Greenberg (1995) suggests adult offspring with mental illness are resources for their aging mothers and the assistance they provide reduces maternal burden. Similarly, parents who received support from their adult offspring with intellectual disabilities experienced greater satisfaction and less burden (Heller & Factor, 1993b; Heller, Miller and Factor, 1997).

Adults with lifelong disabilities make many and varied contributions to their parents. They make significant contributions through the provision of instrumental assistance such as help with household tasks; through financial contributions; and by providing expressive support such as companionship (Greenberg, 1995; Greenberg et al., 1994; Kropf, 1997). Meeting the needs of their adult sons/daughters with disabilities may confer a sense of purpose or usefulness and structure in lives of parents (Gubman & Tessler, 1987). Parents may come to rely upon the support of their offspring with disabilities (Greenberg, Seltzer and Greenley, 1993) and their continued presence in the home may buffer the losses parents experience in their social networks due to death or illness (Kropf, 1997). Tobin (1996) concludes that parents who care for their adult sons/daughters with lifelong disabilities gain an identity and meaning from this role that eludes other parents.

Several researchers argue that reciprocity is an important factor in the permanency planning process (Heller and Factor, 1988, 1993a; Smith & Tobin, 1989; Stehlik, 2000). When viewed as a reciprocal and rewarding relationship, it becomes clear that some parents may want to prolong their caregiving role. The rewards and gratifications both parents and adult sons/daughters give and receive in their relationships may inhibit both the parents' and offsprings' desire to plan for the transfer of care.

6 ACROSS DIAGNOSES - A COMPARISON OF THE CAREGIVING EXPERIENCE OF PARENTS OF ADULT OFFSPRING WITH INTELLECTUAL DISABILITIES AND PARENTS OF ADULT OFFSPRING WITH MENTAL ILLNESS

There are several commonalities and differences in the caregiving experiences of parents of adult sons/daughters with intellectual disabilities and parents of adult sons/daughters with mental illness. As with other family caregiving situations, women are typically charged with caregiving for their adult sons/daughters with disabilities (Guarnaccia & Parra, 1996; Pruchno, Patrick & Burant, 1996a) and some of these older caregivers may be tending to more than one family member at a time, or may provide care to several family members serially (Smith, Tobin & Fullmer,1995a).

Both sets of parents have suffered the disappointment, anguish, and loss associated with receiving an unfavourable diagnosis and the realization that their offspring will not likely lead a fully independent life. They worry about their offsprings' future and who will care for their adult sons/daughters with disabilities when they are no longer able (Pruchno et al., 1996a). Parents of offspring with mental illness and

intellectual disabilities are more likely than the general population to coreside with their adult sons/daughters (Greenberg, Seltzer et al., 1993). Both groups of parents reported gratifications as well as burdens in the caregiving relationship (Greenberg, Seltzer et al.,1993).

There are several important differences in the experiences of parents who care for adult sons/daughters with intellectual disabilities or mental illness, the first of which relate to the caregiving context.

6.1 Contextual Differences

There are four primary contextual differences in the experiences of parents who are caregivers for adult offspring with intellectual disabilities and parents caring for adult offspring with mental illness: etiological attributions and family pathology models (Lefley, 1989); stigma; time of onset; and episodic nature of mental illness (Greenberg et al.,1997; Pruchno et al., 1996a).

6.1.1 Etiological Attributions and Family Pathology Models

Lefley (1989) notes that mental illness, particularly schizophrenia, is unique in that it is treated by medical means but its etiology has traditionally been attributed to the behaviour of others. In the past, families have been viewed as "toxic agents" (pg. 556), who passed along the illness through disordered communication, an emotionally charged environment or by genetically transmitting a biochemical disease.

Gubman and Tessler (1987) argue there are three distinct themes in the literature on families and mental illness. The first assigns causation of the mental illness to the family's interactions and communications. The literature on the causation of mental illness tends to blame mothers, more so than fathers, for their offsprings' pathology (Cook, 1988). The second perspective views families as agents of rehabilitation, with a focus on preventing patient relapse. Winefield and Harvey (1994) suggest studies on the needs of family caregivers for adults with mental illness generally reflect assumptions of the expressed emotion model, which holds that caregiver behaviours influence the probability that the adult with mental illness will relapse. This perspective views caregiver distress as a cause of mental illness and relapse, rather than an outcome. The third theme is family burden, which views family problems in relation to the family member's mental illness.

Current trends favour biochemical theory research and have moved away from viewing the family as the cause of pathology and toward viewing family as a system of support for the offspring with mental illness (Lefley, 1996). Lefley (1989) maintains that despite findings that point to other contributory factors, professionals in the mental health care system have generally see families in a negative light.

The genetic link between caregiver and care recipient, such as in the case of a parent caring for a child with mental illness, makes these caregiving situations unique (Lebowitz & Light, 1996). Lebowitz and Light report studies on individuals with

schizophrenia and their first degree relatives suggest they have higher rates of physical and psychiatric morbidity than the general population. They argue that this subgroup of caregivers may be particularly vulnerable to stress-related disorders. In light of these findings, Lebowitz and Light conclude that aging parents caring for their adult sons/daughters with mental illness differ significantly from other family caregivers and suggest that caregiver stress and burden experienced by this potentially more vulnerable population may have profound adverse effects on caregivers' physical health, their ability to provide care and will ultimately tax the healthcare system.

While parents of adult offspring with intellectual disabilities also share a genetic link, they are typically not held accountable for their offspring's disability and are generally viewed with sympathy (Greenberg et al, 1997).

6.1.2 Stigma

Given the history of prejudice surrounding mental illness, it is not surprising that stigma is the predominant subjective burden experienced by families of adult offspring with mental illness (Greenberg, Greenley, McKee, Brown & Griffin-Francell, 1993).   The stigma historically associated with mental illness is generalized to the families of individuals with mental illness, creating social barriers which may serve to further isolate the family (Kelly & Kropf, 1995; Greenberg, Greenley et al.,1993; Lefley, 1989.). Stigma may have a direct effect on the health of the caregiver. Subjective burden associated with stigma and worry are related to lower levels of physical well-being in mothers of adult sons/daughters with mental illness (Greenberg, Greenley et al., 1993).

Persistent attitudes that blame families for mental illness, despite findings to the contrary, may contribute to a strained relationship between parents and professionals in the mental health system. Lefley (1989) notes that aging parents of previously institutionalized adult offspring with a long-standing mental illness have lived with the anguish associated with their offspring's illness during a period in which parents were routinely and overtly blamed for their child's illness by mental health professionals.

Historically families have not been included in treatment, beyond having the ultimate responsibility for their offsprings' adherence to the program, as treatment was entirely patient focused (Kelly & Kropf, 1995). Recent trends include the family in treatment, but Lefley (1989) cautions that some families perceive the treatment to be imposed upon them without their informed consent and irrelevant in dealing with their immediate concerns.

By contrast, some authors suggest that adults with intellectual disabilities face less stigma, more compassion and typically have access to a greater number and variety of services than do adults with mental illness (Seltzer, Greenberg, Krauss, Gordon & Judge, 1997).

6.1.3 Late Onset

Intellectual disabilities are generally identified during early childhood, whereas mental illness, particularly schizophrenia, typically develop later in life. People with schizophrenia may not experience any symptoms until late adolescence or earlier

adulthood. Generally onset occurs between the ages of 18-35 (Pruchno et al.,1996a). The late and sometimes sudden advent of mental illness does not afford parents as much time to come to terms with their role as caregiver to their adult offspring, compared to receiving the diagnosis during the offspring's childhood. Relationships in the family, long established by the time offspring exhibit symptoms of mental illness, undergo change. Parents and siblings may feel they no longer know their loved one. As well as dealing with their own sense of loss, parents have to deal their offspring's sorrow and frustration as their adult sons/daughters come to terms with their own illness (Lefley, 1989).

6.1.4   Episodic Nature of Mental Illness

The course of mental illness is fraught with ambiguities and unpredictability. Its episodic nature creates circumstances in which parents are unable to predict the level and type of care their offspring will require from day to day (Greenberg, Seltzer et al., 1993). Greenberg, Seltzer et al., in a comparative study of the impact of later-life caregiving on mothers of adult offspring with mental illness and mothers of adult offspring with intellectual disabilities, reported mothers of adults with mental illness indicated they felt like they were "walking on eggshells" (p. 548) when interacting with their offspring, because they were unable to anticipate their offsprings' responses. This theme was absent from the accounts of mothers of adult offspring with intellectual disabilities, which, by contrast, has a generally stable course with more predictable caregiver demands.

6.2. Burden and Gratification

The offspring's diagnosis is a significant predictor of stress and burden in mothers who are caregivers to their adult offspring with disabilities (Greenberg, Seltzer et al,1993).   Mothers of adults with intellectual disabilities experience different types of stressors than do mothers of adults with schizophrenia and mental illness (Pruchno et al.,1996a; Greenberg, Seltzer et al.,1993). Although the former set of caregivers performed more duties related to daily living (e.g., - assisting with personal hygiene, transportation, administering medication, money management), mothers of adults with schizophrenia reported more emotionally unstable, noncompliant and disruptive behaviours on the part of their offspring and a lower quality parent-offspring relationship (Pruchno et al., 1996a; Greenberg Seltzer et al., 1993). They reported more negative caregiving appraisals, fewer positive appraisals, a lower level of positive well-being and a higher level of negative well-being than mothers of adult offspring with intellectual disabilities (Pruchno et al., 1996a).

Overall, mothers who are caregivers to adult offspring with mental illnesses found the experience more burdensome, more disruptive and less fulfilling than mothers who are caregivers to adult offspring with intellectual disabilities (Greenberg et al., 1997;

Pruchno et al.,1996a; Greenberg, Seltzer et al., 1993).

There are several other significant differences in the lives of parents of adults with mental illness and parents of adults with intellectual disabilities. Compared to mothers of adult offspring with intellectual disabilities, mothers of adults with mental illness had higher levels of depressive symptoms (Seltzer, Greenberg & Krauss, 1995), smaller social support networks and their families are characterized as being less cohesive, less expressive and more conflictual (Greenberg, Seltzer et al., 1993). They dealt with more and varied types of behavioural problems and they spent less time apart from their offspring, as fewer adults with mental illness are employed or use day services (Greenberg, Seltzer et al., 1993). Burden was especially high among those parents whose offspring have been repeatedly hospitalized (Cook & Heller, 1999).

Differences in the caregiving context, specifically the late onset and unpredictable course of mental illness (Greenberg, Seltzer, Krauss & Kim, 1997), as well as higher incidence of psychiatric disorders among first degree relatives of adults with mental illness, may explain the differences in experiences in these caregivers (Greenberg, Seltzer et al.,1993).

A search of the literature reveals that there are more investigations of burdens associated with caring for adult sons/daughters with disabilities than of the gratifications. Greenberg, Seltzer et al. (1993) reported both groups of parents experienced gratifications as well as burdens in their relationships with their adult offspring with disabilities. Seltzer et al. (1995) found aging mothers of adult offspring with intellectual disabilities reported more gratification than aging mothers of adult offspring with mental illness. However, Bulger et al. (1993) conclude there is a great degree of caregiver gratification experienced by parents of adults with schizophrenia.

6.3 Coping Strategies and Social Support

Seltzer et al. (1995) investigated the coping strategies that mothers of adults with mental illness and mothers of adults with intellectual disabilities used to mediate stress and maintain their well-being. They conclude that the same coping strategies can have different outcomes, depending upon the caregiving context. They found similar use of problem-focused coping strategies, but found mothers of adults with mental illness reported greater use of emotion-focused coping strategies. Seltzer et al. contend the use of problem-focused strategies is an attempt to master stressful situations and use these situations as a means for personal growth. Emotion-focused coping strategies are seen as being less positive, as they attempt to diminish the stressful situation by avoiding it and have no buffering effects on stress. Problem-focused coping strategies are positively related to maternal well-being and protected mothers of adults with intellectual disabilities from depressive symptoms, but produced no relationship with maternal well-being and protection from depressive symptoms or stress in mothers of adults with mental illness. Seltzer et al. suggest that this difference may be attributed to the limited control caregivers have in the context of caring for adult offspring with mental

illness because of the unpredictable and episodic nature of the course of the illness.

Support group participation had a positive affect on the well-being of mothers of adults with mental illness (Cook & Heller, 1999; Greenberg et al., 1997) but had no such effect on mothers of adults with intellectual disabilities (Greenberg et al., 1997). Greenberg et al. point to differences in the caregiving context by way of explanation. Support groups provide the opportunity for parents to share and learn from each others' experiences in coping with difficult caregiving situations. The parents of adults with intellectual disabilities who participated in the research had been caring for their child for an average of 30 years and had established patterns of coping. The course of intellectual disabilities is relatively stable and brings fewer new challenges, with the exception of those related to aging. On the other hand, parents of adults with mental illness had fewer years experience, and due to the uncertain course of mental illness face unpredictable challenges in their role as caregiver. Hence these parents are more likely to benefit from membership in a support group.

Mothers of adults with mental illness have access to fewer social supports as they have smaller social networks, (Greenberg et al.,1993; Greenberg et al., 1997). Lefley (1989) asserts the demands of providing care for their adult offspring with mental illness and disruptive behaviours on the part of the offspring may adversely affect relationships with friends and family, thereby decreasing the size of the informal support network. However, Kaufman (1998) reported contradictory findings with respect to social supports. In a study of older parents caring for adults with mental illness, Kaufman found the majority of parents reported high levels of support from family and friends and their coping ability was positively influenced by this support.

6.4 Sibling Relationships

Affective bonds between siblings are strongest when the offspring has intellectual disabilities as opposed to schizophrenia and minimal maladaptive behaviours. Sibling ties are not influenced by the functional abilities of the offspring with disabilities or by geographical proximity of the siblings. In terms of the functional assistance provided by siblings, the diagnosis has no influence; need and proximity of siblings are the only predictors (Pruchno et al., 1996b)

Seltzer, Greenberg, Krauss, Gordon et al.(1997) found two factors predicted psychological well-being in siblings of adults with mental illness and siblings of adults with intellectual disabilities: the level of perceived intimacy or distance and the incidence of behaviour problems of the adult with disabilities. Intimacy in the sibling relationship predicted better psychological well-being in siblings of adults with intellectual disabilities, whereas psychological distance predicted psychological well-being in siblings of adults with mental illness. The incidence of behaviour problems in adults with mental illness predicted poorer sibling well-being; no similar relationship was found in siblings of adults with intellectual disabilities however. Siblings of adults with intellectual disabilities are more likely than siblings of adults with mental illness to have a closer relationship and

more face-to-face contact.

Eventually, aging parents will have to surrender their role as caregivers to their adult sons/daughters with disabilities. In a recent study, 60% of siblings of adults with intellectual disabilities expected to assume caregiving responsibilities in the future, while only 33% of siblings of adults with mental illness held this same expectation (Greenberg, Seltzer, Orsmond & Krauss, 1999). Gender is a significant predictor of expectations of future caregiving. In the case of adults with mental illness, the gender of the nondisabled sibling was not a predictor of future caregiving, but the gender of the adult with mental illness was a significant predictor. Siblings of women with mental illness expect to take on caregiving responsibilities in the future. In the case of adults with intellectual disabilities, sisters expect to take on caregiving responsibilities in the future, but the gender of the adult with intellectual disability is not a significant predictor (Greenberg et al.,1999).

Greenberg et al. (1999) suggest that the gender of the adult with mental illness influences her or his siblings' desire to assume care, in that some mental illnesses, such as schizophrenia, have a more debilitating impact on males than females. The gender differences in the course and impact of the illness may make caregiving for brothers with mental illness more difficult than caregiving for sisters with mental illness.

6.5 Service Use And Availability

Historically there have been fewer community-based services for individuals with mental illness than for adults with intellectual disabilities (Seltzer, Greenberg, Krauss & Hong, 1997). Parents of adults with mental illness may expend considerable time and energy trying to access the appropriate services from the mental health, welfare and medical systems, as well as dealing with the legal and justice systems (Lefley, 1996). Families describe frustrations in their dealings with the mental health system, especially with the process of commitment. Caregivers contend that their assessments of their family members' deteriorating condition are routinely discounted by mental health professionals and encounter difficulty in accessing services when their family member is experiencing a psychiatric crisis (Guarnaccia & Parra, 1996).

The majority of family caregivers prefer a residential placement for the adults with mental illness, hence the lack of supervised accommodations is problematic (Lefley, 1989; Winefield & Harvey, 1994). The limited availability of services for adults with mental illness, compared to adults with intellectual disabilities, may cause additional challenges for siblings who take on the role of caregiver (Seltzer, Greenberg, Krauss & Hong, 1997).

6.6 Predictors of the End of Co-resident Caregiving

Seltzer, Greenberg, Krauss and Hong (1997) investigated the predictors and

outcomes of the end of co-resident caregiving in aging mothers of adults with intellectual disabilities and aging mothers of adults with mental illness. They found that in mothers of adults with intellectual disabilities, diminishing ability to provide care led to the transition to out-of-home care. In families of adults with mental illness, caregiver stress associated with maladaptive behaviours on the part of the adult with mental illness and the mother's propensity to focus on and vent her emotions, predicted the end of co-residency. Psychiatric crises that resulted in hospitalization or encounters with the justice system increased the likelihood of the end of co-residence, as did the gender of the offspring. Having a son instead of a daughter with mental illness predicted the end of co-residence.

In terms of the outcomes of the end of co-residence, both groups of caregivers were similar in that they reported a decrease in feelings of burden but no change in depressive symptoms. Both groups had similar high rates of contact with offspring after co-residency ended, 93.6% of adults with intellectual disability and 87% adults with mental illness had at least weekly contact with their mothers. Even though they were no longer co-residing, 48.4% of mothers of offspring with intellectual disability and 34.8% of mothers of adults with mental illness still functioned as active caregivers, and reported continuing responsibility for at least one caregiving task for their offspring.

6.7 Summary

In summary, caring for an adult offspring with mental illness is a more disruptive and less fulfilling experience than caring for an adult offspring with intellectual disabilities (Pruchno et al., 1996a). Mothers of adult offspring with mental illness report poorer relationships, more burden, fewer informal supports (Greenberg, Seltzer et al., 1993) and higher depressive symptoms (Seltzer et al., 1995) than mothers of adults with intellectual disabilities. The difference in the caregiving experiences of these of parents can be attributed to important differences in the caregiving context, such as the late onset and unpredictable course of mental illness (Pruchno et al., 1996a; Seltzer et al., 1995). Seltzer et al. assert these findings illustrate the heterogeneity of the caregiving experience, and the importance of understanding the caregiving context of different groups of care providers and recipients.

7 SIBLINGS

Siblings of adults with intellectual disabilities perceive their brothers/sisters to have a pervasive effect on their lives, and a large majority (87.4%) consider the experience as being mostly positive. By contrast, siblings of adults with mental illness experience less of an impact and just over half (52.6%) rate the experience as mostly negative (Seltzer, Greenberg, Krauss, Gordon et al.,1997).

Seltzer Greenberg, Krauss, Gordon et al. (1997) suggest a possible explanation for this discrepancy in the pervasiveness of the impact of having a sibling with a lifelong

disability may be the time of diagnosis. Individuals with intellectual disabilities are generally diagnosed in childhood, therefore the sibling has grown up knowing their brothers/sisters as a person with an intellectual disability. The majority of the adults with mental illness are diagnosed in late adolescence or early adulthood. In this particular investigation the majority (71.2%) were not diagnosed until after the sibling had reached adulthood. Hence the sibling was less influenced by the mental illness of their brother/sisters.

Reinhard and Horwitz (1995), in a study of caregiving burden of families of adults with mental illness, found siblings provided less caregiving than parents, but their caregiving efforts were a stronger predictor of burden, as caregiving for adult siblings is a nonnormative role. Siblings of adults with mental illness rank family friction (70%), distraction from activities (65%) and upset household routines (54%) as the three most disruptive objective burdens. In terms of subjective burden, siblings rank worry about the future (96%), upset over the loss of the brothers/sisters they knew who have since changed as a result of mental illness (78%), and stigma (68%) as the most pervasive burdens.

7.1 Nature of the Sibling Relationship

Pruchno et al.(1996b) found affective bonds between the adult with life-long disabilities and siblings were strong, and influenced by the specific diagnosis (intellectual disabilities vs. mental illness) and the incidence of maladaptive behaviours. Begun (1989), in her study of sisters of individuals with moderate to profound intellectual disabilities, reported siblings rated their relationships as positive but not intimate.

There is a variance in the degree of emotional connectedness among adults with intellectual disabilities and their siblings. Zetlin (1986), using participant observation, examined 35 adults with intellectual disabilities and their siblings to determine the nature of their relationships. The ranking she developed ranged from very close with frequent contact to hostile with no contact. Of the 35 pairs only one fit into this last category. The remainder had varying degrees of closeness and contact. In the majority of cases the relationships were hierarchal rather than egalitarian, with nondisabled siblings providing instrumental and emotional support to siblings with intellectual disabilities. Sisters and younger siblings, more so than brothers and older siblings, were more likely to be the primary caregiver. Parental expectations influenced sibling involvement and the level of assistance provided to the sibling with disabilities.

7.2 Patterns and Nature of Current Involvement

Involvement refers to the current instrumental and affective support provided by the siblings of adults with life-long disabilities (Greenberg et al.,1999). In most cases,

siblings maintain a consistent pattern of involvement with their brothers/sisters with intellectual disabilities throughout their lives and are an on-going source of support (Greenberg et al, 1999; Krauss, Seltzer, Gordon & Friedman, 1996). Siblings of adults with intellectual disabilities have a wide appreciation for the needs of their bothers/sisters (Krauss et al.) and provide both instrumental and emotional support, albeit significantly more emotional support than instrumental support (G. Seltzer, Begun, M..Seltzer & Krauss, 1991). Pruchno et al.(1996b), in their study of mothers' perceptions of sibling involvement with brothers/sisters with intellectual disabilities or schizophrenia, found that current functional involvement of siblings was predicted by the gender of the adult with disabilities being female, co-residence of siblings and the number of other siblings in the family.

Greater sibling involvement with brothers/sisters with disabilities is associated with close relationships in the family of origin, close ties between siblings (Greenberg et al., 1999) and the presence of positive attitudes towards the adult with mental illness by their siblings (Horwitz, Tessler, Fisher & Gamache, 1992). Family dynamics influence levels of sibling involvement, with high levels of involvement found in families that are more expressive, cohesive, achievement oriented and involved in recreational activities (G. Seltzer et al, 1991).

In families where there is sibling involvement with the adult with intellectual disabilities, one sibling is typically identified as being "the most involved" (p. 313, G. Seltzer et al.,1991). This sibling is most likely to be older than the adult with disabilities, live in near proximity to the family, and have regular, usually weekly, contact. This sibling is most likely to be the same sex as the adult with disabilities, but if not, sisters are more likely than brothers to be the most involved sibling (G. Seltzer et al., 1991).

The reports of the assistance rendered by siblings to their brothers/sisters with disabilities are somewhat at odds with the perceptions of their mothers. The majority of mothers (82.3%) reported that their offspring with life-long disabilities received very little assistance from their nondisabled siblings (Pruchno et al., 1996b). This does not appear to influence the quality of sibling relationships, however. Mothers reported strong ties between offspring with a disability and their siblings, and characterized their relationships as being excellent to good overall (Pruchno et al., 1996b).

Siblings of adults with disabilities who have other competing obligations, e.g., - parenting responsibilities for minor children, marriage or work commitments, reported less current involvement in the care of the adult with disabilities (Greenberg et al., 1999). While family commitments limit current levels of involvement with the adult with disabilities, they do not affect the willingness of the sibling to assume caregiving responsibilities for the adult with disabilities in the future (Greenberg et al., 1999; Pruchno et al., 1996b).

7.3 Expectations of Future Caregiving

Inevitably, aging parents will be forced to relinquish their caregiving role for their

adult sons/daughters with disabilities because of incapacity or death. Given that the majority of persons with intellectual disabilities live with their families during most of their lifetime (Seltzer & Krauss, 1989), it is not surprising that siblings are viewed as potential caregivers to their brothers/sisters with disabilities.

Studies have shown that the number of siblings who expect to assume the caregiving role for their brothers/sisters with intellectual disabilities in the future varies from 36% (Krauss et al., 1996) to 44% (Griffiths and Unger, 1994) to 60% (Greenberg et al.,1999). By comparison, 33% of siblings with mental illness plan to assume caregiving duties in the future (Greenberg et al., 1999). Smith, Hatfield and Miller (2000) suggest siblings' perceptions of the experience of growing up with a brother/sister with mental illness will likely influence their involvement in future caregiving.

While the majority of family members believe families should be responsible for the care of adults with intellectual disabilities and most siblings are willing to take on this role, some parents are reticent to have siblings assume responsibility for their brothers/sisters with disabilities (Griffiths & Unger, 1994; MacLellan & Cosway, 1997). Reasons given by parents who did not want siblings to assume caregiving include disruption to the non-disabled siblings' lives and fears that the burden may be too great for siblings (Griffiths & Unger, 1994; MacLellan & Cosway, 1997).

7.4 Impact of Sibling Involvement on Mother

A higher level of involvement between siblings and adults with intellectual disabilities is related to the mother's well-being (Pruchno et al., 1996b). Mothers whose offspring are involved with their brothers/sisters with intellectual disabilities have better health and life satisfaction and less burden and stress related to caregiving than mothers whose offspring are less involved or mothers who have no other offspring except for the adult son/daughter with disabilities (G. Seltzer et al., 1991).

8 CULTURE

In reference to the impact of culture on the caregiving context, Blatcher, Lopez, Shapiro and Fusco (1997) conclude succinctly, "culture matters" (p. 325), yet is routinely overlooked in research on family caregiving and intellectual disabilities.

Minority group members who care for their adult sons/daughters with intellectual disabilities experience more stress than majority populations, have less access to services, are poorer and are more likely to have had disappointing experiences with agencies (Gammon, 2000). Extracting ethnic and cultural variables from socioeconomic factors is difficult however, (Aranda & Knight, 1997; Pruchno et al.,1997) and while the impact of cultural context on family caregiving experiences is important to understand, Lefley (1997) contends that contradictory findings have offered little with which to improve services for this segment of the population.

Aranda and Knight (1997) using a stress and coping model, reviewed the literature on caregiving in the Latino population and conclude ethnicity and culture play important roles in stress and coping process, and influence the appraisal of stressors, the perception of informal support systems and the use of coping strategies.

In a series of focus group sessions with members of the African American, Chinese American, Haitian American, Hispanic/Latino American, Korean American and selected Native American communities, McCallion, Janicki and Grant-Griffin (1997) recorded a set of themes that emerged around the definition of family, caregiving, values, language and perception of disability. A central issue was the difference in interpretation of these themes both within and among ethnic groups. As with any other caregiving group, the caregiving role is not experienced uniformly across an ethnic group.

Guarnaccia and Parra (1996) identified similar themes emerging from their study of caregiving experiences of Hispanic Americans, African Americans and European Americans with family members with mental illness. They conclude culture, ethnicity and social status play important roles in families' caregiving experiences, and in light of the over-representation of minorities in the public mental health system, they suggest a more comprehensive understanding of the experiences of minority families is essential. Additional issues that must be addressed include: conflicting cultural values; language barriers; racism and discrimination; and the appropriateness of treatment models developed by and for the dominant culture which influence the effectiveness and acceptability of existing services and treatment programs (Guarnaccia & Parra, 1996).

9 PERMANENCY PLANNING

Planning for the future care of adult sons/daughters with disabilities is a complex task. It involves developing a multi-dimensional, comprehensive plan that will ensure the well-being of offspring with disabilities when parents are no longer able to fulfill the caregiving role. It must address residential, legal and financial concerns as well as quality of life issues, and culminate in concrete plans that can be activated at a future date (Heller & Factor, 1994). As well, the plan should consider the psychological and emotional consequences of the transfer of care on the adult son/daughter with disabilities and the caregiver (Wood, 1993). Ideally the plan should be re-evaluated from time to time to assess the impact of any changes in the family's situation, laws, agency programs and services or policies (Freedman & Freedman, 1994).

Smith and Tobin (1989) characterize the permanency planning process as being very emotional and often painful for parents, as it requires them to face their own mortality and envision a time when they will be forced to place their adult sons/daughters in the care of others. Typically parents develop the permanency plan in later life, adding an extra layer of complexity when creating a plan for their own aging (Heller & Factor, 1991). Given the complexity and emotionality of this task, it is not

surprising that many parents do not have a firm permanency plan in place (Freedman, Krauss & Seltzer, 1997; Heller & Factor, 1991; Smith, Tobin & Fullmer, 1995a).

9.1 Prevalence of Permanency Planning

9.2

A search of the literature reveals only one published study on the extent of future planning among aging mothers of adult sons/daughters with mental illness. Smith et al. (2000) found that although 85% of participants had taken some steps towards developing a plan for the future care of their adult sons/daughters with mental illness, only 11% made definite residential plans. A majority of mothers (66%) reported making financial plans for their offsprings' future.

Several studies have produced different findings regarding the incidence of permanency planning in parents of adult offspring with intellectual disabilities. Pruchno and Patrick (1999b) found 83.7% of mothers of adults with intellectual disabilities had taken concrete steps toward establishing firm residential plans for their sons/daughters. Other studies report approximately 45% of mothers had made specific residential plans for their adults offspring with intellectual disabilities (Freedman et al., 1997); 43% of parents of adult sons/daughters had made no concrete plans (Kaufman, Adams & Campbell, 1991); and between approximately one half to three quarters of parents had begun making some plans (Heller & Factor, 1988; Heller & Factor, 1991; Lehmann & Roberto, 1993; Weatherbie, 1995; Wood, 1993).

Pruchno and Patrick (1999b) suggest the various ways that permanency planning is operationalized by researchers may explain the difference in the findings. Smith et al. (1995a) argue residential planning is an on-going process, which they conceptualized as five ascending stages (no discussion, early discussion, serious discussion, provisional plans, concrete plans) rather than a single, specific action that occurs prior to the placement. By defining permanency planning as a process and asking a wide array of questions regarding the tasks involved, instead of asking about specific actions, Pruchno and Patrick suggest they were able to capture a wider variety of permanency planning. By contrast, some studies considered only specific tasks as evidence of planning, such as putting the name of the offspring on a waiting list for residential programs (Freedman et al., 1997). Overall, the literature suggests that a substantial number of aging parents who are caregivers to their adult sons/daughters with disabilities have not made adequate plans for the transfer of care (Kaufman et al, 1991; Smith et al., 2000; Wood, 1993).

9.3 Deterrents to Planning

Why do parents fail to create a permanency plan to secure the future care of their sons/daughters with disabilities? The reasons may be as complex as the task itself. Parents may expect that another family member will take over the caregiving role when they no longer can provide care, yet many parents do not discuss these expectations

with their family (Heller & Factor, 1991; Kaufman et al., 1991). Parents may not have access to the information and assistance they need to develop a realistic permanency plan (Smith et al., 2000). Alternately, parents may have already investigated options for future services for their sons/daughters with lifelong disabilities and found them inadequate or unavailable, hence they feel it is futile to persist in their efforts to plan (Kropf, 1997). Some parents may have neglected to plan for their future care of their sons/daughters with disabilities because they expected their child to pre-decease them (Wood, 1993).

Heller and Factor (1991) noted a strong preference by parents who are caregivers to their adult sons/daughters with disabilities to continue in the role for as long as possible. The parent-offspring relationship may be the source of gratification and identity (MacLellan & Cosway, 1997; Wood, 1993). The emotional and psychological benefits of providing care for, and receiving care from the adult offspring with disabilities, as well as the sense of purpose parents receive from their role, may result in parents postponing the transfer of care (Wood, 1993). As well as emotional rewards, adult sons/daughters with disabilities may also provide instrumental aid and financial assistance to their parents (Kropf, 1997). The tangible support aging parents receive from their adult sons/daughters with disabilities may enable parents to maintain their independence and stay in their own homes for a longer period (Kropf, 1997). Grant (1986) argues aging parents who receive assistance from their offspring are less likely to plan for the transfer of care.

The adult offspring may disagree with the proposed permanency plan. Smith et al. (2000) found 60% of adult sons/daughters with mental illness opposed the permanency plans their mothers developed.   As well, the unpredictability of the course of mental illness may make it difficult for parents to predict what services their offspring will need in the future (Smith et al., 2000). Both of these considerations could impact parents' propensity to plan for the transfer of care in these circumstances.

9.4 Benefits of Planning

There are three primary benefits to having a definite permanency plan in place. The first is the avoidance of the use of emergency placements that may be inadequate or unsuitable (Wood, 1993). Second, emergency residential placements may create great distress or "transfer trauma"(Heller & Factor, 1988) for adults with intellectual disabilities and their families. Having a plan in place that can be activated with the support of family, before reaching a crisis, is optimum. Third, permanency plans provide parents with the sense they have fulfilled their parental obligations and alleviates the feeling of having unfinished business (Smith & Tobin, 1989).

9.5 Factors Associated with Permanency Planning

Planning for the transfer of care is not simply a micro-level phenomenon. While characteristics of both the caregiver and the adult offspring with disabilities affect the types of plans made, the availability of supports and services, as well as the political and social context influence the development of permanency plans.

9.5.1   Characteristics of the Adult with Intellectual Disabilities

Characteristics of the offspring with disabilities influence the permanency planning process. Kaufman et al. (1991) conclude higher levels of adaptive functioning are positively related to likelihood that parents will make permanency plans. Pruchno and Patrick (1999b) found lower levels of functional abilities indirectly influenced permanency planning in that they increased maternal burden and that in turn increased the likelihood of planning for the future use of residential programs. In a similar vein, Griffiths and Unger (1994) found that the greater the level of physical demand, the greater the likelihood parents will choose eventual residential placements instead of family care for their offspring with disabilities.

Investigations on the influence of maladaptive behaviours suggest that while maladaptive behaviours have no impact on the propensity of parents to create a plan for future care (Kaufman et al., 1991), they did influence the type of residential plans developed. Several studies have noted that the higher the incidence of maladaptive behaviours on the part of the adult with disabilities, the more likely parents will seek residential programs (Black et al.,1985; Freedman et al., 1997; Heller & Factor, 1991; Pruchno & Patrick, 1999b; Sherman, 1988).

The gender of the adult with disabilities is also related to residential planning. Parents are more likely to develop a plan for future care for daughters as compared to sons (Kaufman et al., 1991).

9.5.2   Caregiver Characteristics

Two demographic characteristics of caregivers are related to the propensity to plan. Race and socioeconomic status are related to permanency planning, with white caregivers of higher socioeconomic status more likely to have made residential and financial plans for their adult offspring with disabilities (Heller & Factor, 1991, 1988; Kaufman et al., 1991).

Smith et al.(1995a) examined factors related to the stage of planning, and found mothers' perceptions that they were experiencing an increase in negative age-related changes and non-use of avoidance coping strategies were related to higher stages of permanency planning. The level of perceived caregiver burden was associated with the type of residential care preferred by mothers. The greater the perceived burden, the greater the likelihood of mothers planning for future residential placement, as opposed to planning for family care (Heller & Factor, 1991; Pruchno & Patrick, 1999b).

9.5.3   Formal and Informal Supports

Formal service use affects permanency planning in two ways. First, the greater the use of formal services for adult sons/daughters with disabilities, the greater the

likelihood that parents will prefer out-of-home residential placement in the future (Heller & Factor, 1991; Pruchno & Patrick, 1999b). Second, greater use of services is associated with higher stages of planning by parents (Smith et al., 1995a). Smith et al. suggest having experience using services decreases apprehension about using those and other services in the future.

Findings regarding the impact of informal supports on the extent of permanency planning are mixed. Kaufman et al. (1991) found parents who had frequent contact with family and friends were less likely to have created permanency plans than parents with a smaller social network. Kaufman et al. speculate that frequent contact with a large social network encourages parents to assume family or friends will care for adult sons/daughters with disabilities when parents are unable to, even if this arrangement has not been discussed.

These findings are at odds with the conclusion of Smith et al. (1995a) that assistance from other offspring who did not have disabilities had a positive influence on the stage of residential planning. Smith et al. suggest this finding supports that of G. Seltzer et al. (1991) that siblings' involvement in the lives of their brothers/sisters with disabilities may diminish maternal distress associated with the transfer of care.

In terms of the types of residential plans made, parents with fewer informal supports were more apt to plan for use of formal residential programs for adult members with intellectual disabilities (Heller & Factor 1991).

9.5.4   Preferences of Adult Sons/Daughters with Intellectual Disabilities

Few parents discuss planning issues and preferences with their adult sons/daughters with intellectual disabilities (Heller & Factor, 1994; Smith & Tobin, 1989). Smith et al. (2000) suggest adult sons/daughters with mental illness may reject the permanency plans proposed by parents, leaving parents in a difficult position. However, Heller and Factor (1993b) assert that successful planning involves participative decision making among all family members. They suggest involvement of the adult offspring with disabilities in choosing the residential program and in planning preparations such as pre-relocation visits to the facility and a brief trial stay. Heller and Factor (1993b) interviewed adults with disabilities about their preferences for future care and noted that although most expressed anxiety about living without their parents' assistance, they had definite opinions regrading where and with whom they would eventually prefer to reside.

9.5.5   Political and Social Influences

Stehlik (2000) argues the political and social discourses prevalent at the time of birth of the offspring with intellectual disabilities profoundly influence the permanency plans mothers develop. In her study of aging mothers/adult daughters in Australia, she identified the custodial/eugenic meta-discourse as being most prevalent during the period the current cohort of aging mothers gave birth to their offspring. This discourse touted institutionalization for people with intellectual disabilities; allowed for limited programming for children with disabilities as they were not expected to live long;

negatively valued persons with intellectual disabilities and marginalized parents, undermining the importance of parental knowledge of their offsprings' needs. Stehlik argues negative experiences with the formal service system, residential options that are seen as unacceptable and lack of parental involvement in policy development combine to inhibit the propensity of mothers to develop permanency plans.

Smith et al. (1995a) also point to the influence on the incidence of service use of the political and social context at the time the current cohort of the aging mothers became parents. They found the mother's age to be negatively associated with service use and perceived service need. Smith et al. contend the oldest cohort of parents raised their children during a period when institutionalization was the only option available to parents, and having rejected this option, parents continued to care for their offspring in the home without services, even after community based supports became available. Smith et al. raise the issue of the impact of ecological influences such as political and social attitudes that have coloured the experiences of parents of offspring with disabilities. They urge that these aspects be considered as well when assisting parents to develop a permanency plan.

9.6 Residential Planning

Of all the aspects that must be considered when developing a permanency plan, residential plans are identified as being the most emotionally challenging. The issue of where their adult sons/daughters will live when they can no longer be cared for in their lifelong home by their lifelong caregivers is the most pervasive worry of caregivers (Smith et al., 1995b). Parents may believe that by establishing residential plans they are beginning the process of withdrawal from their active parenting role to their sons/daughters with disabilities. Seltzer et al. (1996) suggest that when the probability of an adult son/daughter with disability leaving home increases, such as when their name is put on a waiting list for residential services, so does the parents' distress.

With respect to future living arrangements, the majority of parents hope another offspring or family member will assume care (Heller and Factor, 1991; Smith et al., 2000; Wood & Skiles, 1992). Heller and Factor's (1991) study found the preferred residential arrangements for adult sons/daughters with disabilities was continued home care provided by siblings, other family members or friends (53%) as opposed to a residential program (47%). Of those parents who preferred residential care, community residences (83%) were the clear choice over nursing homes (11%) or institutions (6%).

By contrast, Griffiths and Unger (1994) found only 22% of parents of adult offspring with disabilities expected their other offspring to assume care in the future. Characteristics of the adult offspring, specifically physical incapabilities, increased the likelihood of parents' preference for eventual residential placements instead of family care. Heller and Factor (1991) conclude that higher levels of perceived caregiver burden were associated with parental preference for formal residential placement in the

future, as opposed to family placement.

9.7 Legal and Financial Planning

A review of the literature reveals more studies examining the residential dimension of permanency planning than legal and financial aspects. Legal arrangements must consider the rights of adults with disabilities while safeguarding their interests (Freedman & Freedman, 1994). Typically, legal and financial arrangements involve such legal remedies as: will and estate plans, guardianship, power of attorney, and discretionary trust funds (Freedman & Freedman,1994). Financial provisions must consider the financial needs of adult sons/daughters with intellectual disabilities without jeopardizing government benefits (Heller and Factor, 1994).

In those studies that did consider legal and financial planning, Smith et al. (2000) found a higher rate of financial planning among mothers of adults with mental illness than residential planning. Similarly, aging parents of adult sons/daughters with intellectual disabilities were more likely to make financial arrangements than residential plans (Heller & Factor, 1991; Wood, 1993). However, Weatherbie (1995) found slightly more than half of parents made residential plans, but just under one third made financial plans. She points to uncertainty over provincial policies regarding trusts and wills as being a factor in the lower rate of financial planning in the study, and suggests higher rates of residential planning can be attributed to the residential proximity of siblings and their brother/sisters with disabilities.

9.8 Permanency Planning Resources

Increased interest in the area of permanency planning in the past two decades has resulted in the development of resources to encourage parents to plan for the future care of their offspring with disabilities. Several guides and educational packages have been developed for parents and professionals (Etmanski, 2000; Etmanski, Collins & Cammack,1996; Nova Scotia Centre on Aging, Queen Elizabeth II Health Sciences Centre & Canadian Gerontological Nursing Association, 1997; Royal Trust, 1997) to assist them in preparing permanency plans for adults with disabilities.

9.9 Transitions

An issue related to permanency planning that is given less attention in the literature is the transition of aging adults with disabilities away from the care of their parents. Heller and Factor (1991) found of those who had made plans for the eventual residential placement of their offspring, the majority of parents preferred no change in living arrangements occur until their death or incapacitation, yet a third wanted it to

happen within their lifetime so they could assist in the transition.

Abrupt transitions to residential facilities may result in emotional trauma and crisis for adults with disabilities and their families, especially if a crisis such as the death of the parent precipitated the residential relocation (Heller, 1985). Heller and Factor (1994) suggest to alleviate distress associated with residential relocation, the family make preparations including: discussions about the transition; visits to residential facilities; meeting with families who have already made the transition; counselling; and on-going family contact and involvement in the offspring's life after the relocation.

Jacobson and Kropf (1993) propose the use of the social convoy model as a method of easing residential transitions. The social convoy refers to a group of family and friends with whom the individual with disabilities has a lifelong bond. They maintain that in residential relocations, distress can be reduced if the individual with disabilities is involved in the decision-making process; the possibility of losses in the individuals' social convoy are addressed; and the new residence is personalized and adapted to meet the needs of the individual with disabilities as much as possible.

Lehmann and Roberto (1993) suggest the use of a transition plan as a tool to support family and adults with disabilities through the residential relocation. The plan would be similar to those developed for young adults with intellectual disabilities leaving high school, and would address a range of residential, social, transportation, work and recreational needs.

10 SERVICES

The majority of research on services for individuals with lifelong disabilities and their families focuses on young children and their families (Smith, 1997). This is not surprising as early intervention was assumed to have the greatest positive impact and historically, few people with intellectual disabilities survived into old age (Ansello, 1992). However as society ages and the lifespan of people with disabilities increases, understanding the needs of older families with adult sons/daughters with lifelong disabilities has become increasingly germane.

Out of either choice or necessity, the overwhelming majority of adults with disabilities live with their families, thus strengthening and supporting families is an important aspect of community-based care (Heller, Miller and Hsieh, 1999). The major goals of family support services are to relieve caregiver burden; enhance adaptive coping; facilitate future planning and delay residential placement of the adult offspring with lifelong disabilities (Livingstone & Tindale, 2000; Molaison, Black, Sachs & Smull, 1995). Family support takes many forms and encompasses a variety of services in several areas: medical, financial; transportation; legal; respite care; advocacy; case manager; household assistance and personal supports (Lehmann & Roberto, 1993). Financial assistance from government programs, medical services (Lehmann & Roberto, 1993) and day programs (Molaison et al, 1995) are the most used family support services.

Individualized funding approaches have been implemented in some areas of Canada. This program provides direct funding to families to purchase the assistance and supports they feel are most beneficial and will promote continued community living and participation (Federal/Provincial/Territorial Ministers Responsible for Social Services, 2000). Funding families instead of agencies or institutions represents a significant change in program delivery and promotes the autonomy of individuals with disabilities and their families (Salvatori et al., 1998). Janicki (1999) asserts that even though most adults with intellectual disabilities live in the community, the majority of funding goes to institutional care in the United States. A recent study shows the benefits of individualized funding approaches include greater satisfaction with services, fewer unmet service needs, more positive appraisals of their competency as caregivers and a lower incidence of the desire for residential placements in the near future (Heller, Miller et al., 1999).

10.1 Service Use and Satisfaction

Overall service use, needs and unmet service needs of parents of adult sons/daughters with lifelong disabilities are low, although knowledge of available services is high (Smith, 1997). Older mothers are the least likely to use formal services (Fullmer, Smith and Tobin, 1997; Smith, 1997).

There are several possible explanations for the low rate of utilization of formal services, especially among older mothers. Findings suggest mothers do not feel a need for services when they perceive they can meet caregiving demands, and therefore do not use them (Engelhardt, Brubaker & Lutzer, 1988; Smith, 1997). Older parents may be less able to use services because increasing frailty makes access difficult (Smith et al, 1995b). Lehmann and Roberto (1993) propose that parents may choose not to use the available formal services because they do not meet their needs, or because they believe that formal services should be used only in crisis situations, when all other avenues are exhausted.

Parents may believe that any service use will lead to the institutionalization of their offspring, a fear spawned during the period in which institutional care was the only service offered (Smith et al., 1995a). Earlier unpleasant or frustrating experiences as well as ageism in the formal service sector may also inhibit service use (Smith et al., 1995b). The dearth of services available to parents when their child was born resulted in parents adapting and coping without formal supports and having done so most of their lives, they may not see any need to use services in their later years (Fullmer, Smith et al., 1997; Smith, 1997). As well, Smith points to his finding that poorer maternal health is related to lower service use and suggests because of their age, these older mothers may have poorer health and therefore use fewer services.

Those who use services report overall satisfaction (Freedman, Griffiths, Krauss & Seltzer, 1999; Gammon, 2000; Molaison et al, 1995). Molaison et al. (1995), in a study of mothers of adults offspring with intellectual disabilities, found half of the participants

rated the process of obtaining access to the services as not complicated (50%). The remainder rated the complexity of gaining service access as moderate to high, residential service use being rated as the most complex. The most often cited satisfactions with services were that they provided activities for the adult offspring with disabilities (33%) and the sensitivity and caring attitudes of staff (29%). The most frequent complaint was excessive staff turnover.   Anecdotal information from focus group sessions with aging parents of adult offspring with lifelong disabilities echo this later finding (MacLellan & Cosway, 1997).

10.2 Predictors of Service Use and Needs

Gender is an important predictor of service use, with mothers more apt to use day programs for their sons than daughters (Fullmer, Tobin & Smith, 1997). Mothers with lower incomes and younger daughters, who provided a high level of direct care and reported a high level subjective burden and poorer health, had the greatest service use (Smith, 1997). A different set of factors predict unmet service needs. Married mothers who receive little assistance from offspring without intellectual disabilities and who reported higher levels of subjective burden have more unmet service needs (Smith, 1997).   Smith is unable to explain the impact of marital status, but rules out concomitant spousal caregiving responsibilities, and suggests future research should include both parents.

Fullmer, Tobin et al. (1997) contend older mothers and their daughters with lifelong disabilities are a subgroup who are the most in need of services and the least likely to receive them. Older mothers are more likely to be frail and less likely to use services, but are more likely to need them.

Engelhardt et al.(1988) found neither age, income, health or severity of intellectual disability to be related to service use. In their study of 388 caregivers (87% parents) they conclude caregivers' assessments of their ability to provide care was the only factor related to service use. Smith's (1997) findings support those of Engelhardt et al. Engelhardt et al. further reported that parents who currently feel unable to meet caregiving demands anticipated greater inability in the future.

10.3 Service Needs

There are several areas of unmet service needs that have been identified by parents of adult offspring with lifelong disabilities. Services that provide information on issues surrounding permanency planning (Heller & Factor, 1991; MacLellan & Cosway, 1997; Smith, 1995; Smith et al., 2000); case management (Smith, 1997); respite (Freedman et al., 1999; Grant & McGrath, 1990); and advocacy (Kelly & Kropf, 1995; MacLellan & Cosway, 1997) are the most commonly identified.

 In addition to the previously noted concerns, parents in rural areas noted the

need for leisure activity programs and transportation (Gammon, 2000). Gammon (2000) suggests that families living in rural areas have limited access to services for adults with intellectual disabilities and contends that issues surrounding service delivery cannot be separated from larger social issues such as rural poverty, declining local economies and limited job opportunities, all of which merge to create a complex set of issues for the health and social service delivery systems.

Parents of adult offspring with mental illness also identified the need for information on permanency planning (Kaufman, 1998; Smith et al., 2000) and advocacy. Additionally, they indicate earlier intervention by professionals when the adult offspring is experiencing a psychiatric episode; supervised accommodations for offspring with more disruptive behaviours; more rehabilitation services and more information on mental illness (Winefield & Harvey, 1994) as being pressing unmet needs.

Salvatori et al. (1998) in a review of the Canadian literature on aging with intellectual disabilities, conclude the needs of older adults with intellectual disabilities are not being met within the intellectual disability delivery system, and older adults with disabilities do not have access to programs typically available to seniors such as residential or support services. They argue that despite government edicts on inclusion and integration, most programs for older adults with intellectual disabilities and their families originate from agencies in the intellectual disabilities field.

11 PREPAREDNESS OF SYSTEM TO RESPOND TO CHANGING NEEDS

Historically the service delivery systems for intellectual disabilities and aging were separate, as there was little need for services for adults with intellectual disabilities because of the shortened lifespan of this group. Now, an increase in longevity in tandem with the aging trend of the North American population is creating a stronger demand for services for adults with life-long disabilities and their parents. As well, government directives on integration and inclusion may require agencies to expand their services to include clients with disabilities (Sparks, Temple, Springer & Stoddart, 2000). However, estimates of the number of adults with intellectual disabilities over age 60 vary from 17,000 to 45,000 (Salvatori et al., 1998) and the lack of accurate information regarding the number of potential clients hampers policy planning and service provision (McCallion & Janicki, 1997).

Sparks et al. (2000) argue that adults with intellectual disabilities who live to old age are similar to the general population of seniors with respect to cognitive functioning and overall health status, as more severely impaired individuals generally have a shorter life span. Therefore, Sparks et al. suggest the integration of adults with intellectual disabilities into the general population of adults who are elderly, noting that many services that will be required by aging adults with intellectual disabilities already exist for seniors, such as long-term facilities and recreational programs. Janicki (1999)

argues there are financial and quality of service benefits in agencies cooperating to meet the emerging needs of families, noting it is less costly and disruptive to work with families before they are in a crisis situation

However, in order to merge the systems, personnel need to be cross-trained in issues related to both fields. Sparks et al. (2000) surveyed agencies in the Toronto area serving aging adults with and without intellectual disabilities and found 80% of staff expected to work with older adults with intellectual disabilities in the future, but only 46% felt their services were adequate to meet the needs of these clients. Sixty-one percent felt they were not adequately trained to deal with issues surrounding aging and intellectual disabilities. Respondents indicated additional training was required in such areas as general aging; dementia care; intellectual disabilities; bereavement; medication and health issues; case management; recreation and retirement. Seventy-two percent of service providers indicated the need for changes in individual and family programs to accommodate aging clients, and almost half noted the lack of medical specialists able to serve adults with intellectual disabilities. Gibson (1991) suggests service providers' reports of training needs are particularly germane as personnel are more likely to engage in training if they perceive it as being directly related to their immediate concerns.

In addition to the shortage of cross-trained personnel, several other impediments to intersystem cooperation have been identified, including: absence of clear goals, vision and policies; the involvement of various funding bodies with different funding formulas and eligibilities operating within a climate of fiscal restraint; unfamiliar terminology, philosophy and priorities; no articulation of benefits from intersystem cooperation; and lack of an impartial broker (Ansello, 1992).

Ansello (1992) and Sparks et al. (2000) both point to the potential involvement of university and community colleges in the integration of the two service delivery systems. Ansello suggests an impartial broker, such as a university, can facilitate the meeting of the two systems to consider common needs, goals, and resources. Sparks et al. suggest universities and colleges can assist by including issues pertinent to adults with intellectual disabilities in their curriculum in social work and human services/community services workers programs.

This century will see a greater number of adults with intellectual disabilities live into old age than ever before, and this growing group will place new demands on the formal service system (Janicki, 1999). Yet there has been little attention directed toward assessing the specific needs of adults with disabilities and their families or developing strategies to meet these needs (Salvatori et al., 1998). Although each individual has unique requirements, most will need some level of health, social, psychological and support services (Janicki et al., 1985).

Adults with disabilities who currently reside with their aging parents may require residential placements at some point in the future. This raises questions regarding the nature and availability of housing options. Following deinstitutionalization several models for providing community-based residential services were developed, such as group homes or supported independent living, but there is little agreement as to what

type of living arrangements are most appropriate for older adults with disabilities (Salvatori et al., 1998). Janicki (1999) argues that residential options must consider the issue of aging in place, referring to the ability of the residential environment to accommodate age related changes in adults with disabilities.

A related concern is the availability of residential placements. Current lengthy waiting lists for out-of-home placements for adults with disabilities (Livingstone & Tinsdale, 2000) suggest that the formal service sector will not be prepared to service the increasing numbers of clients who may require residential placements when their aging parents must relinquish their caregiving role. As well, a question that emerges is whether there will be enough support staff to provide the care that is currently provided by families.

Salvatori et al. (1998) report a paucity of services to support employment, retirement and leisure activities for older adults with disabilities in Canada. With the increasing numbers of people approaching old age, retirement and leisure activities are becoming pressing issues. For adults with disabilities who participate in the labour force, retirement may result in the loss of income and friendships as well as lead to a loss of leisure and recreation activities (Mahon & Goatcher, 1999). Mahon and Goatcher, who prefer the term *later-life planning* as opposed to *retirement planning*, found that a later-life planning program for older adults with intellectual disabilities is an effective method of addressing the later-life needs of this group and can positively contribute to their quality of life.

12 FUTURE POLICY, PROGRAM AND RESEARCH DIRECTIONS
13

13.1   Implications for Services, Programs and Policies

In the mid 1980s researchers began investigating in earnest the experiences of older parents caring for their adult sons/daughters with disabilities (Roberto, 1993b). This group of caregivers had previously been invisible for the most part. One reason for this invisibility is the reticence of this group of caregivers to use formal services. Age appears to be a factor in low service use (Fullmer, Smith et al., 1997) and a significant number of older parents caring for adult sons/daughters with disabilities use few if any services (Heller & Factor, 1993b; Hayden & Heller, 1997; Smith et al.,1995a).

Smith et al. (1995b) argue that neither the aging or intellectual disability service systems have been responsive to the needs of older parents caring for adult offspring with disabilities. In the two decades following deinstitutionalization, community-based services to address the residential, social, recreational and vocational needs of adults with intellectual disabilities have been developed based on the tenets of inclusion and integration. Additionally, family supports such as respite care and special services to

allow individuals with disabilities to live in their family home have expanded (Salvatori et al., 1998). Yet there are too few resources to meet needs; restrictive criteria in terms of age, type and level of disability that affect eligibility; and a lack of adequate funding, all of which have left gaps in the existing services (Livingstone and Tinsdale, 2000). Residential options are especially problematic, with lengthy waiting lists across Canada (Livingstone & Tinsdale, 2000).

The primary foci of services in the intellectual disability sector have been the needs of individuals, not families; younger individuals; and vocational rehabilitation training (McCallion & Tobin, 1995) . Salvatori et al. (1998) note the deinstitutionalization movement of the 1970s and 1980s in Ontario targeted young adults with disabilities while those over age 55 were specifically excluded. Few efforts have been made to identify the needs of older adults with intellectual disabilities and their families and to tailor services to meet these needs (Ansello, 1992; Salvatori et al.,1998). This gap is particularly problematic in light of the aging trend of the population in North America. The leading edge of the largest segment of the population will be reaching their sixth decade in the next six years (Foot, 1996), and of this group a portion will require both the services of the aging and intellectual disability networks. Early indications suggest that the social service sector will not be able to adequately respond (Salvatori et al., 1998).

Impediments to service use may exist at several levels. The relationships between parent caregivers and professionals are often characterized as strained or mistrustful. Older parents may resist involvement in the formal service system for their adult offspring because they perceive fewer needs or fear involvement with the system may result in their offspring's removal from the home (Smith et al., 1995a). Logistical considerations such as transportation and building accessibility may prove to be obstacles to older parents with limited mobility or physical and cognitive impairments (Fullmer, Smith et al., 1996). On a broader scale, attitudes such as ageism, which exists among service providers, may hinder parents involvement in the formal support sector (Smith et al.,1995b).

Smith et al. (1995b) further argue that in order for the service sector to become more meaningful and responsive to older families, policies, not just service delivery, must change. They suggest the adoption of the *family as client* focus as opposed to the *individual as client* focus. Families generally have been viewed as resources for the client, not as clients with needs of their own. As families are the primary purveyor of care and support for individuals with disabilities, it is imperative that they are supported in their role (Heller & Factor,1993b; Heller, Miller et al., 1999).

Support programs should be designed to strengthen caregivers' capabilities and improve the quality of the parent-offspring relationship by helping parents identify the gratifications they reap from caregiving and acknowledge the assistance offspring provide to their families (Pickett et al.,1997). Support programs should also enhance informal supports, which appear to be particularly important in reducing caregiver burden (Heller & Factor, 1993a). Siblings are an important support for both their parents and their brothers/sisters with disabilities. Their involvement with the adult with

disabilities will likely continue throughout their lives, and therefore they should be included in the development of current and future service plans (Seltzer, Greenberg, Krauss, Gordon et al., 1997).

Service providers should assist caregivers to define their needs (Hayden & Goldman, 1996) and find resources to address these needs. Hayden and Heller (1997) urge service providers to adapt services to fit families' needs instead of adapting families to fit the services. Recognizing that needs change across the life course, service providers can assist families in assessing their needs and accessing resources to meet these needs at various points in their lives. Additionally, outreach programs should be created to locate families who are under-utilizing or not receiving services (McCallion & Tobin, 1995; Smith et al., 1995b), although finding these families may prove a difficult task.

The lack of cooperation between service delivery systems is an obstacle to service delivery for older families with a member with disabilities (Smith et al., 1994). Salvatori et al. (1998) call for the collaboration of the fields of gerontology, rehabilitation and intellectual disabilities to develop an interdisciplinary approach to meet the needs of aging adults with disabilities and their families.

The paucity of cross-trained personnel is an impediment to this process that must be addressed (Ansello, 1992). Service providers in the Metropolitan Toronto area report significant gaps in required services, such as medical specialists. It is likely that such needs exist in other less cosmopolitan areas in Canada as well.

An issue related to low rate of service use is the significant number of parents who have not created permanency plans to ensure the care of their offspring when they are no longer able. This is a critical concern for several reasons. Providing for the future care of their offspring with disabilities is one of the most pervasive worries of older parents (Brubaker & Brubaker, 1993). Residential options are few and waiting lists are long. Planning for the transfer of care can alleviate strains on the system by avoiding an onslaught of emergency placements upon the death of older parents (Smith & Tobin, 1993). Such emergency placements may be disruptive and traumatic for the individual, inadequate to serve their needs and may have serious negative consequences for future residential relocations (Kaufman, 1998).

The greatest but least met need of older parents is in the area of permanency planning (Heller & Factor, 1991). Smith et al. (2000) note that although the majority of older mothers express the need for services to help them in permanency planning, and even though such services are available, actual use is low. However, service use facilitates permanency planning by reducing parents' apprehension about the service system (Smith et al., 1994) and higher stages of permanency planning are associated with greater use of services for adult offspring with disabilities (Smith et al.,1995a).

A critical task for service providers is to address this double bind situation - older parents perceive a need for services to assist them with permanency planning and service utilization facilitates permanency planning, yet older parents are less likely to use these services. Outreach efforts to increase overall service use by this group of caregivers may partially address this concern. Another option may be to disseminate

permanency planning information through informal workshops for parents or through educational packages and self-help books that address the issue. Parents who avoid service utilization because of negative perceptions of the formal service system may view these resources in a more favourable light.

Support groups for older parents caring for adult offspring with disabilities may serve as a bridge between the two service systems and can address concerns about parents' plans for future care of their adult offspring with disabilities (Mengel, Marcus & Dunkle, 1996). This avenue may reach some of those parents who do not use any formal services, as some research suggests parents of offspring with mental illness who use support groups reported lower service use than those who do not (Cook & Heller, 1999).

13.2 Heterogeneity of the Caregiving Experience

There is great variability in the subjective experiences of parents caring for adult offspring with disabilities. Studies that compare the experiences of parents caring for adults sons/daughters with disabilities and parents caring for adult sons/daughters with mental illness underscore the heterogeneity of the caregiving experience and the importance of the caregiving context in understanding different groups of caregivers (Seltzer et al.,1995). This is also the case for the sibling experience (G. Seltzer, Begun et al., 1991; Seltzer, Greenberg, Krauss, Gordon et al., 1997).

Findings that suggest resources have differential effects on caregiver well-being depending upon the caregiving context highlight the need to look past the commonalities and address the important differences in caregivers' experiences (Greenberg, Seltzer, Krauss et al., 1997). Greenberg, Seltzer, Krauss et al. (1997) assert that in a period characterized by the development of generic services as opposed to specialized services, the temptation is to search for the similarities and downplay the differences. However, the diversity of experiences of parents caring for adult offspring with disabilities speaks to the necessity of providing a variety of services in order to address needs.

13.3 Families, Policies and Empowerment

Time marches on and this current cohort of older parents caring for their adult offspring with disabilities is a time-limited concern (Ansello & Roberto, 1993). The next cohort will have a different set of experiences, issues and needs, having grown up in a different historical, political and social context. Older families have had few services at their disposal and it is unlikely these families had access to special educational services, formal respite care, community-based services or residential options when their offspring were young. Segregation, not inclusion, was the philosophy during their offsprings' youth. Their circumstances are unique. Their needs differ from those of younger families (Heller, 1993) and must be addressed, as demographics dictate an increase in their numbers in the coming years.

Ansello and Roberto (1993) urge policy makers to develop initiatives that will support both the current and next cohort of caregivers for adult offspring with disabilities

by devising policies that solicit and incorporate the input of family caregivers, service providers and persons with disabilities in determining, managing and assessing a variety of services, thereby strengthening the infrastructure of support. Individualized funding approaches which provide direct funding to families and individuals to purchase the services or supports they require are one such initiative. Additionally, they urge the creation of initiatives to strengthen the formal support system and advocate for the need to develop autonomy in both parents and offspring with disabilities.

Policies should encourage inter-departmental and inter-ministerial collaboration to address the disjointed service delivery, reduce service duplication and ensure services meet needs (Salvatori et al., 1998). The Federal/Provincial/Territorial Ministers Responsible for Social Services are working toward that goal through their *In Unison* initiative to address disability issues in Canada. Finally, policies must balance the needs of both younger and older parents with offspring with disabilities, and ensure fair distribution of services and funding for all parents and their offspring with disabilities (Seltzer & Krauss, 1994).

Ansello and Roberto (1993) assert in order for caregivers to become empowered "research must inform policy, which, in turn, must influence and be influenced by good practice. The practice of caregiving itself, whether by family members or by regulated outside personnel, must benefit from ongoing research. Only from such a continuous interactive loop (research to policy to practice to research) will effective empowerment truly occur." (p.173).

13.4 Research Agenda

The proceeding literature review reveals several areas of concern that would benefit from further study. The first is the under-utilization of services by older parents and what future services this group of caregivers may require. Studies on the systemic and cultural barriers to service use should be accompanied by investigations of what services are currently available and how they are used and strategies for matching interventions with perceived needs (Lefley, 1997). As the population ages the number of potential clients increases. Family support programs will become increasingly important to assist parents in caring for their offspring in the home and avoid residential placements which may overwhelm the service delivery system. The current lengthy waiting lists for residential placements punctuates the importance of studying the effectiveness of family support programs (Heller & Factor, 1994).

A second concern is the lack of permanency planning by many older parents. Research should also address the barriers to permanency planning among parents caring for adult offspring with disabilities, as well as the impact of planning on parental well-being and family functioning (Seltzer and Krauss, 1994). Studies are needed to determine the effectiveness of services that facilitate permanency planning, such as support groups, counselling, or offering information and education (Wood, 1993). Future investigations that focus on identifying factors related to the successful transition

of adults with disabilities away from their families and into residential placements are also needed (Lehmann & Roberto, 1993).

Little is known about family caregiving over the life course, such as how parents adapt to extended caregiving to offspring with disabilities and how needs change across the life course. In order to devise effective interventions, these questions must be answered (Seltzer & Krauss, 1994).

Given the aging of the population, research must address the intersection between aging and disability and the implications for policies, service delivery and cross-training needs of service providers (Salvatori et al., 1998). As well, little research exists on the intersection of family, aging and disabilities. Families are the most prevalent and enduring source of care and support for people with disabilities (Janicki, 1999) and should be supported in this role by research that informs policies and services.

Issues such as the generalist versus the specialist approach to service provision need examination (Janicki, 1994). The research agenda should be broadened beyond concerns of younger persons with disabilities to include issues that are pertinent to older persons with disabilities and their families such as work, retirement (Verdugo, 2000) leisure and recreational activities (Mahon & Goatcher, 1999).

The majority of research on older parents caring for adult offspring with disabilities adopts a micro level perspective. Future research should examine the ways that broad social relationships such as ideologies of gender, aging, ability and familialism are present in the everyday life of older parents caring for adult sons/daughters with disabilities. This will provide an entry point to considering how to modify and adapt structural processes at the macro level to meet the needs of this unique group of caregivers.

The life-course perspective, which links micro and macro levels in theory and research methods, can make unique contributions to the knowledge base regarding contextual influences such as the impact of race, gender and class on life and caregiving experiences (Allen et al., 2000). The "long lens" (p. 218) of the life-course perspective allows for a broader consideration of the experiences of aging parents caring for adult sons/daughters with disabilities, and Krauss and Seltzer (1994) argue, offers a salient perspective from which to conduct future research.

14 CONCLUSION

Despite a propensity of researchers to focus on the deleterious outcomes experienced by aging parents caring for adult offspring with disability, the picture that emerges from research is one of both challenges and gratifications. The caregiving experience for these parents is characterized by reciprocity, affection and gratification. While the reciprocity in the relationship is typically not quid pro quo, parents report significant benefits as well as stresses. Overall there is a pattern of stability in their

caregiving experience, even though some parents have been providing care for several decades, and will continue to do so until they are no longer able. However, the caregiving role is not experienced uniformly. While some perceive the role to be gratifying, others feel more burdened than satisfied by the challenges caregiving presents. Perceptions of the caregiving role change over the life course. It appears aging brings unique, but not necessarily overwhelming, challenges to the caregiving role.

Older parents who care for their adult sons/daughters with disabilities are the unrecognized and undervalued linchpin of community-based care in Canada. As such they must be supported in their role by policies, programs and services that respond to their particular needs. The number of aging parents caring for adult offspring with disabilities continues to grow and reality dictates that eventually they will have to relinquish this role and the care for their offspring may fall on other family members and the service delivery system. It essential that policy makers, funding bodies and service providers be prepared to respond to the emerging needs of these families.

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Older Parents Caring for Adult Sons/Daughters with Lifelong Disabilities:

A Literature Review

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