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STRESS AND SOCIAL SUPPORT OF PARENTS WITH AN ADULT MENTALLY RETARDED CHILD

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Dedication

This dissertation is dedicated to the memory of my mother, who displayed a tremendous degree of patience and love in her role as a parent:

Eunice I. Kropf, 1920 - 1985

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Abstract

STRESS AND SOCIAL SUPPORT OF PARENTS WITH AN ADULT MENTALLY RETARDED CHILD.

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Parent-child caregiving is the most basic caregiving situation. However, parents who continue to provide care to an adult mentally retarded child have been an unexamined group of caregivers. This study compared stress levels and social support constellations among these caregivers and two other groups of parents.

The study tested two major hypotheses. Parents who were caregivers for an adult child with mental retardation were predicted to report higher stress levels and smaller social support constellations than the other groups. Two comparison groups were included in the study. One group was parents of an mentally retarded child who did not live in their household. The second comparison group contained parents who had caregiving responsibilities for non-disabled children.

Data were collected in two ways. The three groups of parents (*N* =210) responded to a survey which contained characteristics about themselves and their household, stress and their social supports. Additionally, five caregivers of a mentally retarded adult child were interviewed in the family home.

Partial support was found for both the stress and social support hypotheses. Parents who were caregivers for an adult mentally retarded child reported a number of health symptoms and depressed mood items. These caregivers also reported having the fewest number of personal hours per week. Although all three groups of parents reported equal numbers of social supports, differences were found in the roles of the members of the support system and the type of exchanges in the support systems of the three groups. Implications of the research for social work practice, policy and education are presented. Suggestions about additional research on parents of mentally retarded adults are offered.

CHAPTER 1

Summary of Caregiving Issues

Parent-child Caregiving

Parent-child caregiving is the most basic caregiving situation. The majority of the population has one or more children (Bureau of Statistics, 1987). Parenthood is perceived as a happy and fulfilling event. However, recent studies on parenting reveal that the parenting role is accompanied by increased stress levels and role strain, reports of lowered marital satisfaction and personal happiness (Barnett & Baruch, 1985; Glenn & McLanahan, 1982; Glenn & Weaver, 1979; Steffensmeier, 1982).

Caregiving for a Child with Mental Retardation

While parenting a child is stressful, caring for a child with a disability increases the difficulty of the parental role. The mental retardation of a child is a disabling condition many parents face. The rate of retardation in this country is 3% of the general population (Grossman, 1983) which translates into six million mentally retarded people in the United States (Walz, Harper & Wilson, 1986). A diagnosis of retardation alters how parents perceive their caregiving role and the progress for a child. These changes are frequently associated with losses for the parents (Schild, 1982). Parents feel this stress and loss within recurring situations across the lifespan of their child (Wikler, 1981).

Changes in Caregiving

Two major changes have altered the caregiving situation with a mentally retarded child. One is the overall shift in the philosophy underlying services to mentally retarded people. Historically, parents had two choices for a retarded child, either institutional or home care. Families choosing to keep a child at home had few formal supports available to assist with care. Within the last twenty five years, community-based services have emerged for mentally retarded people, allowing families to keep a child in the home while receiving educational, habilitative and vocational support (Rowitz, 1987). Normalization, recently re-named social role valorization, is the dominant philosophy in providing services to people with disabling conditions (Wolfensberger, 1985). This philosophy emphasizes that less valued groups of society, such as mentally retarded people, need to have equivalent life conditions, choices, and experiences as the more valued social groups. Mentally retarded people are no longer hidden in institutions or family homes but are visible and productive members of their communities.

A second change in caregiving is the length of time a mentally retarded child will require care. Increases in longevity have extended the life of both the general and mentally retarded populations. The average life expectancy for a child born in 1920 was 54.1 years whereas a child born in 1985 could expect to live 74.7 years (Bureau of Statistics, 1987). Life expectancy rates for mentally retarded people parallel the general population, resulting in longer lifespans for people with mental retardation (Lubin & Kiely, 1985). Sophisticated medical and prevention strategies have dramatically increased life expectancies of individuals with certain categories of retardation. A child with Down Syndrome, the most prevalent category of genetic retardation, previously was not expected to live past adolescence (Lubin & Kiely, 1985). Today, these children who survive the first ten years of life can expect to live to age sixty five with an average life expectancy of thirty five years (Gold, Dobrof & Torian, 1987; Thase, 1982).

These trends have important implications for parents. Greater options are available for mentally retarded children which increase parental choices and value decisions (Schild, 1982). Due to the extended lifespans, many parents will continue to provide care for a child into adulthood. Studies have documented a parent caring for "a child" both of whom are in advanced years. Examples of seventy and eighty year old parents caring for fifty year old mentally retarded sons or daughters are not uncommon within the literature (Anglin, 1981; Gold et al., 1987). These situations are examples of an older person, facing possible limitations in health, energy or financial resources caregiving for a son or daughter who is simultaneously facing age related changes.

An important consideration within this caregiving situation is the changes accompanying the aging process of both parent and adult child. Correlates of normal aging include an increase in chronic conditions, sensory motor declines, and decreased reaction time (Zarit, 1980). While changes associated with the aging process do not necessarily imply functional impairments, the presence of these conditions may decrease an individual's ability to perform daily living skills. When a parent of a mentally retarded adult experiences these changes, caring for self and a dependent may be too demanding.

Less information is known about the aging changes within the mentally retarded population than the general population. Studies about aging changes within the mentally retarded elderly frequently employ institutionalized samples without controlling for the effects of institutional environments (DiGiovanni, 1978). Besides generalizing from biased samples, estimating aging changes is problematic due to a lack of consensus about who is an "aging" mentally retarded person (Seltzer & Krauss, 1987). Studies have used various definitions of aging with minimum ages ranging from thirty to fifty five years (Jacobson, Sutton & Janicki, 1985).

Although there is variation in the exact definition of aging in mental retardation literature, a general consensus is that the process begins at an earlier time than in the non-handicapped population. Socio-cultural factors influencing early onset aging include poor nutritional status, unhealthy or sedentary lifestyles, and inaccessibility to quality health care services (Delehanty, 1985; Huber, 1985). Physiological impairments such as genetic factors or brain trauma also hasten age associated changes. Conditions found in the general population may begin at an earlier age in mentally retarded people. Down Syndrome individuals, for example, are a high-risk group for early onset Alzheimer's Disease with a high incidence found within the thirty to forty year old group (Thase, 1982; Wisniewski & Merz, 1985).

The aging changes of both parent and adult child have important implications for continued parenting of a person with mental retardation. Age related changes and declines affecting both the parents and child may produce simultaneous limitations in functioning. A son or daughter may require additional assistance at a time when a parent is less able to provide it. Decisions over residential care for an adult child, for example, can elicit fears of nursing home placement in the parents. The interaction of aging in an adult child and parent may be greater than the separate aging effects of the individuals.

Aging and Caregiving

Parents of mentally retarded adults are in their middle or later years of the lifespan. Mid-life caregiving has received the most attention in the gerontology literature when an adult child provides care to a parent. Besides spouses, daughters or daughter-in-laws are the most frequent caregivers of an impaired family member (Day, 1985; Shanas, 1979). Since the prevalence of this caregiving situation is increasing, mid-life caregiving of a family member is described as a normative, albeit stressful event (Brody, 1985). Studies of mid-life caregivers report high levels of physical, emotional and financial strains associated with caregiving roles (Cantor, 1983; Zimmer & Mellor, 1982). These "women in the middle" are involved in multiple and competing tasks which produce a high level of role strain (Brody, 1981). Competing demands such as child-rearing, employment and parental care leave these caregivers with little time and energy.

Clinicians and researchers have noted the importance of family care in supporting older members to prevent or delay institutionalization. Over 80% of all long term care services to people over sixty are provided by the family (Hooyman, 1983). A study comparing nursing home and community samples found the greatest difference between these two groups was social support, not health, variables (Silverstone & Burach-Weiss, 1982). Clinicians and service providers have started to include the family in interventions with older clients. The goals involve assisting family and other informal caregivers by providing support and education to diminish stress associated with the role.

Need for Research

Little information is known about the parents who are caregivers for a mentally retarded adult. This situation of perpetual parenthood (Jennings, 1987) has a double source of role strain occurring from both the specific tasks and the extended time of parenting. Older parents have recently been included in studies, most frequently with the intent of locating substitute caregivers (Dobrof, 1985). The support systems of these parents have only been addressed in a cursory way. Studies have not evaluated the supports available to assist parents with their own aging needs. This fact is unfortunate since these parents have dealt with the tasks of caregiving for numerous years, decreasing their opportunity to establish support networks (Jennings, 1987).

The supports available to these parents is a significant issue for the social work profession. Due to changes in mental retardation services and longer lifespans, greater numbers of parents will continue to be caregivers into their own old age. The importance of social support is well documented within the gerontology literature (Cantor, 1985; Shanas, 1979; Zimmer & Mellor, 1982) yet little is known about the supports of people who have continued within a parenting role. The needs of older parents include more than just services for their mentally retarded son or daughter.

In an effort to better understand the caregiving situation for adult mentally retarded children, the literature was reviewed. This review included both theoretical and empirical literature on stress and social support. The next chapter provides a review of the relevant literature.

CHAPTER 2

Summary of Relevant Literature

Caregiving involves at least two people, one of whom is dependent upon the other for some assistance. The care of a child is usually a temporary situation since children acquire skills which lead to autonomy and independence. Parents of the mentally retarded do not fully relinquish their caregiver status since many of these children will require supervision all their lives.

The literature review for this study focused on the parenting role for an adult mentally retarded child. The review includes role theory since parenting a retarded child is an ambiguous role which exceeds the usual time period of caregiving. Family systems theory was reviewed since the parent role is enacted within the family arena. Literature on social support was also reviewed, specifically the exchanges between people and members of their support system. Subsequent sections of the review investigated three ambiguous caregiving roles: adult child caring for a parent, parent caring for a handicapped child and parents caring for a mentally retarded adult. The following sections summarize the literature in these areas.

Role Theory

Role theory was chosen initially to offer explanatory and predictive power for a caregiving situation. Parents perform tasks associated with their role as caregiver of their child. The responsibilities associated with caregiving for a child govern certain behaviors of the parents. Concepts from role theory which have relevance to caregiving situations are outlined within the following sections.

The domain of role theory is the behaviors which characterize people occupying certain positions in society. Role theory started to gain interest within the 1920s and 30s (Biddle & Thomas, 1966). Internationally, this era was a time of expansive social and political change. Historical events such as World War I and the Great Depression had a tremendous impact upon individuals and family systems. As more men became soldiers, for example, women's roles changed to include those previously filled by men within the labor force and the home. In addition to changing gender roles, increased industrialization changed immigration and migration patterns as different ethnic and racial groups began working in urban factories. The poor economy of the early 1930s forced many middle income families into poverty. The events of this period had a marked effect upon social roles. These changes precipitated problems in functioning for many individuals (Garton &

Otto, 1964).

As a profession, social work is concerned with both individual and social dimensions of problematic conditions. Role theory has been incorporated into social work practice to assist in clarifying clients' needs. Perlman (1968) states that social work clients seek help from an agency because of difficulties in performing their social roles. An approach to problems considering only psychological aspects neglects situational demands which can cause discomfort and pain for clients. Role theory helps bring into context the situational aspects of client problems.

While role theory is applicable to many different systems, there is little consensus about what specifically constitutes a role (Biddle, 1979). Roles have been defined as identities which include a set of expectations. These expectations correspond to behaviors performed by actors within the role (Biddle, 1979; Biddle and Thomas, 1966; Perlman, 1968). Actors occupying similar role positions demonstrate common behaviors when performing their roles. The expectations corresponding to a role govern the behaviors actors choose to satisfactorily complete the role performance.

The degree of expectation around the various behaviors associated with a role is the degree of consensus. Roles with high consensus are normative and those with a low degree are ambiguous roles (Biddle, 1979). Ambiguous roles are problematic for actors because the larger social system does not recognize or define the necessary behaviors to complete the role (Perlman, 1968). Actors have little guidance, support and information about performing ambiguous roles in a satisfactory way (Ursprung, 1986).

Roles are performed in conjunction with other role actors. The actors with whom one comes in contact fill counterpositions (Biddle & Thomas, 1966). The role of parent, for example, implies a counterposition of child. The sum of other actors with whom one interacts is a role set. A role set has been defined as the actors with whom a given actor will interact while performing a role (Gross, Mason & MacEachron, 1958). Some interactions have positive outcomes for the actors and provide a source of support.

From a social work practice perspective, social workers see clients who experience difficulty in interacting with others in their role set. Ambiguous roles are problematic since expectations are unclear about how to perform in a role (Perlman, 1968). Actors in ambiguous roles are unsure how to interact with actors filling counterpositions.

A second problem frequently presented by social work clients is an uneven fit between a role actor's resources and the demands of a role (Perlman, 1968; Rapaport & Rosow, 1966). When role demands exceed resources, the consequence is strain (Biddle & Thomas, 1966; Biddle, 1979). The feelings that accompany role strain are incompetence, embarrassment, or shame (Biddle, 1979). These negative perceptions of self can generalize to other roles. The feelings of inadequacy are a common problem presented by social work clients. For example, the parent who feels incompetent as a caregiver may begin to question competence in other roles such as worker and spouse. Social work practitioners work with clients who feel inadequate in multiple roles even though strain is associated with a single role. The source of role strain and the resources needed to augment role performance are critical components of effective interventions with social work clients.

In summary, role theory offers useful concepts with relevance for caregivers of a mentally retarded adult. This caregiving role is ambiguous since few expections exist about associated tasks for performance. Parents in this caregiving role experience role strain with the common consequence of self-perceived inadequacy. Social work practitioners frequently encounter clients who are experiencing difficulties in performing roles. Assessing role demands and environmental fit are necessary components of effective social work practice.

Family Systems Theory

The role investigated in this research is the parenting role which occurs in the context of a family unit. Numerous counterpositions exist, such as spouse or grandparent. Since the parent role is enacted within a family context, the literature of family systems theory was reviewed.

Family theory combines numerous theoretical perspectives and disciplines. Various classification schemes have been used to determine similarities and differences between different models of family functioning. Laird and Allen (1982) report that family theories contain the common concerns of communication, rules, organization and structure, differentiation and growth, transaction with environment, and behavioral and social learning processes of families. While models of family may look different from one another, the real difference is in the priority a theorist gives to certain aspects of family functioning.

Current models of family functioning attempt to distinguish those factors which identify families with optimal functioning from those units with lower functioning levels (Green, 1988). In the literature, two major family system models are especially prominent. Both models emphasize the same core constructs of closeness of family relationships, responsiveness of family members to change, and the nature of the family communication process (Green, 1986). The Beavers-Timberlawn Model views family health as equated with competence of the system (Lewis, Beavers, Gossett & Phillips, 1976). Family competence includes five different dimensions: family structure and power, mythology and beliefs, problem-solving ability, autonomy, and family affect and feelings (Green, 1986). This model views family competence on a linear continuum. Families possessing higher degrees of competence in the five dimensions will be assessed as having higher levels of competence.

The Circumplex Model proposed by Olson, Sprenkle and Russell (1979) offers another explanation for family functioning. This model conceptualizes family functioning as having a curvilinear distribution. Optimal functioning is a balance between too little or too much of the dimensions outlined in the model. The first dimension is cohesion or the emotional bonding and closeness of family members. Lower family functioning is associated with over-bonded members (enmeshed) or extremely autonomous members (disengaged). The second major dimension is adaptability which is the family's ability to change in response to situational or developmental issues. Families that resist change are classified as rigid. Families that are constantly changing or responding to change are chaotic (Green, 1986). The Circumplex model predicts that families which function most effectively are those systems which fall between the extremes of both dimensions.

In summary, family systems theory attempts to explain functioning within a family unit. While models vary, commonalities exist between the predominant models. The constructs of communication, relationship, and adaptation to change characterize both the Beavers-Timberlawn (Lewis et al., 1976) and Circumplex (Olson et al., 1979) models.

Social Support Literature

Social support has the effect of buffering or preventing stress experienced by individuals. Interest in social support began in the mid 1970s with the work of two epidemiologists (Cassel, 1976; Cobb, 1976). These early researchers discussed the importance of social supports on the effect of a disease process. These studies move away from a purely medical model of illness and began to address stress levels. The presence or absence of supportive others was studied on outcome health variables. Results of both studies report that people with support systems are better able to handle stress and enhance their capacity to resist negative effects on physical health.

Caplan (1974) emphasized the importance of social supports for individual's mental health. His work discusses the importance of formal service networks interacting with personal support systems. This view includes the use of community, or macro-level supports, to enhance mental health. The mobilization of community and personal support systems can effectively mitigate stressful situations.

The theoretical basis for social support is the exchange which takes place between people and their environment. Bronfenbrenner (1979) proposes an ecological model emphasizing environmental and social influences upon individuals. The ecological model moves away from viewing people as influenced solely by intrapsychic factors to an emphasis on exchanges between individuals and surrounding social systems (Beckett & Coley, 1987; Hartman, 1978). The interactive perspective views behaviors both as influencing and being influenced by other systems and social forces.

Social exchange theory emphasizes interactions between people and their environment. Social exchange theory conceptualizes human behavior as an attempt to maximize the rewards of social interaction and minimize the costs (Blau, 1964; Homans, 1961). Exchanges are expected to continue only as long as actors perceive them as profitable (Dowd, 1975, 1980). Social exchange theory posits that an interdependent relationship exists between people which influences behavioral interactions (Chadwick-Jones, 1976).

Dowd (1975, 1978) discusses the declining status and power within the roles held by older people in our society. This situation creates an imbalance in the exchange relationships. Older people have less access to powerful commodities such as high status, money and valued information. Their ability to maximize profits in relationships is diminished from these environmental and socio-cultural barriers to resources. Beckett & Coley

(1987) emphasize the importance of understanding the environmental barriers and limitations when evaluating the interaction of a person with a larger social system.

Social support provides a link between role theory and social exchange theory. Pearlin (1985) proposes that members of a role set interact and exchange support. However, definitions of social support remain ambiguous since the constructs of social support and social network are frequently interchanged within the literature. Studies which do distinguish between a support and a social network define a social network as a more diffuse construct (Cook, 1987; Schilling, Gilchrist, & Schinke, 1984; Simons & West, 1984-85; Specht, 1986). Social supports are those linkages which include an exchange where the outcome is either a decrease of stress or a global enhancement of well-being.

Social support can be categorized by the type of aid provided by network members. Instrumental support is the provision of material goods or services. The communication of love, esteem, and acceptance is emotional, or expressive support (Sherman, Ward & LaGory, 1988). Informational support provides knowledge, linkage or referral to other sources of social support (Unger & Powell, 1980). Support can be either tangible or intangible (Gottlieb, 1983).

Two variables are important in determining whether an exchange is considered support (Simons & West, 1984-85).

One is the degree of helpfulness, meaning the degree to which an exchange enhances well-being or decreases negative conditions for the recipient. The second variable is the fit between the need for support and the type of support available. Support networks which are too dense or homogeneous may not provide a sufficient range of options to be helpful for a recipient (Schilling, 1987). Network members with similar characteristics and a high degree of interaction reinforce existing patterns of behavior which may not meet certain support needs (Hirsch, 1980).

While a high degree of density and homogeniety in a network can limit the availability of support, some similarity between members is desirable. Age is one variable found to enhance the exchange of support with older people. Age homogeneous networks increase reciprocity between members of similar status. Reciprocity is the degree of symmetry involved in the exchange (Goodman, 1985). Relationships which have a greater degree of reciprocity have a higher satisfaction rates for both members of the exchange (Goodman, 1985). Studies of housing for the elderly reported that degrees of life satisfaction were greater for individuals with a higher ratio of same aged cohorts in support networks. In studies of age segregated living environments, Rosow (1967) and Osgood (1982) found high levels of life satisfaction among people with age peers as network members. For older people, the inclusion of others of a same age cohort in a support network decreases a status imbalance and promotes exchanges with a higher degree of reciprocity.

In summary, social support involves the exchanges between members of a social network. The interactions are perceived as helpful by the recipient of the exchange. Certain network characteristics enhance or inhibit supportive exchanges. Overly dense or homogeneous networks may inhibit support since members offer a limited range of supportive options. Studies of the elderly report that reciprocity enhances the degree of satisfaction with an exchange. Same aged cohorts in a support network increases reciprocity for older people with network members.

Social Work Practice Theory

Many social work theories emphasize the need to assess problematic roles of clients. McBroom (1970) discusses the importance for social work practitioners to assess the consequences of clients' ambiguous social roles. She outlines a typology of troublesome role conditions. One category is an unsocialized role where clients lack socialization into a given role. A second category is an inadequately socialized role where learning has been incomplete. The final category is a specific socialization situation where roles are situational and cannot be generalizied to different environments. Both client and environmental variables contribute to problematic role enactment. Social workers need to include both types of variables in assessments of clients. Specific interventive techniques which assist clients in any of these problems of socialization are knowledge-giving, clarifying, modeling and creating opportunities to increase role competence (McBroom, 1970).

Competence is an important dimension in socialization to a role. Competence has been defined as the "repetoire of skills, knowledge and qualities that enable each person to interact effectively with the environment" (Maluccio, 1979, p. 284). Dimensions of competence include self-confidence in performing role tasks, ability to make decisions, and trust in one's judgment. Competence includes the ability to cope with changes in society rather than dealing with the status quo (McBroom, 1970). Competence behaviors are learned. The role of the social work practitioner is to facilitate tasks which increase clients' level of competence.

Social work practice theory is not solely client-focused. Environmental inputs of problems and needs are included in various theoretical formulations. The ecological approach categorizes problems in living as classified into three types: life transitions which create new demands and self images, environmental demands which drain resources, and relationship stress (Germain & Gitterman, 1980). The goal of ecological social work practice is to intervene in a way to maximize the fit between personal resources and environmental demands.

Social work practice models view the environment as potentially supporting individuals. Seltzer (1985) discusses the composition of social support networks within the older mentally retarded population. Silverstone and Burach-Weiss (1982) report that frail elderly with social supports have lower admission rates in nursing homes than those elderly with no available social supports. For many social work clients, informal helpers are key people in maintaining adequate functioning levels both in situations of acute and chronic stress.

Social workers frequently encounter clients with difficulty in satisfactorily performing roles (McBroom, 1970; Perlman, 1968). Practitioners are responsible for assisting clients in increasing their competence in roles by employing interventions which are both client- and environmentally-focused. The environment can provide support to clients to assist in increasing role competence. Practitioners can employ or create social support structures to assist clients in satisfactorily performing roles.

The following sections report on three caregiving roles. The first is the caregiving for an impaired parent. This role involves caregiving between two adults. The second role involves the parent who cares for a mentally retarded child, which includes caregiving for a child with a disability. The third role consists of the parent who is a caregiver for a mentally retarded adult child. This role combines the situation of adult to adult caregiving and provision of care to a disabled child. The stress of these caregiving situations and the effects of social support will be explored for each of the three roles.

Ambiguous Caregiving Roles

Care of an Impaired Parent

An adult child assuming care for an older parent is an example of an ambiguous caregiving role. A caregiver has been defined as the principle person providing or coordinating resources for caregiving (Zarit, Reever & Bach-Peterson, 1980). Care of a parent is an increasingly common situation since the aging population has grown. The care of an older family member is now being described as a normative family stress (Brody, 1985).

Caregiver Variables

Family care of the elderly is estimated to comprise about 80% of the long term care system in this country (Hooyman, 1983). Although usually designated as family care, the majority of responsibility is assumed by one person, usually a wife, daughter or daughter-in-law (Day, 1985; Ory, 1985; Shanas, 1979; Soldo & Myllyluoma, 1983).

Many of the caregivers hold multiple roles. These women perform tasks of child-rearing, employment and parental care simultaneously. Brody (1981) calls these caregivers the "women in the middle", describing both their age and their role as caregivers for older and younger generations. Even though role possibilities for women have expanded, younger generations continue to express opinions that they should assume responsibility for care when parents age (Brody, Johnsen, Fulcomer & Lang, 1983).

Families expend large amounts of resources in caregiving. In a national study of family support, Shanas (1979) found that 10% of all older people were homebound, indicating that many very frail people remain in the community. That percentage is double the 5% rate usually cited for institutionalized elderly (Beavers & Miller, 1985). A longitudinal study by Johnson and Catalano (1983) found that caregivers did not abandon older members even if they were in very frail health. Since family caregivers provide the majority of long term care to the elderly, the model of care has been described as a hierarchial-compensatory system with children or a spouse as the preferred source of care for an older person (Cantor, 1985). Friends, neighbors and other members of informal networks substitute when families are not available (Cantor, 1979). Formal agencies designed to provide services to the elderly are used when the informal supports of family members are unavailable.

Caregiver Stress

The time, effort and cost of caregiving can be a burden for caregivers. Two types of burden have been identified within the literature. Objective burden is a consequence of the actual tasks or demands of caregiving. Caregiving varies by type of activities performed, length of time in caregiving role, and the functional level of care recipient. Objective burden is a measurement of the type and quantity of caregiving tasks performed. In studying objective burden in caregivers, Clark and Rakowski (1983) found that the most stressful tasks were assisting with adult daily living skills. Helping an older person with feeding, dressing and toileting are examples of tasks which contribute to increased burden for the caregiver. These tasks need to be performed regularly within a short time frame. Caregivers who perform these tasks are required to rearrange personal schedules to provide assistance.

Zarit et al. (1980) measured burden of caregivers, using a twenty one item instrument. In the sample of twenty nine care recipients, multiple cognitive and behavioral impairments were present. The most frequent type of impairment was limitation in daily living. The items which represented the most burden for caregivers were the lack of time for themselves and the dependency of the care recipient. An inverse correlation was found between the caregivers' perception of burden and the number of family visits. Caregivers who had relatives visit felt they were better able to handle the responsibilites of care. Snyder and Keefe (1985) studied the unmet needs of family caregivers. In a sample of 117, 70% reported that their own health declined by performing caregiving tasks. These caregivers reported few resources to assist with care. The group providing care for the longest time reported the greatest number of health concerns.

Another dimension of burden is a subjective component. Clark and Rakowski (1983) found that the emotional components of caregiving contribute to perceptions of burden, regardless of specific caregiving tasks. Variables which contributed to subjective burden were the lack of knowledge about the condition of the dependent, and incongruence between caregiver's other responsibilities and caregiving needs. Cantor (1983) reported that caregivers who perceived that providing care caused major life style changes reported high levels of worry and problems performing other roles. Montgomery, Gonyea and Hooyman (1985) sorted burden into subjective and objective dimensions. While the two dimensions were correlated (r=.34), the coefficient suggests that different factors contribute to different dimensions of burden. A multiple regression analysis found two factors which were significant in predicting subjective burden were the age and income level of the caregiver. People who were younger and had higher incomes expressed higher levels of perceived burden regardless of their caregiving tasks. When caregiver tasks were regressed on measures of objective burden, the tasks which were significant were those that needed to be performed at a set time consistently, such as activities of daily living.

Environmental Variables

Environmental variables are important factors in determining the effects in caregiving. One variable which increases role strain of caregiving is having both provider and recipient live in the same home. A secondary analysis of a national data set examined intra-household caregiving (Soldo & Myllyluoma, 1983). The families who expressed the highest degrees of difficulty in caregiving were those who provided care to an unmarried, older relative within the home. These caregivers had few supports combined with competing tasks and demands on their time. Cantor's (1983) study on the effects of caregivers of the frail elderly found that the most severe role strains were reported by spouses, all of whom lived in the same household as the care recipient. During personal interviews, these caregivers reported loss in outside activities and personal time due to caregiving responsibilites.

Two studies have specifically looked at the well-being of spousal caregivers. Fengler and Goodrich (1979) studied life satisfaction in elderly wives caring for a disabled husband within the home. Wives scored higher than husbands on a measure of well-being yet both groups scored below means for their age cohort. Further analyses were performed on wives to see which women were better able to cope with caregiving roles. The women who had the lowest life satisfaction scores were those who had lower income and high degrees of role overload, measured by the number of competing responsibilties. Women who scored the highest more frequently included their husbands as someone who provided them with emotional support.

A study by Lichtenberg (1988) measured mental health problems in caregivers of a disabled spouse. The dependent variable was the presence or absence of two common mental health problems in the elderly: depression and hypochondriasis. Within the caregiving sample, 46% scored below the cut-off on either one or both of these mental health problems. Predictor variables used in this study were measures of stress defined as recent life changes (Holmes & Rahe, 1967) and daily hassles, financial situation, physical health, social activity and status of care receiver. An interesting finding was that the group which reported the most severe mental health problems were the caregivers who recently made a transition from their caregiving role. The members of this group had discontinued caregiving within the last six months. Current caregivers and those who discontinued caregiving longer than six months prior to the study reported fewer mental health problems.

In summary, the adult caregiving literature indicates that caring for an impaired adult is a stressful role. Studies which have measured demands of caregiving found both subjective and objective forms of stress. People in caregiving roles experience stress from both the actual tasks of caregiving and their perception of how lifestyles are altered to accomodate caregiving demands. Intra-household caregiving, the situation where care provider and recipient reside within the same home, is especially stressful for caregivers. This situation is associated with lower life satisfaction scores and higher prevalence of certain mental health problems. The transition out of the role of caregiver is another time of stress since new roles are established and existing relationships are modified.

Care for a Child with Mental Retardation

A situation faced by many parents is the mental retardation of their child. Perlman (1968) specifically mentions this parenting situation as an example of an ambiguous role. Although there is no one etiology, mental retardation has been defined as " significant subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior, and manifested during the developmental period" (Grossman, 1977 p. 5). Levels of retardation vary in severity. Eighty percent (80%) of people with retardation function in the mild range, where the retardation is due to an unknown cause. The mildly retarded are found in disproportionate numbers within the lower socio-economic class. Those people functioning in the more severe ranges comprise 20% of the retarded population. These levels of retardation are usually due to traumatic or genetic factors such as a pre-natal accident, complication at delivery or genetic abnormality. People with the more severe levels of retardation are equally distributed among all social classes (Wikler & Berkowitz, 1983).

The effect of a diagnosis of retardation can be devastating for parents. Numerous changes occur in families with a retarded child. Expectations and child-rearing practices are different from those performed with non-handicapped children (Schilling, 1987). Changes in caregiving tasks, responsibilities and timeframes are potential sources of stress for these parents. For example, parents who continue to feed, bathe, and dress a teen-age child may feel little hope that these tasks will ever be accomplished independently. The sight of grandchildren mastering tasks before a mentally retarded adolescent can exacerbate feelings of frustration and entrapment for parents. These stresses are not time-limited but recur at points over the course of the child and family development. Descrepancies between expectations and actual behaviors of the child are stress points over the course of development. A handicapped child's deficits are frequently more apparent than progress. Since mastery in mentally retarded people is often made in incremental steps, parents may have difficulty seeing when skill attainment is taking place. Parents may focus on dissimilarities of a handicapped child and non-handicapped peers instead of achievements of their child.

Chronic Sorrow Model of Stress

One model which attempts to explain how parents adjust to caregiving tasks for a mentally retarded child is the chronic sorrow model. This model was initially proposed by Olshansky (1962) to emphasize the need for professionals to continue to work with families on adjustment issues across the lifespan of the child. Instead of a linear progression through stages of adjustment, this model proposes that parents re-experience loss at certain points across the child's life course. Wikler, Wasow and Hatfield (1981) identify five points in a child's development where the different progression of a mentally retarded child is especially striking to the parents. These time periods are when developmental milestones would have been achieved if the child was not mentally retarded such as when the child would have started to walk, initiated verbal language, entered a regular school system, entered puberty, and reached the twenty first birthday which is a cultural symbol of adulthood.

A typology of stress points for parents with a mentally retarded child was proposed by Wikler (1981). Parents experience both chronic and episodic stress. Chronic stress is continuous over the life of the child and includes stigmatized social interactions for family members, prolonged length of care, lack of information about services, and grief over the loss of the non-handicapped child. Episodic stress occurs when expectations of a child's development do not correspond to actual behaviors. This type of stress is more prevalent at certain points in the child's life cycle.

Two studies have tested the chronic sorrow model. Wikler et al. (1981) surveyed both parents of handicapped children (N=32) and social work practitioners (N=32). The parent group was a clinical sample obtained from a diagnostic unit of a university medical center. The social work group was obtained from a listing of practitioners within the university community who had some knowledge of mental retardation. Both groups received mailed questionnaires about stressful events in parenting a child with a disability. Social workers were also asked to identify potential times when stress could be expected in families. Responses of both the parent and professional groups were compared to ascertain whether social workers had an accurate perception of stress points. Both groups responded affirmitively to a direct question on whether raising a handicapped child is stressful (65% of social workers and 63% of parents). However, the groups differed on the time periods designated as most stressful. Social workers overestimated the stress associated with earlier life events of the child and under-estimated stress associated with events later in development, such as adolescence and young adulthood. The event which was consistently under-estimated by the social work group was the stress associated with a child's twenty first birthday, designated as a crisis point by the majority of parents.

A second study by Wikler (1986) divided families into groups by chronological age of the child. The dependent variable was the level of stress in families, operationalized as the sum score on measures of stress and resources (Holmes & Rahe, 1967; Holroyd, 1974). Families with a child between ages 16 - 19 and 22 - 25 were considered transitional families. Children within these age ranges are in one of the transitional phases of the model, such as puberty and entering a vocational setting. These periods represent times of episodic stress for families when differences between a disabled child and non-disabled peers are very apparent. Data were collected at two points, an initial collection and two years follow-up. Transitional families reported higher stress on variables measuring perceived competence in parenting skills than non-transitional families.

These empirical analyses lend support to the chronic stress model. One limitation of the studies is the use of small, homogeneous samples. Larger, heterogeneous samples were recommended by the researchers as a way of broadening the generalizability of the model. A second recommendation was to research family social support networks. This additional information would assist in understanding the types of supports used by families during periods of episodic stress.

Within the literature, there is a high degree of consensus that caregiving for a mentally retarded child is stressful. Studies have made comparisons to ascertain which caregiving situations are accompanied by higher stress levels for parents. Three comparisons of stress levels have been made: parents with a handicapped child and parents of non-handicapped children, different caregiving roles within families of handicapped children, and families with children with different handicapping conditions.

Comparisons of Parental Stress

Ten studies have assessed the level of caregiver stress in families raising a mentally retarded child. Roth

(1982) discusses the effects of a handicapped child upon family economy. A child's disability alters family resources in two ways. One factor is the actual cost of raising the child, including such expenses as adaptive clothing, equipment, medication and the length of time the child depends on family resources. The second factor is the opportunity cost of care which describes the opportunities a family forfeits due to caregiving. An example of an opportunity cost is using money for the child's care instead retirement investing. A second example is rejecting a job promotion that involves re-location so a child can remain in the same district to continue to receive support services.

Studies of stress levels have compared families with a handicapped child to a control group of families with non-handicapped children. Tavormina, Boll, Dunn, Luscomb and Tayor (1981) administered instruments to a clinical sample of parents raising a physically disabled child (N=144). The parents were being seen in an outpatient department of a pediatric hospital. Five instruments were used to measure confidence in parenting: parental illness, special problems of the child, quality of family functioning, and parental personality type. Both mothers and fathers scored below standardized norms on measures of confidence in parenting roles. Parents of a handicapped child also reported a greater number of overall behavior problems in the child with the mothers reporting a greater number than fathers.

Two studies compared stress levels of mothers of mentally retarded and non-mentally retarded children. Quine and Pahl (1985) used the Malaise Inventory (Rutter, Graham & Yule, 1970) to measure emotional and physical well-being of the respondents. The Malaise Inventory is a twenty-four item self-report instrument designed to measure respondents' emotional and physical/psychosomatic symptoms in recent weeks. The mean scores for both groups indicated that there is stress associated with parenting regardless of the functioning level of the child. An item analysis revealed differences between the two groups. The mothers of mentally retarded children reported higher stress levels than the mothers of non-retarded children.

Research on pre-school handicapped children and controls in New Zealand also compared maternal stress (Wilton & Renaut, 1986). Questionnaires measuring stress levels were administered to a study group of mothers of severe and profoundly retarded children (N=40) and mothers of non-mentally retarded children who served as a comparison group (N=40). The study group reported significantly greater degrees of stress than comparison mothers on eight variables measuring personal and family problems. The study group reported higher degrees of stress related to poor maternal health, negative attitudes toward the child, overprotective parenting, lack of social support, overcommitment of responsibilities, lack of family integration, and experiencing financial problems.

A study on the degree of life change between a group of mothers with mentally retarded children and a comparison group of mothers of non-handicapped children also reported higher levels of stress in the study group (West, 1985). Stress was operationalized as the amount of life change taking place for the family. All three groups of mothers were given the Schedule of Recent Experiences (Holmes & Rahe, 1967) and a self-report questionnaire on the degree of life changes. The mothers completed the questionnaire retrospectively estimating life change within four time periods: the last 0 - 6 months, 6 months to one year, 1 - 2 years, and 2 - 3 years. The comparison group perceived that their life change scores had decreased overtime. Mothers of retarded children reported scores which remained constant as the time periods increased. Mothers in the study group whose children had both mental retardation and a physical disability reported scores indicating that stress increased over time. These four studies of parents indicate that the parent role itself is stressful and parenting a handicapped child increases the associated stress.

Within families, the different caregiving roles assumed by parents are associated with different levels of stress. In a literature review on stress, Byrne and Cunningham (1985) reported on stress levels within a family of a handicapped child. The authors reported that a frequent problem addressed in these studies is the stress involved with different family roles. Mothers were found to have the highest stress levels as measured by self reports of well-being, responsibility for performing caregiving tasks and perceived interaction with individuals outside the family unit. Stress associated with parenting was related to the subjective factors of the caregiving role, such as feeling isolated in social relationships.

A study by Dunst, Trivette and Cross (1986) measured differences between child-rearing responsibilities in parents of a handicapped child. Mothers reported significantly higher numbers of physical and emotional health problems and more child-care demands than fathers. The amount of time spent by mothers in performing all caregiving tasks was greater for mothers than fathers. Spending time with the child decreased the mothers' opportunity to spend their time in other ways.

A third comparison of stress levels in families of mentally retarded children involves the influence of the child's condition on the family's perception of stress. Levison and Starling (1981) created an index of stigma, hypothesizing that greater stigma attached to a child corresponded to greater social withdrawal in the parents.

Factors contributing to the stigma were the child's gender and physical appearance. The results of the research indicated that significantly more families with a male child felt some degree of stigma than families with a female child. No support was found for the hypothesis that the absence of a disabling appearance increases the stigma perceived by the parents.

Comparisons have also been made between families with different aged children. The literature review by Byrne and Cunningham (1985) reported that the chronological age of the mentally retarded child is less a predictor of parental stress than the stage of family life or behaviors exhibited by the child. Tausig (1985) studied the relationship between family stress and residential decisions of families in New York. An assumption of the study was that a request to place the child in a residential facility indicated a high level of stress present within the family. Family stress was measured by the Schedule of Recent Events (Holmes & Rahe 1967) with a separate subscale including specific tasks associated with the care of a disabled child. In the group of parents with younger children, which was defined as twenty one years or less, the best predictor of placement requests was the child's social behaviors. The only significant variable for the older group was the child's IQ level which was viewed as a rough estimate of adaptive functioning.

Families most frequently requested placement for an older child when functional ability was low.

Suezle and Keenan (1981) reported on service utilization patterns in families with a handicapped child age twenty-one or younger. Unmet needs in families appeared to have a bi-modal distribution. The two groups with high amounts of unmet needs were families with pre-school children and those with young adults. In the chronic sorrow model, both of these groups represent transitional families. Pre-school children are about to enter the educational system and young adults are preparing to enter vocational placements.

Another study compared family stress across various behaviors exhibited by the handicapped child. Quine and Pahl (1985) compared families of a handicapped child by the number and severity of exhibited maladaptive behaviors. Families whose child exhibited more severe or frequent behavior problems scored lower on a measure of well-being. Well-being was hypothesized to be inversely correlated with family stress. Families with higher stress levels were expected to score lower on a measure of well-being. The behaviors which elicited the greatest stress for the parents were nighttime disturbances of the children and the presence of multiple impairing conditions.

In summary, families with a handicapped child have been the subject of numerous research studies. While caregiving for any child is associated with stress, the presence of a handicapping condition appears to increase stress for parents. Researchers have attempted to isolate variables affecting stress levels of parents. The child's age appears to contribute less than the specific family life stage. Transitional periods are especially stressful as parents re-experience the loss of the non-handicapped child. This type of stress is episodic and is due to discrepancies between parental expectations and developmental progress of the child. Children with multiple physical or behavioral impairments increase the level of stress experienced by the parents. While most studies measured family stress, those studies which measured levels of stress experienced by individual family members reported greater stress for the mother in her role of caregiver.

Social Support of Parents

Social support networks serve the function of mitigating or buffering stress (Gottlieb, 1983; Wilcox & Vernberg, 1983). Social support networks have the potential to assist individuals in adapting to the environment (Schilling & Schinke, 1983). With the assumption that raising a handicapped child elevates stress for the parents, availability and use of supports in these families has been explored.

Three models have been proposed to explain functioning within families of handicapped children. An adaptation model of family stress was proposed by Crnic, Friedrich and Greenberg (1983). The adaptation model posits that the degree of family adaptation to a handicapping condition of the child is the dependent variable. Family stress is the independent variable in the model. Families who have lower degrees of stress will exhibit a higher degree of adaptation. The model includes two intervening variables, the personal coping mechanisms of the parents and the ecological context of the family system. The ecology includes supports available to assist with child-rearing tasks. This model proposes that parental reaction to raising a handicapped child combines with available resources for the family to buffer stress related to this caregiving situation. Both personal coping style of the parents and resources of the environment, including the presence of supportive others, assists the family in adapting to the caregiving situation for a handicapped child.

A second model incorporates a temporal dimension to family adaptation. Schilling and Schinke (1983) propose a model of personal coping and social supports for these families. The temporal model addresses the functional changes associated with coping and support over time. A proposition of the model is that with time, some adaptive coping strategies or support can become ineffective or detrimental for parents and child. An example is the isolation of a child who exhibits severe behavioral outbursts. While isolating the child may be an effective short-term strategy, the cumulative effect is alienation for the family. Anderson and Carter (1984) define alienation as an absence of links between a system and other significant systems in the environment. When energy is expended within the family unit leaving less energy available for exchanges with the environment, the family risks alienation from other systems.

For children functioning in the trainable or moderate range of retardation, a taxomomy of family life styles was constructed by Mink, Nihara and Meyers (1983). This study used a cluster analysis to minimize intra-group and maximize inter-group differences of families. Five clusters were established, representing different combinations of parental employment status, amount of stress experienced by family members and level of the family's and the child's self-esteem. Although no measure of social support was directly included within this study, a retrospective analysis of the clusters of families revealed different types of support networks associated with each. The families which evidenced the highest degrees of functioning appeared to have the greatest array and exchange of supports.

Comparisons of social support systems between families with non-handicapped and handicapped children have been conducted. The literature review by Byrne and Cunningham (1985) reported different support networks between the two groups of families. The social support systems of families are smaller and more dense when a child is present with a handicapping condition. Due to the child-rearing demands from the disability, these parents have less time, energy and opportunity to build diverse social networks.

Researchers have examined the impact of support networks in families with a mentally retarded child. Two studies found that the social support provided by a marital partner has a significant buffering effect on the measure of well-being for mothers (Friedrich, 1979; Friedrich, Wilturner & Cohen, 1985). Social support was measured as the degree of reported marital satisfaction, peer availability and family support. Mothers who reported support from a spouse scored significantly better on a measure of well-being than those who did not include a spouse within their support network.

Another study reported that greater supports available to parents have beneficial effects on the child. Dunst et al. (1986) studied supports of parents with children in an early intervention program. These children had one of three handicapping conditions: a physical disability, mental retardation or an assessment of being developmentally at-risk. Support was operationalized as the number and type of resources available to help with child-rearing. On a measure of parental well-being, two areas of support were significant in predicting the physical and emotional health of the parents. First, parental satisfaction with support systems was a significant main effect variable. Second, a greater number of support sources combined with a lower number of problems exhibited by the child was the second statistically significant variable. Additional analyses indicated that respondents who were more satisfied with support systems were less overprotective of their child. A second finding was parents who reported supportive social networks mentioned fewer troublesome behaviors in their child.

In summary, studies comparing caregiver stress indicate that parents raising a mentally retarded child do experience higher degrees of stress than control parents. Stress levels vary within caregiving roles, with mothers reporting higher levels of stress than fathers. Social stigma and behavior problems of a child also increase stress levels for parents. The stage of the family life cycle also affects parents' stress levels. Parents report higher levels of stress during certain episodes when the delayed progress of their child is especially evident, such as beginning to walk, talk, enter school, graduate, and enter the workforce.

The positive effect of social support systems for families providing care to a handicapped child have been examined. Studies examining the effects of support report higher degrees of functioning in families with more available social support. Stress levels of mothers decreased when a spouse was perceived as a source of support. Available supports for parents correspond to positive outcomes for the child, such as lower incidences of maladaptive behaviors and a greater degree of autonomy.

Most of the studies exploring family stress and support have used populations with mentally retarded children. As reported earlier, life expectancies for mentally retarded people have been increasing. As a result, more families are caregiving for mentally retarded adult children. Research is exploring the process of aging for mentally retarded people and the influence of age upon caregiving requirements and tasks. The next section will discuss the aging process in mentally retarded people. The issues which will be included are the definition of aging for mentally retarded people, the needs of this older group, and parenting issues for a mentally retarded adult.

Care for an Adult with Mental Retardation

Most research in the area of mental retardation has focused on children and young adults. The older mentally retarded person has only recently been the subject of research. Few studies have researched caregivers of adults with mental retardation.

Aging in the Mentally Retarded Population

An issue contributing to the gap in research is the problem of defining the "older" mentally retarded person. Within mental retardation literature, there is a consensus that aging should be defined at an earlier chronological age than within the general population (Walz et al., 1986). A different definition is proposed since mentally retarded people experience an earlier decline in behavioral capacity, an earler onset of Alzheimer's Disease especially with Down Syndrome, and a shorter lifespan than non-handicapped people (Seltzer & Seltzer, 1985; Tait, 1983; Thase, 1982). Studies on the older mentally retarded person have generally defined "older" as mid-fifties instead of the common definition of sixty or sixty-five years of age (Seltzer & Krauss, 1987; Seltzer & Seltzer, 1985; Walz et al., 1986).

Prevalence estimates that use fifty five as the commencement of aging have been used to determine the size of the older mentally retarded group within this country. Janicki and MacEachron (1984) estimated the number of all developmentally disabled people in New York. The total count in the state was 49,954. The fifty five or older group totalled 7,823, or 16% of the developmentally disabled population. Using the standard 3% prevalence rate for mental retardation, 1,380,000 people are estimated to be both mentally retarded and over fifty five in the United

States (Seltzer & Seltzer, 1985). A second study used a more conservative 1% prevelance rate to account for the higher mortality rate in the younger cohorts of mentally retarded people. Using the more conservative percentage, the population of mentally retarded adults over fifty five years of age in the nation would be estimated at 460,000 (Seltzer, 1985).

Comparisons of Mentally Retarded Adults

Besides the chronological definitions of aging, a life span approach has been proposed to define aging in the mentally retarded population. This approach uses an adaptive functioning measure which combines behavior and functional performance. Eyman and Widaman (1987) studied a large sample of mentally retarded people in Calfornia (*N* =30,749) to measure changes in adaptive functioning with age. Different developmental courses were found based upon the level of retardation for the person. The more severely retarded group had flatter skill attainment curves, indicating a slower rate of skill development. The more mildly retarded evidenced less physical decrements with age than those people with more severe impairments. Changes associated with chronological age appear to be different between people of different levels of severity, indicating that different definitions of aging may even be appropriate within the mentally retarded population as a whole. The changes accompanying the aging process vary by functioning level among mentally retarded people.

The types of changes associated with aging within the older mentally retarded population have been a topic of study. In a review of the literature, DiGiovanni (1978) reports that a problem with much of this research is the use of institutionalized samples which are biased toward those people with severe impairments. This fact is critical since no more than 5% of all mentally retarded people live within institutional settings at any given time (Seltzer & Seltzer, 1985). Early descriptions of aging changes among mentally retarded people employed institutional, not representative samples.

More recent studies which have included community samples have reported comparisons of mentally retarded and non-retarded people. A high incidence of early onset Alzheimer's Disease is found within people with Down Syndrome (Tait, 1983; Thase, 1982). In this group, the disease typically begins in the twenties or thirties (Wisniewski & Merz, 1985). Other physical changes differing from the general population include a higher level of neuro-muscular disease, respitory disease and cardiac-pulmonary problems (Rudelli, 1985; Walz et al., 1986). These changes are a combination of conditions associated with retardation and the poor health habits and diet associated with this population.

Since many mentally retarded adults are unable to live independently, living arrangements of this group have been compared to younger cohorts. Two studies using very large sample sizes addressed questions about the residential status of older mentally retarded adults. The Eyman and Widaman (1987) survey of the mentally retarded population in California reported that the highest percentage of the sample lived in their own homes (47%). This sample included adults of all ages and functional levels. Older people in the mild and moderate ranges remained in their homes at a higher rate than those in the more severe ranges of retardation. The Janicki and MacEachron (1984) study in New York of mentally retarded people over age fifty five reported that there was no difference between those people living in the community and those living in institutions based upon gender or racial/ethnic characteristics. However, persons in the community had fewer physical disabilities and a less severe level of retardation than the institutionalized group. People living independently or within the family home exhibited the highest attainment of daily living skills and level of independence.

Two other studies which explored the living arrangements of the mentally retarded population did report differences between racial/ethnic groups and place of residence. Meyers, Borthwick and Eyman (1985) examined a sample of mentally retarded adults in California. The use of a large data set ($\underline{N}$ =59,319) enabled the researchers to examine racial/ethnic differences among families. Across all ages and levels of retardation, the minority families had higher percentages of retarded people living within their home than did the white families. Eyman, Boroskin and Hostetter (1977) used a combined sample of 8,004 families from the states of California, Nevada and Colorado. Comparing individuals of different ages and levels of retardation, the study reported that 50% of white compared to 65% of Black or Hispanic families with a mentally retarded member provided home care. For the severely retarded, 33% of white compared to 60% of Black or Hispanic families cared for the person at home. Only 5% of the white families and Black families cared for a profoundly retarded person at home, compared to 17% of Hispanic families.

The researchers hypothesized that three differences between racial/ethnic groups contributed to the caregiving patterns. First, communities in which minority groups live frequently do not provide the full range of services available in predominately white communities. Second, minority group members may not be aware of possible resources due to lack of knowledge about services or language barriers. Third, Black and Hispanic families may have a different constellation of social supports which influences caregiving patterns. White families may rely less on the informal support systems of extended family and friends for assistance with caregiving than Black or Hispanic families.

Service Needs of Mentally Retarded Adults

Due to increased lifespans, research studies have begun to address the unique needs of mentally retarded people as they age. Many needs are different from both the younger mentally retarded person and non-handicapped cohorts (Cotten, Sison & Starr, 1981). The life events and characteristics of mentally retarded people contribute to the unique needs of this aging group.

One need area is access to appropriate services. Although an agreement exists in the mental retardation field that the aging process begins earlier than in the general population, other service sectors do not re-define eligibility criteria for mentally retarded individuals (Seltzer & Krauss, 1987). Eligibility for services to the elderly continue to be defined in terms of chronological, not adaptive age. This criterion excludes mentally retarded people from access to appropriate aging network services, such as day care, at an earlier age.

Other service needs of the mentally retarded result from the cumulative effects of functioning as a mentally retarded person in society (Walz et al., 1986). For example, day activity programs are services used by many mentally retarded adults. Unfortunately, the age of participants are seldom considered when making program decisions. Elderly mentally retarded people have little use for vocational or independent living skills. Programs for the older group do not modify goals based upon age. The older individuals are forced to choose between programs having little relevance for their life stage or no program at all. Older mentally retarded people face barriers to access existing services and a lack of services to meet their unique needs.

A second area of need for the mentally retarded population identified in the literature is the need for both social and residential autonomy. Two studies explored life satisfaction among mentally retarded adults. Flynn and Saleem (1986) interviewed a sample of twelve adults whose ages ranged from 19 to 44 years. All lived at home with their parents. A content analysis of the interviews indicated that the two changes most desired by these adults were a more independent living situation and a work environment. Cattermole, Jahoda and Markova (1988) interviewed a sample of mentally retarded adults who had recently moved into community-based residences from their family homes ($\underline{N}$ =12). Using a semi-structured interview format, the researchers reported that eight of the twelve had initiated placement requests with their parents. The sample described living arrangements with family as over-protective and isolating. The residential move was made to increase their living skills and social contacts.

The social isolation of older mentally retarded people is another area of need. In a literature review of informal support systems, Seltzer (1985) reported that the majority of members of an older mentally retarded person's support system were family and service providers. Fewer friends were included when compared to non-handicapped aged peers. Older mentally retarded people are frequently viewed as undesirable friends since there is an imbalance in reciprocity in the relationship (Seltzer & Seltzer, 1985). The status and power differentials inhibit friendships betwen mentally retarded and non-handicapped people.

Since family members are such important components of the informal support network of a mentally retarded adult, the death of a parent is a difficult adjustment. This event represents the loss of a caregiver and a major source informal support. Respite care, normally advocated as a temporary break for caregivers, also has the benefit of helping the mentally retarded person transition out of the family home (Janicki, Krauss, Cotten & Seltzer, 1986; Joyce, Singer & Isralowitz, 1983).

The aging process for mentally retarded adults is different from the general population in many ways. This population develops unique physical, emotional and social issues of aging. Mentally retarded adults are different from mentally retarded children and from the older non-disabled persons. Parents who provide care for mentally retarded adults face new challenges over the course of caregiving. At the same time, they face issues of their own aging process.

Parental Stress

Providing care for a mentally retarded adult combines stress associated with other ambiguous caregiving roles. Mid-life caregiving for a single adult residing within the same household has been described as the most stressful type of adult care (Soldo & Myllyluoma, 1983). This situation describes most mentally retarded adults (Seltzer, 1985). Parents who continue to be caregivers have provided care since the birth of their retarded child. The life-long dependency of a mentally retarded child increases the social isolation of these parents as they attend to psychosocial tasks of their own aging process (Jennings, 1987).

Increased life expectancies have only recently prompted researchers and service providers to examine older families providing care to a mentally retarded adult. The special needs of the older parent have begun to receive attention within the literature (Brunn, 1985; Dobrof, 1985). Developmental issues of aging may be more difficult for these parents due to the continued caregiving responsibilites for their adult child. Parents facing decisions about residential care, for example, face issues of separation after numerous years invested in parenting (Goodman, 1978; Winik, Zetlin & Kaufman, 1985). The perception that the parental role is never complete can elicit feelings of chronic sorrow (Wikler, 1981). As with other periods of episodic stress, parents must face the magnitude of difference between their mentally retarded adult child and non-handicapped peers. The mentally retarded adult who requires assistance with basic skills such as dressing and feeding is a stark contrast to same-aged peers who are establishing families and careers. The inability of the mentally retarded adult to establish roles usually associated with adulthood can evoke the feelings of loss for parents.

Social Support of Parents

In addition to the psychosocial needs precipitated by the caregiving role, older parents have needs for formal and informal social support. Studies of formal service needs of these parents have reported increased needs for health, legal, homemaking and planning for both themselves and their dependent (Caserta, Connelly, Lund & Poulton, 1987). The need for residential services has been compared in families with younger and older mentally retarded members (Tausig, 1985). Factors affecting the decision-making process for residential care differ by age of the child. While behavior is the best predictor for younger children, the best predictor of a placement request for adults is their level of functioning. A placement request in families with an older child appears to be a consequence of the family's inability to provide caregiving tasks. While requests for residental care of a younger child tend to be associated with the personal characteristics, family functioning is the best predictor for requests for an older child.

Other studies have assessed the degree to which existing formal supports meet the needs of older parents. Caserta et al. (1987) studied unmet formal service needs. Parents were categorized into two groups based upon their age: those from 50 - 59 years of age, those who were 60 years and older. A question addressed in this research was whether one group of parents would report a higher number of unmet needs. The findings indicated that the younger parents (ages 50 - 59 years) reported greater unmet needs than the 60 and over group. Formal service needs of older parents seem to progress in a non-linear mode. Although not examined directly, the researchers state that the aging service network may be filling service gaps for the over 60 year old group.

A day program is one service that assists many families caring for a mentally retarded adult. The study by Gold et al. (1987) of older parents reported that all but three of their sample (_N_ =42) used a day program for their adult child. Almost all (91%) of those parents using day programs felt that this service was beneficial. The majority of these families did not use any other services. Only 38% used recreational programs, 13% used in-home attendents, 8% used respite care, and 4% used some type of crisis intervention program.

The informal support needs of these parents have received little attention in the literature. When informal support issues have been explored, questions were limited to support for parents in their caregiving roles. As a result, little information is known about the supports available for the parents' personal needs. Two studies have examined informal supports of older parents. Mulcahey (1986) interviewed parents of mentally retarded adults about future legal and residential plans for their adult child. Seventy percent (70%) of the sample (N =90) had no residential plans with a large number of these parents stating that they hoped a sibling would assume care. Gold et al. (1987) reported 50% of the parents in their sample had another person in the home to assist with care. Most frequently this person was the respondent's spouse.

Although parents who provide care for a mentally retarded adult face multiple stress areas in their lives, little research has investigated the support systems available to these parents. The few existing studies were limited to support for parents in their role as caregivers. No study has evaluated the personal supports of these parents.

The parent role is one which is accompanied by some amount of stress. When a child has a disability, such as mental retardation, expectations and tasks of parenting change. Lifespans of both non-disabled and disabled populations have increased, with a concommitant increase in the length of time parents provide care to a disabled adult child.

The caregiver role for someone with a disability is accompanied by stress. Most of the studies on adult to adult caregiving are in the gerontology literature where an adult child provides care to an elderly parent. Studies in the mental retardation literature are predominately focused on parents of a young child. Parents who provide care for an adult mentally retarded child combine the stress of caring for another adult and a person with a disability. These parents have been labelled the hidden or forgotten caregivers (Jennings, 1987) and few studies have addressed the double source of strain involved in these stressful roles.

The literature review reports on the effects of caregiving on the stress level and social support systems of the caregiver. Although few studies have examined the population of parents with a mentally retarded adult, a prediction would be that their stress level would be higher and their social support constellation smaller than parents who did not have responsibility for such a child. The goal of this research was to better understand parents who continue in their caregiving role by comparing their stress and social supports to other parents.

CHAPTER 3

Study Design:

Measuring Stress and Social Support Among Caregivers

This chapter describes the design of the research including a description of the study, conceptual models of the research, hypotheses, measurement, sample procedures, pre-test of the instrument, the data collection strategy, and the data analysis plan.

Description of the Study

The study compared stress and social support among parents occupying three caregiving roles. These roles include parents currently providing care for an adult mentally retarded child, parents who are no longer caregivers for an adult mentally retarded child, and parents of non-handicapped children.

The study was designed to address two major questions. The first question explored the extent to which the three caregiving roles were associated with varying levels of stress. The second question addressed the social supports used by parents who assume different caregiving roles.

Both of these questions were derived from the review of literature on adult caregiving and mental retardation. The assumption underlying the study is that older parents are not exempt from facing the issues of their own aging process. The physical, social, and emotional changes of aging are combined with the stresses of extended caregiving. Older parents may require additional supports as a result of the combination of caregiving responsibilities and their own aging process.

Previous Research

Most of the previous research in the area of mental retardation employed samples of families with children who are mentally retarded. Ten articles have included families where the mentally retarded individual was an adult member. Three of the studies have compared parents of mentally retarded children and adults. The three studies are summarized in Table 1.

Insert Table 1 here

Five studies have used samples solely of parents of adult children. These studies are summarized in Table 2.

Insert Table 2 here

Two additional articles discussed practice with parents of mentally retarded adults. These articles are summarized in Table 3.

Table 1

Studies Comparing Families with Younger and Older Children

STUDY	DATA COLLECTION	QUESTION/ HYPOTHESIS	INSTRUMENTS	RESULTS
Suezle & Keenan (1981) N=330	mailed survey	what is the difference between service needs and use for families of different aged M.R. children	57 page survey researcher formulated	parents of younger children used more services and had greater supports than parents of older children
Tausig (1985) N=251	case file review	do individual or family variables best predict a request for residential placement of a retarded child	residential placement application	behavior variables were best predictors for children under 21 and family stress variables were best predictors for child over 21
Wikler (1986) N=60	mailed survey	do families whose M.R. child is in a transitional period experience more stress than families whose child is not in transition	Questions on Resources & Stress (Holroyd, 1974) and Schedule of Recent Events (Holmes & Rahe, 1967)	family stress scores were higher for families where child was in transition, this study operationalized as entering adolescence or young adulthood

Table 2

Studies With Adult Children Only

STUDY	DATA COLLECTION	QUESTION/ HYPOTHESIS	INSTRUMENTS	RESULTS
Goodman (1978) N=23	personal interview	what happens to parents as M.R. child ages	researcher constructed semi-structured interview	parents reported high degrees of fear about their child's future and high degrees of physical illness
Winik, Zetlin, & Kaufman (1985) N=29	participant observation and parent personal interviews	how does the nature of the relationship between M.R. adult and parent influence adjustment in community living	field summary of M.R. adults transitioning into a community living situation and a 120 item parent survey	relations fell into two categories: dependent where M.R. person was dependent on parents for many tasks of living and supportive where M.R. person received some but not all assistance from parents
Mulcahey (1986) N=80	personal interview	what types of legal and residential plans do parents of M.R. adults have formulated	semi-structured interview format	most parents had no plans for legal or residential issues for M.R. child with health status of parent being the best predictor of having formal plans

Table 2 (continued)

Studies With Adult Children Only

STUDY	DATA COLLECTION	QUESTION/ HYPOTHESIS	INSTRUMENTS	RESULTS
Gold, Dobrof, & Torian (1987) N=42 parents N=60 agencies	personal interview and agency surveys	what is perception of older parents own service needs and how aware are agencies about needs of these parents	open-ended question interview and survey for agencies	parents expressed great needs for help in caregiving, esp. in obtaining future residential placements for son or daughter while agencies in aging network identify few clients who are identified as caregivers of M.R. adult
Caserta, Connelly, Lund & Poulton (1987) N=198	personal interviews	what are the formal service needs of older parents and which variables best predict a need for services	personal competence measure and self-rating health scale and a scale of formal service needs	significant number of older parents require formal services to help with care-giving of M.R. adult with poor health status being the best predictor of unmet needs

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Insert Table 3 here

A review of these articles indicates that parents of older children have different needs from parents of younger children. The research indicates that parents report problems in performing their caregiving role that cross the entire lifespan of a mentally retarded son or daughter. The needs of parents with adult mentally retarded children have recently begun to receive attention in the social work practice literature.

Study Design

The study used three groups of parents. The groups were determined by classifying parents on two variables: their caregiving status and the dependent condition of their adult child. Caregiving status of parents was classified as either active or past caregiving. Active caregivers were parents currently providing care to a dependent adult child. Past caregivers were those parents who no longer are providing care for a son or daughter. The second classification variable was the condition of the dependent adult. The categories of this variable were disabled and non-disabled. For the purposes of this study, the disabled group was limited to adults with mental retardation. Figure 1 represents a typology of these caregiving roles.

Table 3

Practice Issues with Older Parents

AUTHOR	ISSUES ADDRESSED
Brunn (1985)	Describes a family and children's agency model of practice with parents of mentally retarded adults. Services are built upon these assumptions: the focus is continuing relationship between parent and adult child, realization that end of life issues include unfinished parenting, and parental need for continued education about aging process and changes of mentally retarded people.
Jennings (1987)	Describes the experience and sources of stress for aging parents. These parents face unique issues: recognition that aging will alter caregiving abilities, the M.R. person will always need some support and caregiving, the cumulative isolation felt by these parents, lack of respite services, cumulative financial drain on resources, and inadequate counseling by professionals who do not address later life issues in these families.

Insert Figure 1 here

Three of the four groups of the typology were included in the research. The first group were the active caregivers of a mentally retarded adult, labelled the active caregivers. One comparison group included past caregivers of a mentally retarded adult, labelled past caregivers. These parents have a mentally retarded adult child who did not reside in their household. An additional comparison group was past caregivers of non-disabled dependents, labelled the non-caregiver group. This group was comprised of parents who raised children without disabilities.

The final group, active caregivers of non-disabled adults, was not included in the study. Adult children in this category most frequently reside with their parents to receive tangible assistance; such as money, food, or shelter, and the decision to remain or return to the family home is mostly related to financial problems of the adult child (Bane, 1976; Bianchi, 1987; Mancini & Blieszner, 1985).

This living situation is stressful for the parents. Problems due to different lifestyles between adult child and parent are common (Mancini & Blieszner, 1985). The marital relationship can also suffer as tension affects

Figure 1. Typology of Caregiver Roles

		Caregiving Status	
		Active	Past
Dependent Status	Disabled	Current caregiver of M.R. adult	Past caregiver of M.R. adult
	Non-Disabled	Current caregiver of non-handicapped adult	Past caregiver of non-handicapped adult

relationships between other household members. However, the expectation of these parents is that assistance will be temporary and their adult child will achieve an independent status. The type of assistance provided in this situation is different from parents caring for an adult mentally retarded child who frequently are responsible for a variety of assistance to their adult child. The support needed by an individual with mental retardation can include assistance with activities of daily living, transportation, as well as financial assistance.

An second difference between these two caregiving situations is the length of time the adult child is expected to reside within the household. Adult children without disabilities frequently seek assistance from parents in a crisis situation; such as a divorce, or unemployment. After the situation has stabilized, the adult child may be able to resume independent functioning. Adults with mental retardation, however, may require assistance for an indefinite amount of time. Because the type of assistance provided and the length of time for caregiving are different, active caregivers of adult non-disabled children were not included in the study.

Conceptual Models

The focus of this study is on parents in three caregiving roles. The context of performing a caregiving role is influenced by a number of other relationships in the environment. The models which support this research depict the dynamic connection between an individual and his or her role relations. Three models are presented to illustrate the relationship between the different levels of social units.

The theoretical model is an ecological perspective of social order. This model accounts for the relationship between an individual and the context and setting of the person. Figure 2 depicts different levels of systems ranging from the individual to the pervasive cultural system.

Insert Figure 2 here

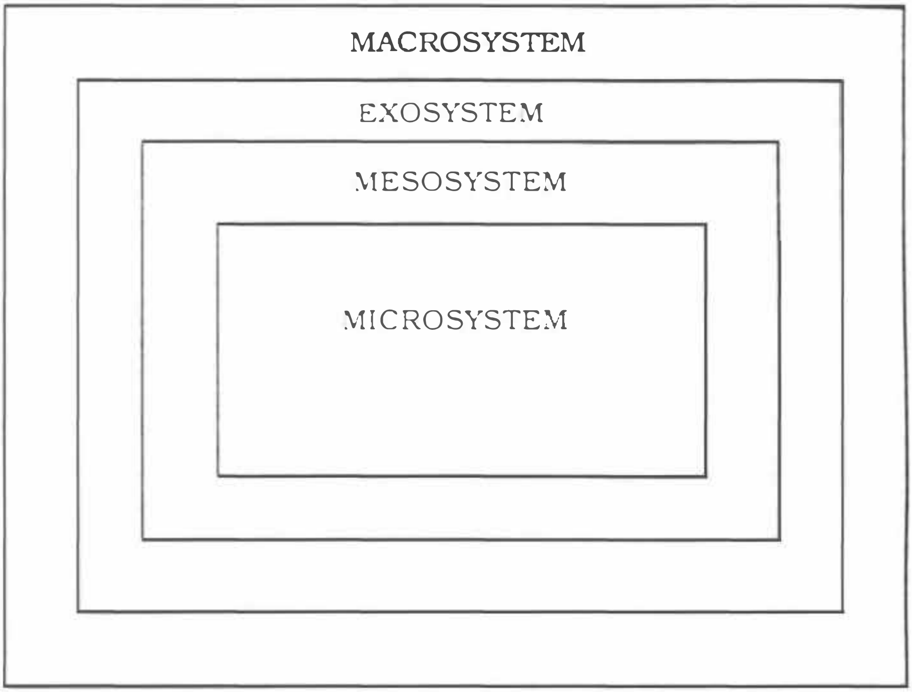
Since the microsystem is embedded within multiple systems, the diagram portrays that a role, such as caregiver, must be viewed within the context of other systems (the meso, exo and macro systems).

The second is an empirical model. This model represents the theoretical model in researchable order.

Insert Figure 3 here

The model demonstrates that different system levels are dynamic and mutually influenced. The microsystem, representing the individual, includes both internal

Figure 2. Theoretical Model



MICROSYSTEM

Patterns of activities, roles and interpersonal relationships experinced by a person and the psychological functioning of the individual (Beckett & Coley, 1987).

MESOSYSTEM

Inter-relationships between microsystem, for example, a family relating to a school system.

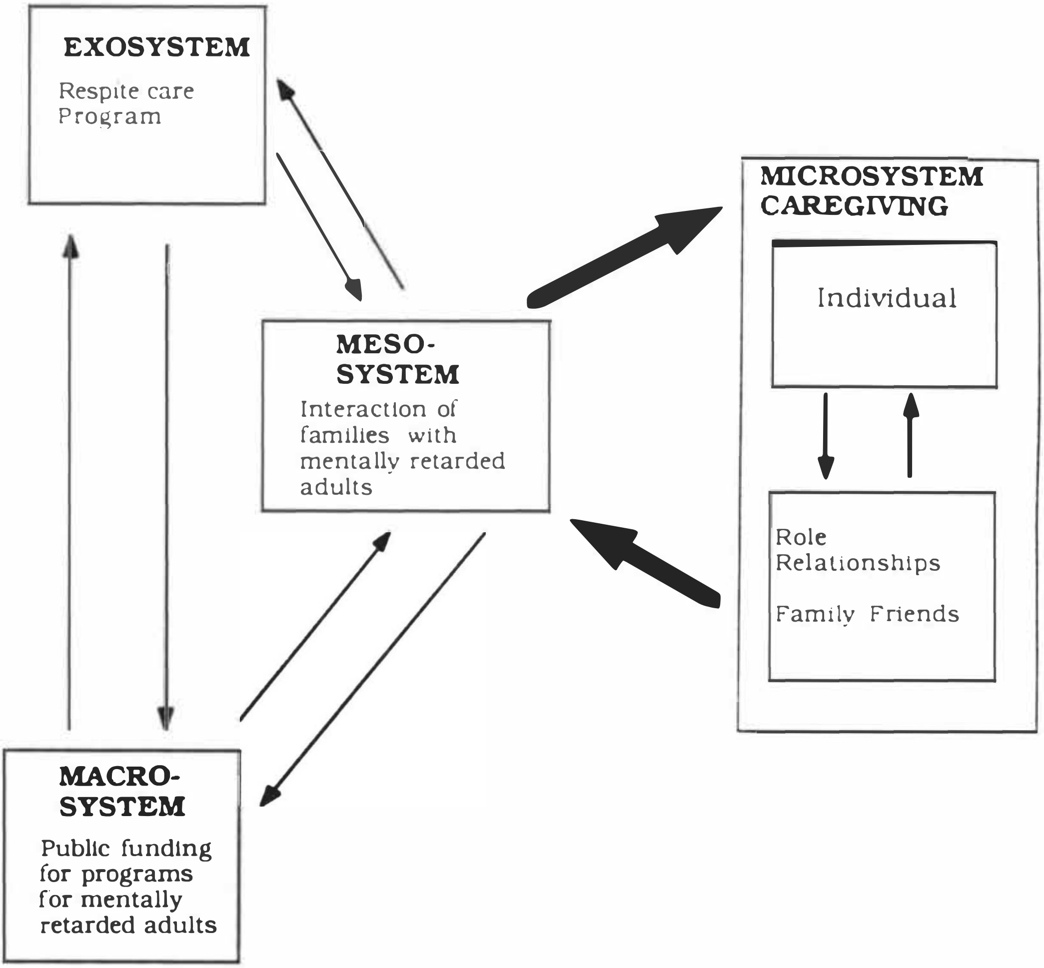
EXOSYSTEM

Environmental factors which have an indirect effect on an individual, for example, the affect of a parent's social support network on the development of a mentally retarded child.

MACROSYSTEM

Cultural, sub-cultural and general belief patterns, for example, attitudes toward housing mentally retarded people in the community.

Figure 3. Empirical Model



processes (Beckett & Coley, 1987) and role relationships. An example using a caregiving situation helps illustrate the dynamic quality of these different systems. If the stress associated with the caregiving role (microsystem) increases due to longer lifespans of parents and a child with mental retardation, changes may occur in priorities for funding (macrosystem) to establish a greater number of respite care programs (exosystem) for families. Available respite providers give the family an opportunity interact with other families (mesosystem). In turn, this socialization decreases the stress felt by the caregiver (microsystem).

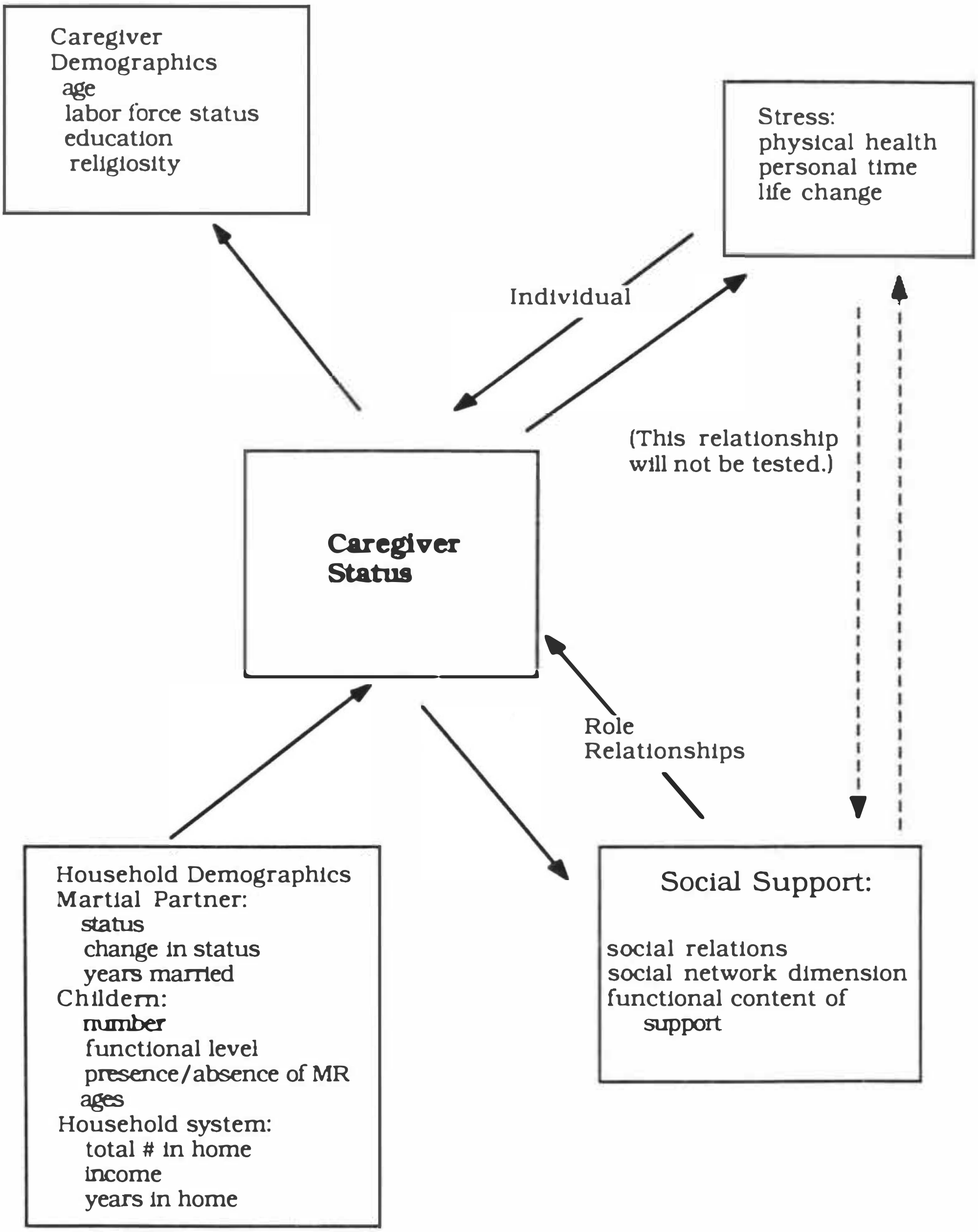
The third model guides the research of this study. The microsystem was selected as the level of analysis with the individual caregiver as the unit of analysis.

Insert Figure 4 here

The two major research questions are about the functioning of the caregiver. The first question explored the effect of caregiving status upon the reported stress of the caregiver. The second question explored the effect of caregiving status upon the social support network of the caregiver. These two global questions guided the hypotheses for this research.

The research included development of six main

Figure 4. Research Model



hypotheses. Each hypothesis predicts a relationship between parents in different caregiving roles and a dimension of stress or social support. Hypotheses 1 and 2 compare active and past caregivers. Hypotheses 3 and 4 compare active and non-caregivers. Hypotheses 5 and 6 compare past and non-caregivers.

Hypotheses of the Study

Active Caregiver Hypotheses

HYPOTHESIS 1: Active caregivers of mentally retarded adults will report higher degrees of stress than past caregivers.

Sub-hypotheses are proposed as follows:

1) active caregivers will report a greater number of physical health problems than past caregivers
2) active caregivers will report fewer hours available for personal time than past caregivers
3) active caregivers will report a greater number of life changes than past caregivers

HYPOTHESIS 2: Active caregivers will report a different social support constellation than past caregivers.

Sub-hypotheses are proposed as follows:

Social Relation Dimensions:

1) active caregivers will report fewer people in a social support network than past caregivers
2) active caregivers will report fewer contacts with members identified as supports than past

caregivers

Social Network Dimensions:

1) active caregivers will report fewer age cohorts as members of their social support network than past caregivers
2) active caregivers will identify more people in formal roles as supports than past caregivers

Functional Content of Support Dimensions:

1) active caregivers will report fewer reciprocal exchanges within the social support system than past caregivers
2) active caregivers will report lower degrees of satisfaction with their social support system than past caregivers
3) active caregiving parents will report fewer expressive and a greater number of instrumental exchanges within their social support system than past active caregiving parents

HYPOTHESIS 3: Active caregivers of mentally retarded adults will report higher degrees of stress than non-caregivers.

Sub-hypotheses are proposed as follows:

1) active caregivers will report more physical health problems than non-caregivers
2) active caregivers will report fewer hours available for personal time than non-caregivers

3) active caregivers will report a higher number of life changes than non-caregivers

HYPOTHESIS 4: Active caregivers will report a different social support constellation than non-caregivers.

Sub-hypotheses are proposed as follows:

Social Relation Dimensions:

1) active caregivers will report fewer people in a social support network than non-caregivers
2) active caregivers will report fewer contacts with members identified as supports than non-caregivers

Social Network Dimensions:

1) active caregivers will report fewer same age cohorts as members of their social support network than non-caregivers
2) active caregivers will identify more people in formal roles as supports than non-caregivers

Functional Content of Support Dimensions:

1) active caregivers will report fewer reciprocal exchanges within the social support system than non-caregivers
2) active caregivers will report lower degrees of satisfaction with their social support system than non-caregivers
3) active caregivers will report fewer expressive and a greater number of instrumental exchanges within their social support system than non-caregivers

Past Caregiver Hypotheses

HYPOTHESIS 5: Past caregivers of mentally retarded adults will report higher degrees of stress than non-caregivers. Sub-hypotheses are proposed as follows:

1) past caregivers will report more physical health problems than non-caregivers
2) past caregivers will report fewer hours available for personal time than non-caregivers
3) past caregivers will report a higher number of life changes than non-caregivers

HYPOTHESIS 6: Past caregivers will report a different social support constellation than non-caregivers. Sub-hypotheses are proposed as follows:

Social Relation Dimensions:

1) past caregivers will report fewer people in a social support network than non-caregivers
2) past caregivers will report fewer contacts with members identified as supports than non-caregivers

Social Network Dimensions:

1) past caregivers will report fewer same age cohorts as members of their social support network than non-caregivers
2) past caregivers will identify more people in formal roles as supports than non-caregivers

Functional Content of Support Dimensions:

1) past caregivers will report fewer reciprocal

exchanges within the social support system than non-caregivers

2) past caregivers will report lower degrees of satisfaction with their social support system than non-caregivers

3) past caregivers will report fewer expressive and a greater number of instrumental exchanges within their socials support system than non-caregivers

Figure 5 visually represents the hypotheses of differences between parents in the three caregiving roles.

Insert Figure 5 here

Family Interview Data

The hypotheses of stress and social support predict differences between parents in different caregiving roles. The theoretical and empirical models depict the interaction between systems of different levels. An additional area of inquiry of the study was the impact of an adult child who is mentally retarded upon the family as a unit. Interviews were held with five families to explore their family functioning. Questions guiding the open-ended interviews with the five caregiving families centered on functioning within the family unit and interactions of the family in the community.

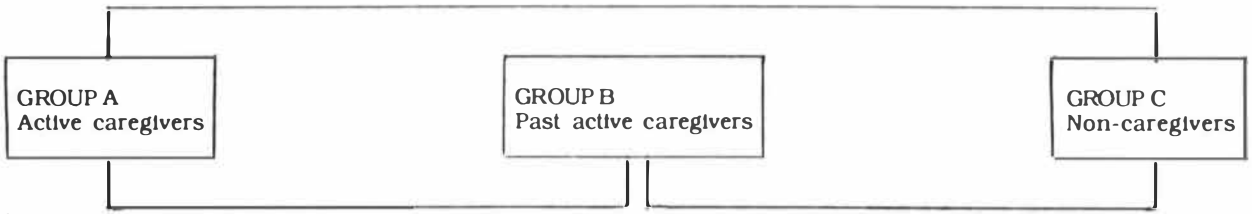
Three general research questions were explored with

Figure 5. Representation of Proposed Hypotheses

HYP 3 & 4

Stress:	physical health	A>C
	personal time	A<C
	life change	A>C

Social Support:	network members	A<C
	contacts	A<C
	age cohorts	A<C
	formal roles	A>C
	reciprocity	A<C
	satisfaction	A<C
	instrumental	A>C
	expressive	A<C



HYP 1 & 2

Stress:	physical health	A>B
	personal time	A<B
	life change	A>B

Social Support:	network members	A<B
	contacts	A<B
	age cohorts	A<B
	formal roles	A>B
	reciprocity	A<B
	satisfaction	A<B
	instrumental	A>B
	expressive	A<B

HYP 5 & 6

Stress:	physical health	B>C
	personal time	B<C
	life change	B>C

Social Support:	network members	B<C
	contacts	B<C
	age cohorts	B<C
	formal roles	B>C
	reciprocity	B<C
	satisfaction	B<C
	instrumental	B>C
	expressive	B<C

OVERALL RESEARCH QUESTIONS:	Stress:	Do different groups of caregivers report different stress levels?
	Social Supports:	Do different groups of caregivers report different social support constellations?

the five families. These areas correspond to the dimensions of family functioning common to the Beavers-Timberlawn (Lewis et al., 1976) and Circumplex (Olson et al., 1979) models. The three research questions are:

1) What characterizes communication patterns in families where a mentally retarded adult resides with the parents?
    - What are the lines of communication within the family members?
    - How much exchange does the family have with other systems in the environment?
2) How are changes handled in these families?
    - Does the family have plans for their future?
    - Historically, how has the family handled crises situations which have occurred?
3) How close are the bonds between family members in a household which contains a mentally retarded adult?
    - What activities are the families involved in as a system?
    - What activities do family members do independently?
    - How satisfied are members with the current degree of closeness within the family system?

These three overall question areas were the basis for the family interviews. These interviews were conducted to enrich the data from the surveys about active caregivers by providing insight and understanding in family functioning.

Measurement

Variables which measured the three constructs of the research model were selected. Characteristics of the caregivers and their households were included. Stress contained the three dimensions of health, free time, and life change events. Social support included three dimensions of social relations, social network, and functional content of the support. The variables of the study are discussed in the following sections.

Characteristic Variables

The characteristic variables were categorized as either individual or household demographics. Individual variables were associated with characteristics of the caregivers. These included gender, race, current and past work status, perception of religiosity, religious affiliation, number of religious activities attended per week, education, and age.

The household items corresponded to relationships of the family members or variables which were attributed to the entire household unit. These included marital status, length of marital status, place of residence, disabilites of household members, income, number of children, number in household, and years in home.

The active and past caregiver groups had items concerning their son or daughter with mental retardation. Both groups of parents included these variables: gender of child; independence in activities of daily living, such as walking, dressing, bathing, feeding, going to the bathroom, preparing simple meals, using public transportation, and getting around the neighborhood; and age of child. Past caregivers also had items about current situation of their child which included present living situation, years since the child left home, number of times talking on the telephone, visiting, and overnight stays per month, and miles between residences.

Stress Variables

Three of the study hypotheses compare caregiver groups on stress variables. From the examination of the caregiving and mental retardation literature, three dimensions of stress were used in this study. Health status, amount of personal time, and degree of life events were dimensions of stress measured in previous research. The studies employing each of these dimensions of stress are summarized in the following sections.

Health Status

Six previous studies have used physical health as a dimension of stress. Table 4 summarizes the studies which have reported on physical health status.

Insert Table 4 here

These studies suggest that a number of physical health impairments are reported by caregivers. The number and severity of these conditions may increase as the length of caregiving increases.

This study employs four self-report measures of physical health. Previous studies have used self-reports of health conditions since these measures correlate highly with objective measures of physical health (Caserta et al., 1987).

Four health measurements were used in this study. Three were part of the Health and Daily Living Manual developed by the Social Ecology Laboratory of Stanford University Medical Centers (Moos, Cronkite, Billings, & Finney, 1985). Each index is summarized and comparative data are provided, when available.

The Physical Symptom Index contained eleven possible health symptoms. The parents reported the presence of any of these items within the past 12 months. Examples of these items were: "felt weak all over", "had trembling hands", and "had frequent and severe headaches".

Two other studies were reviewed that used the Physical Symptom Index as a stress measure. A study investigating the relationship between environmental stressors and

Table 4

Studies Using Health Variables

STUDY	FINDINGS
Cantor (1983)	There is an inverse correlation between length of caregiving and the health status of caregivers.
Caserta et al. (1987)	For parents of mentally retarded adults, poor health status was a significant predictor of a need for formal services.
Gold et al. (1987)	Parents of mentally retarded adults reported multiple health problems including arthritis, visual impairments, and hypertension.
Goodman (1978)	As a group, older parents of mentally retarded adults reported a high number of health problems.
Johnson & Catalano (1983)	Longitudinal study of family members who assumed caregiving roles reported that between the first and second measurement, caregivers reported more physical health impairments.
Snyder & Keefe (1985)	Study of effects of providing care, caregiving role was associated with increase in physical health ailments and less time to devote to positive health promotion activities.
Zimmer & Mellor (1982)	Strains associated with caregiving exacerbate existing physical impairments.

depression reported a Cronbach's alpha of .80 for this index (Billings & Moos, 1984a). The depressed group (_n_ = 424) experienced an average of five or six symptoms while the non-depressed controls (_n_ =424) reported an average of two symptoms. The average age of the sample was 40 years. The second study used a random community sample (_N_ =249) obtained in the San Francisco area (Cronkite & Moos, 1984). Men reported an average of 2.3 of these symptoms with women reporting an average of 1.7. The average age in this sample was 47 years for men and 44 years for women.

A second health status measure, the Depressed Mood Index, included six items. Examples of the items were: "feeling like you couldn't get going", "feeling your memory wasn't right", and "feeling nothing turned out right for you". Parents reported any of the feelings they had experienced within the past 12 months.

One study employing a community sample (_N_ =249) used this index (Cronkite & Moos, 1984). Women in this study reported an average of 2.3 items and men reported an average of 1.6. Studies which have reported reliability data for this index have reported Cronbach's alpha ranging between .71 to .91 (Billings & Moos, 1984a; Holahan & Moos, 1981, 1982).

The third health measure was the Physical Diagnosis Index. Parents reported on the presence of 14 health conditions diagnosed by a physician. Respondents were asked to indicate whether they had been diagnosed with these conditions or had experienced any problems connected to a previous diagnosis within the past year.

Three studies were reviewed which included this measure of stress. One study (*N* =818) compared depressed patients to matched non-depressed controls (Billings, Cronkite & Moos, 1983). The patient group reported an average of one medical condition (1.17 for men and .81 for women). The control group reported fewer of these items (.28 for men and .60 for women). A second study (*N* =314) compared depressed patients and their spouses to non-depressed couples (Mitchell, Cronkite & Moos, 1983). The depressed patients reported the most conditions (*M* =1.08) compared to their spouse (*M* =.85) or the control couples (*M* =.41). The third study using a clinically depressed sample (*N* =233) measured symptoms 12 months post-treatment (Mitchell & Moos, 1984). The group reported an average of .98 of these conditions. The average ages of the participants in the three studies ranged from 39 to 44 years.

Two other items on physical health were included. Respondents were they asked how they rated their overall physical health compared to other people their same age. Finally, parents reported whether they engaged in any of seven activities which included: "eating 3 meals daily", "sleeping 6 - 8 hours per night", and "smoking cigarettes".

Personal Time

Besides health status, the literature also suggests that a component of caregiving stress is the lack of personal time available to the caregiver. Table 5 summarizes the four studies which have included a measure of personal time .

Insert Table 5 here

Two items were included which measured personal time available to the caregivers. The first was a question on the number of hours available per week to the respondents to do whatever they chose. A second item was a question about their satisfaction with the amount of available time. Respondents reported whether they were very satisfied, satisfied, dissatistied because of too many hours, or dissatisfied because of too few hours of free time available to them.

Life Events

A third dimension of stress was the life events experienced by the caregivers. Four studies have used measures of global life changes. Table 6 summarizes these studies.

Insert Table 6 here

Table 5

Caregiver Studies Using Personal Time Variables

STUDY	FINDINGS
Barnett & Baruch (1985)	Study of mothers of non-handicapped children and teens. Mothers reported high degrees of role strain and multiple competing roles. These demands left little time for mothers to address personal needs. Role demands were especially prevalent in mothers of older children.
Clark & Rakowski (1983)	Literature review on the personal tasks of caregivers and the effects of caregiving tasks. The loss of personal time was one of the most stressful adjustments for caregivers.
Fengler & Goodrich (1979)	Study of role overload in caregivers. A dimension of role overload was the degree to which caregivers had demands which completed for personal time.
Zarit et al. (1980)	Study of burden in caregivers of older adults. One item which represented the highest degree of burden was a lack of time for self.

Table 6

Studies Using Life Change Variables

STUDY	FINDINGS
Clark & Rakowski (1983)	A stressful part of caregiving is the unpredictability associated with tasks. Caregivers reported the inability to predict or make decisions about their future because of the caregiving role.
Jenkins (1985)	Research on mothers of the mentally ill reported that the degree of life change was related to a measure of psychological adjustment of the caregiver. Mothers with higher degrees of life change had lower psychological adjustment scores.
Lichtenberg (1988)	Study on spouses of impaired men reported a higher degree of life change for those wives who were caregivers.
Tausig (1985)	Study about residential care decisions by parents of the mentally retarded used a life change measure as one dimension of family stress.

A number of other studies have included the Life Event Index as a stress measure. Three studies employed clinical samples. In two studies of depressed patients, (*N* =233 and *N* =424) each sample experienced between two and three negative life events within the past year (Billings & Moos, 1984b; Mitchell & Moos, 1984). Positive life events were measured in one of these studies (Mitchell & Moos, 1984). The sample reported an average of .75 positive events within the previous year. A third clinical sample (*N* =113) included patients in a drug treatment program (Finney, Moos & Mewborn, 1980). The sample reported an average of .85 positive and 1.3 negative life events six months after treatment.

Two studies have used the Life Event Index with community samples. One study (*N* =267) controlled for gender and employment status. Employed men reported an average of .93 negative events compared to 1.0 for employed women (Holahan & Moos, 1982). A second study (*N* =249) reported an average of .90 negative life events experienced by women compared to .94 of these events reported by men (Mitchell & Moos, 1984). The average age in these studies ranged from 42 to 49 years of age.

Social Support Variables

Since research on social support has become more prevalent in the social science and psychology literature, greater attention is being paid to measurement and methodological issues. One problem in the research on social support is a lack of conceptual clarity in definitions. In an early definition, Caplan (1974) defined social support as feedback and validation which provides information and guidance to a person. Cobb (1979) delineates the dimensions of the construct social support which are: instrumental, such as counseling; active, such as mothering; and material, such as goods and services. House (1981) defines social support as an interpersonal transaction which includes: emotional concern, such as love or liking; instrumental aid, such as goods and services; information, such as linking to resources, and self-appraisal such as feedback.

Due to the lack of conceptual clarity, many researchers have constructed study-specific measurements, ranging from one global question to a 100 item scale (House & Kahn, 1985). Many of these instruments lack construct validity defined as the extent to which a measurement instrument reflects the domain of the construct (Carmines & Zellor, 1979). Many existing social support instruments measure social support unidimensionally, such as the number of supports or degree of contact with supports. Currently, social support researchers are recommending that instruments need to measure more than one dimension of support (Depner, Wethington & Ingersoll-Dayton, 1984; House & Kahn, 1985).

A third problem is the design of social support research. Many studies have employed retrospective designs to measure the impact of social support upon a stressful event. An example is the measurement of social support following a divorce. A hypothesis in this type of study is that social support is provided to enable an individual to cope with the stress of the event. The ex-post facto design is unable to measure the degree of change in support as a consequence of the event (Depner et al., 1984). This design also fails to account for the buffering potential of support. A retrospective design cannot determine the change in stress as a result of social support.

More than one dimension of social support was measured in this study. House & Kahn (1985) suggest that the domain of social support include social relationship variables, structural variables and functional variables. This research used an existing instrument for which there is an accepted level of reliability and validity. Recommendations from the social support literature emphasize the need to refine existing instruments instead of continuing to create new ones (House & Kahn, 1985). The research did not employ a retrospective design where social support is measured after the occurrence of a given event, such as a request for a residential placement of a mentally retarded child.

As stated earlier, social support has been defined in many ways. A social support network is a sub-set of a person's larger social network (Pearlin, 1985) which includes a subjective feeling that the exchange enhances the recipient's well-being (Antonucci, 1983; Shumake & Brownell, 1984). Support can be found in individuals, groups or institutions (Schilling et al., 1984). This study combined elements from existing definitions to define social support. For this research, social support was defined as exchanges between individuals within a person's social network which are perceived by the recipient as enhancing well-being.

The variables selected to measure social support in this study represented the three dimensions recommended by House & Kahn (1985) in their review of the social support literature. One dimension of social support is the existence and quantity of support. A second dimension is the structure of support, specifically number of age cohorts and roles of support providers. The third aspect is the functional dimension which includes the type of support provided, the degree of reciprocity within the exchanges, and the individual's satisfaction with the support received.

The instrument which measured social support in this study was the Social Relationship Scale (McFarlane, Neale, Norman, Roy & Streiner, 1981). This scale was chosen for several reasons. First, the Social Relationship Scale

(SRS) is a multidimensional measurement of social support. Respondents were asked to supply information about their social support across different areas of life stress. This format does not make the assumption that someone is equally supportive in every situation. Parents identified which members of their support system were helpful in the areas of home and family, health, personal and social, and money and financial issues. The SRS also reports items on the number in the respondents' social support system, their satisfaction with support, counterpositions of the members of the support system and reciprocity within the exchange. As defined in role theory, a counterposition is the complimentary role, for example, the counterposition of a parent role is a child role (Biddle & Thomas, 1966).

The SRS has several positive measurement features. The format does not bias respondents to identify certain sources of support or elicit socially appropriate responses (McFarlane et al., 1981). Respondents were asked to identify the initials of up to eight people who they perceived as supportive. Additionally, reports on the reliability and validity of the SRS have been positive. To assess the criterion validity, McFarlane et al. (1981) used the SRS with a sample of general population subjects (N=518). The instrument was able to differentiate a clinical sample receiving marital treatment from a non-clinical sample. These authors also measured reliability by the test-retest method. Correlations were computed for group of community college students after a one week interval. Individual correlations ranged from .62 to .99 with a median of .91. This coefficient indicates high reliability for the SRS at retest. A separate review of measures of social support reported the advantages of the SRS over other measures. The SRS provides more information about support than other measures, including quantitative and qualitative dimensions, reciprocity in the exchanges, and role relationships (McDowell & Newell, 1980; Tardy, 1985).

Two additional measures were included in the survey to assess the social support of the three parent groups. One additional measure asked respondents to identify the closeness in age between themselves and each of their identified supports. The respondents reported whether each individual was five years either younger or older, or their same age.

The second addition was the type and frequency of support received. Parents were asked to report how often the following events occurred: they talked about personal or private issues with someone, they had someone loan them something, they were given advice, they were told that someone liked what they did, they had someone help them take care of something, and they were shown physical affection. Respondent reported whether they had received each type of support at all, a little bit, some, or quite a bit within the last month.

In summary, health, personal time, and degree of life change were used as measures of stress in this study. Instruments from the Health and Daily Living Manual (Moos et al., 1985) were used to measure health and life events. An additional dimension, health activities performed, was included in the survey.

Measurement issues in social support were also examined. Measurement of this construct is complicated by the abundance of measurement instruments and the lack of conceptual clarity. This research used the Social Relationship Scale (McFarlane et al., 1981). The SRS was selected because it is multidimensional and measures social support across different areas of functioning. Since respondents identified members of their own support system, socially appropriate responses were minimized. The SRS also has good reliability and validity data reported in the literature.

Sampling Procedures

No sampling frame exists that represents the population of all active caregivers of mentally retarded adults. A sampling frame is the operational procedure and the materials used to account for the population when drawing a sample (Warwick & Lininger, 1975). Fowler (1984) describes three general classes of sampling frames:

sampling which is done from a complete list of individuals in the population under study, sampling which is done by a set of people who go to a certain place or receive a certain service, or sampling performed in two or more stages. The second type of sampling frame was chosen for the research. This method is a non-probability sampling procedure which means that all elements of the population do not have a chance of being selected. Non-probability sampling has limitations since the data cannot be generalized to all parents of mentally retarded adults. Research on this group of parents, however, is in the initial stages. The use of a non-probability sample seems appropriate at this stage of the research.

Community Services Boards

Respondents in the active and past caregiving groups were secured through the community mental health service delivery system. In Virginia, mental retardation services are delivered by agencies representing counties and/or cities. Each service delivery area has a system where every mentally retarded client is served by a casemanager. Casemanagers are accountable to a supervisor who oversees services. Since files are kept for all clients using mental retardation services, casemanagers have access to information about the living arrangement of each client. Casemanagers were used to identify parents on their caseload who met the criteria for participation.

Five community services boards (CSBs) participated in this study. The CSBs are all located in east central Virginia (See Appendix A for map). The participating areas were the City of Richmond; Chesterfield County; Hanover County; Henrico District which consists of Henrico, Charles City and New Kent Counties; and Petersburg District which consists of the City of Petersburg, the City of Hopewell, Dinwiddie, Greenville, Prince George, Surry and Sussex Counties. The combined land area includes both rural, suburban and urban areas. Appendix B contains land area and population data for the locations that participated in the research (MapMaker Software, 1988).

Each CSB was contacted during March through April, 1989, to discuss the goal and process of the study. One CSB chose not to participate in the study because of conflicts with an internal research agenda. A substitute CSB was selected with characteristics similar to the non-participating location.

The role of the CSBs in the research was to identify parents of adult mentally retarded children in their service area. These parents were categorized into either the active or past caregiving group.

Study Group: Active caregivers

Active caregivers were defined as birth parents of a mentally retarded adult child who are the primary caregivers for that person within their household. These parents were eligible for participation in the study if their adult child met these criteria:

1) currently receiving one or more mental retardation service(s)
2) having an active or open file through the service system
3) being at least 18 years of age
4) living with one or both birth parents

Comparison Group 1: Past caregivers

Past caregivers were defined as birth parents of a mentally retarded child who were not providing caregiving for the person within the family household. These parents were eligible for participation if their adult child met these criteria:

1) currently receiving one or more mental retardation service(s)
2) having an active or open file through the service system
3) being at least 18 years of age
4) not currently living with one or both parents
5) at one time lived in the same household as his or her parent(s)

An initial meeting was scheduled with the casemanager supervisors in the CSBs. Each supervisor was given a packet which included a question and answer sheet on the project (See Appendix C) and a draft of the questionnaire.

The supervisors were responsible for collecting the names/addresses of the parents who were identified by each of their casemanagers. Each supervisor was contacted approximately two weeks after the initial meeting to receive a count of the total number of parents who were identifed by the casemanagers in their agency.

Non-Caregiver Parent Group

The final group of caregivers were secured through five area churches. The faiths represented in this group were Baptist, Methodist, and Catholic. These denominations were selected based on the analysis of responses of religious affiliation from active and past caregiver groups. An initial meeting was scheduled with the clergy in the five churches. The definition used to identify these parents is presented below.

Comparison Group 2: Non-Caregivers

Non-caregivers were defined as birth parents of a child or children without mental retardation or other known disability. These parents were eligible for inclusion in the study if they met three criteria:

1) birth parents of a non-disabled child(ren)
2) having at least one child over the age of 18
3) having no child over age 18 in the household

The clergy used only the first and second criteria to identify parents in their congregations. The final criterion was enforced after surveys were returned from parents who met the first two criteria. This decision was based on an assumption that clergy may not be knowledgeable about household membership composition. The clergy more readily knew if parents in their congregations were living with an adult child then knowing the age of that child. To eliminate any possible bias that parents who were identified were the most familiar to the clergy, the final criterion was enforced to exclude those respondents who reported that they resided with an adult child.

Pre-test of Questionnaire

Parent Group

Prior to the mailing of the questionnaire, two groups were involved in a pre-test and critique of the survey instrument. One group was a support group for parents of mentally retarded adolescents, sponsored through Hanover CSB. These parents were selected because they were not eligible for participation in the study due to the age of their children. However, this group was very interested in the research and agreed to participate in the pre-test.

The parents were involved in two ways. First, they answered and returned the survey draft which was then reviewed and examined to determine if the items were answered correctly. A second task was to provide feedback about their perception of the questionnaire (see Appendix D for cover letter to pre-test parents and feedback sheet). The parents were asked to estimate time to complete the survey, clarity of instructions, and readability.

Seven parents returned the survey and feedback form. This number represented a 70% response rate. A review of the completed questionnaires revealed that the items contained little missing data or incorrect responses. The feedback forms failed to reveal problems in the construction of the survey. The survey took respondents an average of 33 minutes to complete. One respondent commented that the print size was too large, however, no one else mentioned the size as a problem. A final question on the feedback form asked parents if they would have taken the time to complete this survey if they had received it in the mail. All seven respondents state that they would have taken time to complete it.

Information from this group was helpful in this stage of the research. The questionnaires returned by this group appeared to be accurate and complete.

Professional Group

A group of human service professionals were asked to provide feedback about the questionnaire. The Human Subject Committee of Chesterfield CSB reviewed the survey draft. This group is composed of four members, two of whom have doctoral degrees and experience in conducting research projects. Two issues of concern were raised by this group of professionals.

The first issue raised was on the readability of the survey. In response to this concern, an analysis of the reading level of the questionnaire was conducted. The SMOG Index was used to determine how much education a reader would need for comprehesion of the material (Mullens, 1983). The vocabulary of both instructions and items of the questionnaire were analyzed. The overall readability of the questionnaire was between a 6th and 7th grade level, with the raw score of 6.74.

A second issue presented by members of the Human Subject Committee was the length of the questionnaire. This specific concern was the PERI Life Event Scale, which contained a total of 102 items (Dohrenwend et al., 1981). This instument was originally chosen to measure degree of life changes. However, due to the concern about length and difficulty of the instrument, the Life Event Index (Moos et al., 1985) was substituted. A final version of the questionnaire is included in Appendix E.

Data Collection

The data were collected in three stages. Stage 1 was securing parents in the active and past caregiving groups through the CSBs. Stage 2 was securing non-caregiving parents through churches. Stage 3 was conducting family interviews with five families identified by the CSBs. (Appendix F provides a chronological outline of the tasks of the data collection phase.) Data were collected by mailed questionnaire in Stages 1 and 2. In Stage 3, data were collected by interviews conducted within the household of each family.

Survey Data

The casemanager supervisors and church clergy were provided with an information packet describing the research. The casemanager supervisors received an informational packet which included a copy of the research model, diagram of the hypotheses, and question and answer sheet on the research which included a rationale for using the CSBs to identify parents.

Cautions were taken to assure confidentiality of clients in the CSBs. Packets containing the questionnaires were labelled and mailed by agency staff. The packets contained a cover letter which explained the research and assured the parents that their identities were unknown to the researcher (See Appendix G for a sample cover letter to parents).

A number of strategies were employed to increase the return rate of the questionnaires. One was to include an incentive for the parents to take time to complete and return the questionnaire. With input from staff in the CSBs, stickers were printed with a logo stating, "Parents are People Too!" Each cover letter contained a set of stickers for the parents. A second strategy was to conduct a follow-up mailing one week after the questionnaires were mailed. Each casemananger supervisor was given a set of postcards which were mailed through the CSB. This correspondence reminded parents that they had received a questionnaire within the past week and to return it as soon as possible. The strategies of providing an incentive and doing a one week follow-up mailing are associated with higher return rates in mailed surveys (Dillman, 1978). A third strategy used to increase response rates was personalizing the cover letter and postcard. In a study which explored surveys mailed to physicians, personalizing the mailing increased the response rates up to 53.1% (Maheaux, Legault & Lambert, 1989). Each cover letter was co-signed by the researcher and casemanager. The casemanager's name increased familarity with someone associated with the research. Additionally, each postcard contained a handwritten thank-you and signature of the researcher.

One hundred fifty one (151) surveys were returned by the combined group of active and past caregivers. Broken down geographically, 44 were from Richmond and Henrico District each, 24 were from Hanover, 23 were from Chesterfield, and 16 were from Petersburg Distict. Table 7 summarizes the surveys returned within each CSB by caregiver group.

Insert Table 7 here

Table 7

Surveys Returned by Community Services Boards (CSBs)

	Active Caregiver		Past Caregiver	
CSB	Number Returned	% Returned	Number Returned	% Returned
Chesterfield County	12	36%	11	48%
Hanover County	17	59	7	54
Henrico District	29	50	15	79
Petersburg District	9	36	7	47
Richmond City	29	40	15	33
Total	96		55	

The second stage of the data collection process was to secure non-caregiver parents. Prior the selection for this group, a preliminary analysis of surveys returned from the active and past caregiver groups was performed. Churches were contacted from the second data collection phase which represented the religious affiliations of the other two groups. The three most common faiths were Baptist, Methodist, and Catholic. Five churches participated in the study.

An initial meeting was conducted between the researcher and the clergy of the five churches to discuss the purpose of the study. The process for mailing the questionnaires to the non-caregivers was the same as the process used with the CSBs. The clergy co-signed the letter which accompanied the survey. The non-caregivers received a set of stickers and a follow-up post card. A total of 111 surveys were mailed. Seventy-four were returned, which represents a 67% response rate for the non-caregiver group.

Family Interview Data

Family interview data were collected from a group of parents who are active caregivers. One active caregiving family was identified within each of the five geographical areas constituting the sampling frame. These families were selected with the assistance of the casemanager supervisors. The five families were initially contacted through their casemanager for consent in participation. Next, arrangements for the interview were arranged between the researcher and the family. All families agreed to participate.

The interview consisted of one meeting between the researcher and the family in the family's house. This environment was selected as the context for the interview due to the importance of the household setting in understanding family functioning. This context is the arena in which families are least defensive about being investigated (Kantor & Lehr, 1975). The duration of the interview with each family ranged from one to two hours. All interviews were tape recorded and later transcribed by the researcher.

Data Analysis Plan

The data of the study were analyzed in two ways. Survey data were analyzed using procedures from the Statistical Package for the Social Sciences (SPSS-X) through the IBM mainframe system at Virginia Commonwealth University. Analysis of the family interview data was modelled after the constant comparative method which was initially advocated by Glaser and Strauss (1967). Both data analysis procedures are summarized in the following sections.

Survey Data

Bivariate Comparisons

The three caregiver groups were compared using individual and household characteristics. Nominal variables, such as sex and marital status, were compared using a chi square test of significance. This procedure determines whether a statistically significant difference exists between observed and expected frequencies. The observed frequency is the actual frequency for the sample and the expected frequency is the number expected by chance alone (Huck et al., 1974). A critical value for chi square is based upon degrees of freedom, which is a product of the rows and columns of a contingency table (Norusis, 1983). If cells had low observed frequencies, categories were collapsed. For example, marital status was collapsed into categories of married and not married.

Interval level characteristic variables, such as age and length of marital status, were compared using a oneway analysis of variance. An analysis of variance calculates the sum of squares within the groups and between the groups. A significant value implies that the null hypothesis of no differences between the group means can be rejected. An option of the oneway analysis of variance procedure, the multiple comparison test, determines which group means differ. The Scheffe test was selected for this study because it is the most conservative of these tests and requires larger differences between the means to achieve significance (Huck et al., 1974; Norusis, 1983).

The bivariate comparisons did not predict directional differences between the groups. Non-directional hypotheses require that the critical alpha be divided to detect differences in either direction (Huck et al., 1974). The alpha level of .05 was divided in half to yield a critical alpha level of .025 for the bivariate comparisons.

Factor Analysis

Before proceeding with the tests of the hypotheses, a factor analysis was performed on two indices of the survey instrument. A factor analysis is defined as a statistical technique which is used to reduce a set of variables into a smaller number of variables (Kim & Muellor, 1978). A factor analysis was performed using the health activities and the type of social support items.

For the health activity items, the respondents reported whether they had engaged in any of seven activities on a regular basis within the past 12 months. An assumption was made that some of the activities represent positive health habits while others represent negative habits. A factor analysis can be used in this situation to test the assumption that there are two dimensions represented among a set of variables. This is defined as the confirmatory purpose of factor analysis (Kim & Muellor, 1978).

Prior to proceeding with the factor analysis, the items were checked to determine whether the requirements of the procedure were met. The relationships between the items were examined to determine whether they appeared to be related to underlying constructs using three procedures. The first procedure involved Bartlett's test of sphericity which tests the hypothesis that the relationships between the items are either perfect or null correlations (Norusis, 1988). This hypothesis was rejected based upon a value of 64.92, $\underline{p} = .000$. The second procedure was an examination of the anti-image correlation matrix which is the negative matrix of partial correlations between the seven health activity items. The coefficients in the anti-image matrix were low, with absolute values ranging between .013 and .339. The final procedure to assess the appropriateness of running a factor analysis was the Kaiser-Meyer-Olkin (KMO) measure of sampling adequacy. This value is a measure of partial correlations between each pair of variables to the overall correlation coefficient (Norusis, 1985). Any value below .5 is unacceptable to continue with a factor analysis (Kaiser, 1974). The KMO value of .563 found for the seven health activity items was acceptable for proceeding with the analysis.

Two factors were extracted for these items. Factor 1 accounted for 23.2% of the variance with an eigenvalue of 1.62. The four activities which loaded on Factor 1 were:

eating 3 meals daily (.754), sleeping 6-8 hours (.680), exercising (.581) and visiting a doctor regularly (.680). These items are the activities which may have a positive impact on health status. Factor 2 accounted for 19.8% of the variance, with an eigenvalue of 1.38. The three activities which loaded on this factor were: smoking cigarettes (.732), consuming caffeine (.637) and daily alcohol consumption (.406). This factor represents those activities which may have a negative impact on health. The assumption that the seven health activities have a differential impact upon health is supported by the results of the factor analysis.

A second factor analysis was performed on the type of social support items. Measurement in social support research is frequently study specific, which leads to a lack of construct validity in the measurement instruments (House & Kahn, 1985). Classification of the seven items of this study was difficult since multiple definitions of types of support exist in the literature. In this study, a factor analysis was performed using the seven items to determine if these items could be reduced into two or more types. This use of factor analysis is defined as exploratory, since an unidentified number of dimensions are predicted to be represented within a set of variables (Kim & Muellor, 1978).

A factor analysis was performed to determine whether the seven items reflect different types of support. The appropriateness of performing a factor analysis on the types of support items was assessed. The hypothesis that the correlation matrix contained only null or perfect correlations was rejected based upon the Bartlett test of sphericity (value=249.31, p =.000). Secondly, the examination of the anti-image correlation matrix revealed weak absolute values which ranged from .007 to .490. Finally, a KMO value of .754 was above the minimum level sufficient for a factor analysis. The results of these three procedures supported the decision to proceed with a factor analysis of the seven social support items.

Two factors were extracted from the seven items. Factor 1 contained four loadings which represented the variables of talking about personal and private issues (.53), having someone tell you they liked what you did (.67), having someone do something relaxing and fun with you (.81) and receiving physical affection (.81). Factor 1 is comprised of expressive support items, those which communicate affection and acceptance to someone. This factor accounted for 40.9% of the variance with an eigenvalue of 2.86. The remaining three items loaded in Factor 2, which accounted for an additional 15.6% of the variance with an eigenvalue of 1.09. The remaining items were loaning you something (.82), giving you advice (.70) and helping you take care of something (.60). Factor 2 consisted of the instrumental support items. These two factors are consistent with other studies where a distinction is made between the instrumental and expressive types of support (Sherman et al., 1988; Unger and Powell, 1980).

Hypothesis Testing

The hypotheses of the study predicted differences between the three caregiver groups on stress and social support variables. The statistical procedure which was used to test the hypotheses was a oneway analysis of variance since all variables, except one, were interval level. The one variable which was measured at the ordinal level was the degree of contact the respondents had with members of their social support network. Respondents reported whether they received each of seven items of support a lot, some, a little, or not at all within the past month. Although this is an ordinal measurement, an argument has been presented that parametric statistics are appropriate for analyzing ordinal data if the sample is a sufficient size (Huck et al., 1974). Since the sample used in this research is moderately large, a oneway analysis of variance was used to test the hypotheses containing the contact with support variable. The Scheffe multiple comparison test was used to determine significant differences between the groups for all hypotheses of the study.

A significance level of .05 was specified for all hypothesis tests. The level of significance is a probability that defines how rare or unlikely sample data must be before a null hypotheses of no difference between the groups can be rejected (Huck et al., 1974). In hypotheses testing, two types of errors can be made when determining whether to accept or reject a null hypothesis. A Type I error, also called a false rejection error, is the situation of rejecting a true null hypothesis. The probability of committing a Type I error is equal to alpha. A Type II error, called a false acceptance error, occurs when a false null hypothesis is not rejected. Type I and Type II errors are related to each other (Bohrenstedt & Knoke, 1982; Huck et al., 1974). The probability of committing a Type I error can be reduced by establishing a stringent alpha level, for example, an alpha of .001. However, increasing the alpha level increases the chance of a Type II error. Since this study has an exploratory purpose, the decision was made to risk the chance of finding a relationship when none actual exists. Due to the number of hypotheses tested in this study and the specified alpha of .05, a possibility exists that significant findings of the research may be a result of the failure to not reject a false null hypotheses of no difference between the three caregiver groups. However, this risk is one frequently encountered in exploratory research where the goal of the study is to identify relationships between a set of variables.

Discriminant Analysis

Discriminant analysis is a multivariate data analysis procedure. This technique uses a set of predictor variables and a discriminating variable which defines the membership of cases into two or more mutually exclusive groups. Predictor variables are either measured at the integer or ratio level or are dummy variables. Within this study, the discriminating variable was the caregiving status of the parents.

Discriminant analysis has two purposes (Klecka, 1980). One is to classify cases based upon group characteristics that each case most closely resembles. The second purpose is to interpret the differences between groups based upon a set of characteristics, which was the purpose for this study.

Different methods can be used to combine variables which discriminate between the groups. Within this study, a stepwise selection process was used to create the functions. This process selects individual variables by backward and forward elimination. The variable with the smallest value for Wilk's lambda is entered into the function at each step (Norusis, 1985). Wilk's lambda is a ratio of within group sum of squares to total sum of squares (Klecka, 1980). Variables which have already met the criterion must maintain an acceptable value to remain in the function.

Six discriminant analyses were run using both single and multiple construct models. The single models entered characteristic variables, stress, and social support separately. These models tested the hypotheses that the respondents could be classified into caregiver groups solely by the characteristics, stress, or social support variables. The multiple models combined characteristics with stress and social support variables. The hypotheses which supported these models were the combination of characteristics with stress and social support would increase the classification by caregiver status.

Family Interview Data

Family interview data were collected from a group of parents who are active caregivers. One active caregiving family was identified within each of the five geographical areas constituting the sampling frame. These families were selected with the assistance of the casemanager supervisors. The five families were initially contacted through their casemanager for consent in participation. Next, arrangements for the interview were arranged between the researcher and the family. All families agreed to participate.

The interview consisted of one meeting between the researcher and the family in the family's house. This environment was selected as the context for the interview due to the importance of the household setting in understanding family functioning. This context is the arena in which families are least defensive about being investigated (Kantor & Lehr, 1975). The duration of the interview with each family ranged from one to two hours. All interviews were tape recorded and later transcribed by the researcher.

Data collection interviews have been classified into three dimensions (Guba & Lincoln, 1985). One dimension is the degree of structure of the interview, with highly structured interviews characterized by specific, pre-established questions. This interview was more unstructured since the families were asked to describe the family system on the dimensions of activities and bonds of the members, communications, and method of processing change. The second dimension describes the degree to which participants are aware of purpose for the interview. This interview was overt, which means the families were fully aware of the purpose of the interview and how the data would be used. The last dimension is the relationship between the interviewer and participants. On this dimension, the interview most closely matched the rapport interview, which is characterized by a researcher who is perceived by the participants as filling a certain role. The five families were told that the interviewer was a doctoral student working on dissertation research. This interview classification matches the structure of other data collection interviews (Guba & Lincoln, 1985).

Two procedures were used in summarizing and analyzing the interview data. The first step was an analysis of each interview as a whole. The bonds between family members and external systems were determined. The quality of the communications and interactions between family members and external systems was also analyzed. An eco-map was constructed for each family. This type of graphic has been advocated as a method of portraying the relationships and communication processes within the family system and with other external systems in the environment (Beckett & Coley, 1987; Hartman, 1978).

The second procedure followed the constant comparison method which was initially advocated by Glaser & Strauss (1967). Two judges were involved based upon their expert knowledge about mental retardation and the scientific method. One judge has a Master of Rehabilitation degree and works as a national teleconference trainer for supported employment of people with disabilites. The second judge has a Master of Special Education degree and is employed as a supported employment supervisor for people with physical disabilities.

Both judges were given transcripts of the five interviews and read them independently. Next, the researcher divided the interviews into units, defined as the smallest piece of information which has individual meaning (Guba & Lincoln, 1985). Each unit was coded with identifying information about the family and the family member who contributed it. The judges reviewed the units together to determine whether modifications were needed. A unit was expanded or divided if both judges agreed.

After the five interviews were divided, the judges classified the units into categories. The units were sorted into stacks with units which represented similar themes or patterns. After all units had been classified, stacks which were judged to represent different dimensions of a single theme were combined. This process continued until both judges agreed that the remaining stacks did not represent related themes or patterns.

After these final stacks were constructed, the judges assessed the reliability of the classification schema. In interview data, reliability has been defined as the dependability of the the classification system (Guba & Lincoln, 1985). The final stacks were reviewed to determine if any single unit was dissimilar to others. Any dissimilar units were re-classified into more appropriate stacks. The final task of the judges was to label each stack according to the concept or theme which was described.

The purpose of the interviews with five active caregiving families was to gain insight about families with an adult mentally retarded child. Although differences between families exist, data were examined to determine commonality between all the families. Commonality was defined as a stack which contained one or more units from all five families. These stacks contained themes which were common to all the active caregiver families who participated in the interviews. The themes have heuristic value in gaining insight into commonalities between families who perform caregiving for an adult child with mental retardation.

The following chapters summarize the data from the survey and the family interviews.

CHAPTER 4

Results of the Survey Data

This chapter summarizes the results from the analysis of survey data. The first section describes the sample on demographic, stress and social support variables. The next section reports on the hypotheses of the study. The final section of this chapter summarizes and discusses the six discriminant analysis models.

The sample of parents is described by caregiver group. The first section describes each group on individual and household variables. Bivariate comparisons, using crosstabulation and oneway analysis of variance procedures, were run to compare the three groups on characteristic variables. The next sections are descriptions of each caregiver group on the both stress and social supports.

Caregiver Characteristics

Three groups of caregivers were surveyed. Characteristics of each group are described. The variables which were included were gender, race, age, education, employment status and religiosity.

Active Caregivers

Ninety six (*n* =96) parents within the active caregiver group returned the survey. The response for this group was 45%. The majority of this group (85%) were women. The parents were mostly white (63%). Blacks were the only other race represented (37%). The ages of the parents in the active caregiver group ranged from 35 to 80 years, with an average age of 57 years (SD =10.7).

Level of education and labor force involvement of these parents were also reported. Fourteen (14%) percent of these parents had less than a ninth grade education. The majority attended high school (59%) and the remaining parents (27%) had some post high school education. Most of these parents were in the labor force (49%). The remaining parents were either homemakers (25%), or not in the labor force (27%) which includes retirement. The past work experience of these parents was mostly full-time employment (58%). Twenty seven percent (27%) reported that their previous work was a homemaker and the remaining parents reported a part-time work history (15%).

A final individual measure was the religiosity of the parents. The most common affiliation reported was Baptist (54%), followed by Methodist (18%) and Catholic (7%). Other Protestant religions were also represented within these parents (21%). The average number of religious activities reported by this group was one per week, with 37% reporting zero activities. Fifteen percent (15%) of the parents perceived themselves as more religious than others. The remaining parents (85%) perceived themselves as about the same or less religious than others.

Past Caregivers

Fifty five (*n* =55) of the respondents were members of the past caregiver group. The response rate for these parents was 48%. The majority of the respondents in this group were women (82%) and white (70%). Blacks were the only other racial group responding (30%). The age range of these parents was between 35 and 81 years old, with an average age of 58 years (*SD* =9.46).

Eleven percent (11%) reported less than a ninth grade education. Forty-six percent (46%) attended some high school or had a high school diploma. The remaining parents (44%) had some level of post high school education. Most of these parents were in the labor force (58%). The remaining parents were divided between homemakers (22%), and those who were unemployed (20%). The past-work situation for this group was mainly full-time employment (45%), being a homemaker (43%), and being employed part-time (12%).

The religiosity of these parents was somewhat different from the active caregiving group. The most common religious affiliation was Baptist (45%), however, the second most common denomination was Catholic (22%), followed by other Protestants (20%) and Methodists (12%). Twenty nine percent (29%) of the parents perceived themselves as more religious than others. The remaining parents (71%) perceived themselves about the same or less religious than others.

Non-Caregivers

A total of seventy four (n =74) surveys were returned from members of the non-caregiving group. However, not all of these respondents met the criteria for inclusion in the statistical analyses. Some of these parents lived the same household as an adult child. The fifteen who reported living with a child over age 18 were excluded from the sample. The revised total of non-caregivers was 59 respondents. The response rate for this group was 67%.

These parents were typically white females, similar to the other two groups. Women represented 79% of this group, as did whites (79%). Blacks represented 21% of the group with no other races reported. The ages ranged from 37 to 81 years, with an average age of 64 years (SD =10.7).

The education and labor force participation differed slightly from the other groups. Seven percent (7%) of these parents completed an eighth grade education or less, with 61% attending or graduating from high school and 32% having some post secondary education. The majority of these parents were not in the labor force (49%), mainly due to retirement. The rest of the parents were divided between homemakers and people in the labor force (25% each). Most parents had previous worked in full-time employment situations (69%). Homemakers (24%) and part-time employees (7%) were reported with less frequency.

Since church clergy were the identifying source for this group, the religious affiliations of these parents reflected the church denominations that participated in the study. Baptist was the most common membership (59%) followed by Catholics (21%) and Methodists (18%). An average of two religious activities per week were reported by the parents. Twenty five percent (25%) perceived themselves as more religious than others. The remaining parents (75%) perceived themselves as about the same or less religious than others.

Household Characteristics

In addition to individual variables, characteristics about the household of the parents were contained in the survey. These variables included marital status, number of children, functional status of the adult with mental retardation for both active and past caregivers, other disabilities of household members, income, place and length of residence. The next section describes each of the groups on household characteristics.

Active Caregivers

One component of the household characteristics was the marital status of the parents. The majority of the active caregiver group were married (61%), widow/widowers (19%) and divorced parents (17%). Two percent (2%) were never married. For those parents who were currently married, the average length of time in the marriage was 31 years (*SD* =

12.0). Parents who were not married were in their current marital status for an average of 13 years (SD =9.4).

The active caregiver parents reported an average of three children. Sixty seven percent (67%) reported that their adult with mental retardation was the only child in the household. One third (33%) reported additional children in the home, ranging from 8 to 60 years of age.

Most of the adult children with mental retardation were men (59%). The average age of the person with mental retardation was 30 years (SD =8.1). The oldest was reported to be 58 years old. Most of the sons and daughters with retardation required limited assistance in activities of daily living (ADLs). These parents reported that their adult child could accomplish an average of five of the eight ADLs independently.

Other household variables included the number of people in the home, family income and years lived in the home. These families had an average of three people in the household. In addition to the presence of mental retardation, six parents reported the presence of a physical disability, six reported mental illness, and two reported a traumatic brain injury in a household member. Most parents reported incomes of between $10,001 to $25,000 (28%) or $25,001 to $40,000 per year (22%). However, 20% of these families reported household incomes below $10,000. An additional 30% of the parents reported annual incomes above $40,000 per year.

The households were located within the five service areas of the participating CSBs. Richmond and Henrico District each comprised 30% of these households. The remaining households were divided between the other locations of Hanover (17%), Chesterfield (13%) and Petersburg District (9%). The parents reported that they had lived in their current residence an average of 17 years (SD =13.0).

Past Caregivers

Most of the past caregivers were married (57%). Nineteen percent (19%) of the parents were divorced or separated and an additional 14% were widowed. Ten percent (10%) of the parents in this group were never married. The average length for those who were currently married was 32 years (SD =13.2). Parents in this group who were no longer married had been divorced, separated or widowed for an average of 12 years (SD =5.4). The parents in this group had an average of four children. Sixteen percent (16%) had children living in the household.

The adult child with mental retardation was most often a son (58%). The average age of the mentally retarded adult was 31 years (SD =9.1). The oldest was reported as 60 years of age. As with the active caregiver group, the adult child was reported to be able to perform an average of five of the eight ADL tasks independently.

The past caregivers reported an average of two people residing in the household. Three caregivers reported that a household member had a disabling condition with two reports of mental illness and one of a physical disability. Twenty four (24%) of these parents reported incomes of below $10,000 per year. The income of $10,001 to $25,000 per year was reported by 16% of the parents, with an additional 16% reporting incomes of $25,001 to $40,000. The remaining parents (44%) reported annual incomes of greater than $40,000.

The residence of these caregivers was distributed between the five CSB regions. Richmond and Henrico District each contained 30% of the parents. Twenty percent (20%) resided in Chesterfield. Hanover and Petersburg District each contained 11%. These caregivers lived in average of 14 years (_SD_ =11.9) in their current residence.

Non-caregivers

The majority of parents within the non-caregiving group were married (75%). The other parents were either widowed (21%) or divorced (4%). The average length for marital status was 37 years (_SD_ =12.4) for the married couples, and 14 years (_SD_ =10.8) for those who were currently unmarried.

This group reported having an average of three children. Ninety percent (90%) of these parents did not have a child living in the household. Of the 10% with children, the average age of the child was 15 years.

These parents reported living in an household which had an average of two members. Nine caregivers reported that someone in their household had a handicapping condition; five reported a physical disability, one reported a brain injury, and three reported unspecified conditions. The income levels reported by these parents were 9% with annual incomes below $10,000, 37% reporting incomes between $10,001 to $25,000 per year, 15% reporting incomes between $25,001 to $40,000, and 39% reporting annual incomes exceeding $40,000.

These household were from four of the CSB areas. Chesterfield County contained 30% of the parents. The remaining parents were distributed between Hanover County (27%), City of Richmond (23%), and Henrico County (20%). These parents reported an average of 21 years (SD =15.5) in their current residence.

Bivariate comparisons were run to test the null hypothesis of no difference between the three caregiver groups on characteristic variables. Table 8 summarizes these comparisons.

Insert Table 8 here

Caregiver Differences

Significant differences between the groups were found

Table 8

Bivariate Comparisons of Caregiver Characteristics Variables

	Caregiver Groups				
Variable	Active	Past	Non	Significance	
Race					
White	63.2%	70.4%	76.6%	X^2=3.97	df=2
Black	36.8	29.6	21.4	p=.137	
Sex					
Female	85.3%	81.8%	78.6%	X^2=1.12	df=2
Male	14.7	18.2	21.4	p=.571	
Age	M=56.7	M=58.1	M=63.7	F=8.02	df=2,197
(Yrs.)	SD=10.7	SD=9.5	SD=10.7	p=.000	
Education					
< 9th Grade	13.5%	10.9%	6.8%	X^2=5.99	df=4
High School	59.4	45.5	61.0	p=.199	
Post High School	27.1	43.6	32.2		
Current Employment					
In Labor Force	48.9%	58.2%	25.5%	X^2=15.84	df=3
Not in Labor Force	26.6	20.0	49.1	p=.003	
Homemaker	24.5	21.8	25.5		
Past Employment					
Full-time	57.6%	44.9%	69.1%	X^2=8.08	df=4
Part-time	15.2	12.2	7.3	p=.089	
Homemaker	27.2	42.9	23.6		
Religious Affiliation					
Baptist	54.2%	44.9%	58.9%	X^2=17.4	df=6
Methodist	18.1	12.1	17.9	p=.008	
Catholic	7.2	22.4	21.4		
Other Protestant	20.5	20.4	1.8		
Perceived Religiosity					
More	15.3%	29.4%	25.5%	X^2=4.24	df=2
Not More	84.7	70.6	74.5	p=.120	

on three variables of the individual caregivers. The average age of the respondents differed between the three groups, based upon a oneway analysis of variance (F value=8.0, df =2,197, p =.000). The Scheffe multiple ranges test was used to discriminate which groups differed (alpha = .05). This procedure is the most conservative of the numerous post-hoc tests (Huck et al., 1974). A post hoc analysis of the three revealed that the non-caregivers were older than both other groups at an alpha of .05.

As seen in Table 8, a statistically significant difference was found between the groups based on current employment status (X^2 =15.8, df =4, p =.003). Three work situations were compared: labor force participation (either part- or full-time), no labor force participation (laid-off, unemployed, retired) and a homemaker. More of the non-caregivers were not currently working (49%). Additionally, a greater number of the past caregivers reported that they were employed (58%) than the other two groups.

Religious affiliation was the final caregiver variable where statistically significant differences were found (X^2 =17.4, df =6, p =.008). Catholics were underrepresented in the active caregiver group. Additionally, the non-caregivers had fewer members of Protestant groups other than Baptists or Methodists.

In summary, statistically significant differences were found between the individual caregivers on the variables of age, current employment and religious affiliation. Non-caregivers were older than the other two groups and were more frequently not in the labor force currently. Active caregivers represented a religious difference being of Protestant, not Catholic, faith.

Household Differences

The three groups differed significantly on one household variable. Non-caregivers lived in their home a longer time (*M* =21.9 years) compared to past caregivers (*M* =13.7 years). The active caregivers did not differ significantly from the other two groups on length of residence.

A difference approached significance on the location of the family residence ($X^2 = 17.4$, $df = 8$, $p = .03$). Both active and past caregivers were concentrated more in Richmond and Henrico District. None of the non-caregivers lived in Petersburg District.

In summary, the three groups differed significantly on one household variable. Non-caregivers lived a longer time in their current home than past caregivers. The residential location of the respondents was a household variable which approached significance. A larger percentage of non-caregivers lived in the counties of Hanover and Chesterfield than the other groups.

Insert Table 9 here

Stress Measures

Three dimensions of stress were measured. These were the physical health status of the parents, the amount of personal time available, and the degree of change taking place in their life. Physical health status contained four measures: the number of health related activities which were part of the respondents' routine, items on the Physical Symptom, Depressed Mood, and Health Diagnosis Indices. Personal time was measured in number of hours available to the caregiver each week. The degree of life changes was the items reported on the Life Event Index. The following section describes each of the groups on stress variables.

Active Caregivers

The parents in this group engaged in an average of five of the seven health activities. Three of these activities were categorized as health promotion activities. The other two were identified as those activities which have a negative influence on health.

The other health measures involved the current health status of the parents. Active caregivers experienced an average of two items of the Depressed Mood Index. Thirty

Table 9

Bivariate Comparisons of Caregiver Household Variables

	Caregiver Groups				
Variable	Active	Past	Non	Significance	
Marital Status					
Married	60.6%	57.4%	75.0%	X^2=4.40	*df*=2
Not Married	39.4	42.6	25.0	*p*=.110	
Length of Marital Status					
Married	*M*=31.35	*M*=31.9	*M*=37.1	F=2.85	*df*=2,125
Yrs.	*SD*=12.0	*SD*=13.3	*SD*=12.4	*p*=.061	
Not Married	*M*=13.3	*M*=12.4	*M*=13.9	F=.113	*df*=2,60
Yrs.	*SD*=9.4	*SD*=5.4	*SD*=10.8	*p*=.893	
Annual Income					
< $10,000	19.8%	23.6%	8.5%	X^2=11.69	*df*=6
$10,001-25,000	28.1	16.4	37.3	*p*=.069	
$25,001-40,000	21.9	16.4	15.3		
> $40,000	30.2	43.6	39.0		
Years in Home	*M*=16.9	*M*=13.7	*M*=20.9	F=3.74	*df*=2,199
Yr.	*SD*=13.0	*SD*=11.9	*SD*=15.5	*p*=.025	
Residence					
Richmond	30.2%	28.3%	23.2%	X^2=17.39	*df*=8
Henrico	30.2	28.3	19.6	*p*=.0263	
Hanover	17.7	11.3	26.8		
Chesterfield	12.5	20.8	30.4		
Petersburg	9.4	11.3	0.0		

two parents had not experienced any of the items within the past year. These parents reported an average of three health symptoms, measured by the Physical Symptom Index. Eighteen percent (18%) of the remaining respondents stated that they did not have any of these symptoms within the past year. An average of one health diagnosis was reported on the Health Diagnosis Index. Overall, most of the active caregivers perceived their health as better than others their same age (58.%). One-third (33%) felt their health was about the same as other people their same age and the remaining parents (8%) perceived their health was worse than their cohorts.

The second dimension of stress was the number of personal hours available to the parents. The average per week reported by this group was 17.2 hours (*SD* =17.0). In addition, 11% reported that they had no free time. As a group, these parents reported satisfaction with their free time. Most respondents stated that they were either very satisfied or satisfied with their personal time (66%). The remaining parents reported dissatisfaction because of too few free time hours (34%).

A final dimension of stress was the degree of life changed experienced by the caregivers as measured by the Life Events Index. The active caregiver group reported an average of 2.7 total events which they had experienced in the year. The parents reported an average of 1.4 (*SD* =1.5) negative events, .70 positive events (*SD* =.80) and .63, (*SD* =.84) equivocal events within the previous year.

Past Caregivers

The past caregivers responded similarly on the health activity items to the active caregivers. Past caregivers engaged in three positive health activities. Additionally, the group reported two negative health activities.

In reporting the number of Depressed Mood items, an average of two were reported by these parents. Twenty two percent (22%) reported that they had not experienced any of these disturbances within the past year.

On the Physical Symptom Index, the group experienced an average of two symptoms within the past year. Twenty two percent (22%) of this group reported they had not experienced any symptoms. The group reported an average of one item on the Health Diagnosis Index. Overall, this group perceived their health as better than others the same age (56%). Thirty seven percent (37%) of these parents perceived their health as the same and only eight percent (8%) reported their health as worse than others in their age cohort.

The past caregivers reported an average of 20.5 hours per week (*SD* =20.1) of personal time. Six percent (6%) of the members of this group stated that they had no time for themselves over the course of a usual week. Sixty-four percent (64%) reported that they were either very satisfied or satisified with this amount of time. The remaining parents (36%) reported dissatisfaction resulting from too few hours of free time.

Past caregivers reported the same number of life change events within the past year as the active caregivers. The average number of events was 2.7 for past caregivers. These parents experienced an average of 1.33 negative, .67 (SD =.88) positive, and .73 (SD =.99) equivocal events.

Non-Caregivers

The non-caregiver group reported an average of five activities which affect overall health status. As with the other two groups, the average number of positive activities was three and the negative was two activities.

These parents reported an average of one Depressed Mood item within the past year. Forty-three percent (43%) of the parents reported that they had not experienced any of the items. This group reported an average of two health symptoms within the past year. Twenty six (26%) percent reported that they did not have any of the symptoms. For the health diagnoses, the group average was one condition. Overall, this group rated their physical health as better than others within the same age category (75%). Twenty three percent (23%) judged their health as the same while two percent (2%) rated their health as worse than others.

These non-caregiver parents reported an average of

26.2 hours of free time per week (*SD* =14.5). This group reported high levels of satisfaction regarding the free time they had available. Eighty-two (82%) percent reported they were either very satisfied or satisfied with this amount of time. Eighteen percent (18%) of the parents expressed dissatisfaction with the amount of free time. Fourteen percent (14%) of the dissatisfied parents reported that their free time was not enough. The remaining members of the dissatisfied group (4%) reported they had too much time.

On the measure of life change, the non-caregiving group experienced an average of three events in the last year. This group experienced an average of 1.4 (*SD* =1.4) negative, and one (*SD* =1.4) positive and .67 (*SD* =.92) equivocal event.

Social Support Measures

This section describes the three caregiver groups on the social support variables. Three dimensions of support were used in the study. The social relation dimension includes the overall number of members, the distribution of these members across home and family, health, personal and social, and money and finances sub-networks. The second dimension of social support is the structure of the support network, which includes the roles of the different network members and the proximity in age to the respondent. The final dimension is the functional content of the support and includes the degree of reciprocity in the exchanges of the network, satisfaction with supports, and type of support received. The following sections describe the social supports for each of the three groups.

Active Caregivers

The active parent group reported an average of 3.8 members in their overall support network (*SD* =2.5). Sixteen percent (16%) of the respondents in this group had empty networks, meaning their networks contained no members. Membership composition of the overall network was broken into four sub-networks. The average number of members in each were 2.3 (*SD* =1.7) in home and family, 1.9 (*SD* =1.3) in health, 2.2 (*SD* =1.7) in personal and social, and 1.2 (*SD* = 1.2) in money and finances sub-networks.

The structural dimension of social support included the roles and ages of network members. A family member other than a spouse or child (32%) was the most common network member. The other roles represented were: friends (28%), children (15%), a spouse (12%), a helping professional (8%), neighbors (5%), and other individuals (1%). The greatest number of these supports were younger than the respondent (50%), followed by older (31%) and same age (19%) members.

The final dimension of social support was the functional content which includes the reciprocity of the exchange, satisfaction with supports, and the type of support received. Reciprocity was measured in each of the four sub-networks. Parents identified people to whom they provided support in each sub-network area. A reciprocity ratio was calculated for each of the sub-networks based upon the number of people who provided the respondents with support divided by the number to whom the respondent provided support, multipled by 100. The reciprocity ratios for active caregivers were: 90.7 for health, 77.4 for personal and social, 76.7 for money and finances, and 72.25 for home and family sub-networks. Health received the highest satisfaction rating with 96% of the parents reporting that they were either very satisfied or satisfied with their health supports. Money and finances received the second highest rating (95%), followed by personal and social (95%) and home and family (91%) sub-networks.

Past Caregivers

The past caregivers reported an average of 3.6 individuals in their overall support network. Sixteen percent (16%) of the group had empty networks. Across the different sub-networks, the parents reported an average of 2.0 (*SD* =1.8) supports for home and family, 1.7 (*SD* =11.5) for health, 1.8 (*SD* =1.8) for personal and social and 1.3 (*SD* =1.5) for money and finances.

The roles of the network members were analyzed. The role most frequently reported in the overall network was a friend (28%), followed by a family member other than a child or spouse (27%), a child (21%), a spouse (10%), a helping professional (5%), and a neighbor (1%). The majority of these members were younger than the respondent (57%), followed by people the same age (23%) and older (20%) members.

The final dimension of support was the functional content. This included the reciprocity in the exchanges, satisfaction with support, and type of support received. The highest reciprocity ratio for these parents was in the health sub-network, which was 103.7. The remaining ratios were 68.5 for home and family, 65.3 for money and finances, and 56.0 for personal and social sub-networks. Similar to the active caregiver group, these parents reported high levels of satisfaction with their support. For all sub-networks, most parents reported they were either very satisfied or satisfied with their supports. The percentage of parents who were satisfied with supports was highest for home and family (95%), followed by personal and social (92%), health (92%), and money and finances (90%).

Non-caregivers

The parents in the non-caregiving group identified an average of 3.9 individuals in their overall support network. Seven percent (7%) of these parents reported empty networks. The averages in the sub-networks were: 2.5 (*SD* =1.5) members for home and family, 2.1 (*SD* =1.5) for health, 2.0 (SD =1.6) for personal and social, and 1.5 (SD =1.6) for money and finances.

The roles of the network members were analyzed for the non-caregiver group. The most common role was a friend (33%). Other roles which were represented were: child (22%), other family member besides a child or spouse (18%), spouse (16%), neighbor (5%), helping professionals (5%), and other (1%). Most of the supports were younger than the non-caregivers (54%). Twenty eight percent (28%) were the same age and 18% were older than this group.

These parents had high reciprocity ratios and satisfaction ratings for all four sub-networks. Each sub-network had a reciprocity ratio which was greater than 100. The actual ratios were: 128.9 for health, 124.2 for personal and social, 124.1 for home and family, and 101.5 for money and finances sub-networks. The satisfaction with supports was also high in this group. All the parents (100%) reported that they were very satisfied or satisfied with their supports. No respondent reported dissatisfaction in any of the four sub-networks.

Study Hypotheses

Stress Hypotheses

The stress hypotheses predicted that active caregivers would report higher degress of stress than the other groups. Non-caregivers were predicted to report the lowest degrees of stress in the three groups. The stress hypotheses are listed below.

<u>HYPOTHESIS 1:</u> Active caregivers of mentally retarded adults will report higher degrees of stress than past caregivers.

<u>HYPOTHESIS 3:</u> Active caregivers of mentally retarded adults will report higher degrees of stress than non-caregivers.

<u>HYPOTHESIS 5:</u> Past caregivers of mentally retarded adults will report higher degrees of stress than non-caregivers.

Physical Health

These three hypotheses were further specified by identifying three measures of stress. These were physical health, personal time available to caregivers, and the experience of life change events. The physical health dimension involved three sub-hypotheses. These three were:

1. Active caregivers will report a greater number of physical health problems than past caregivers.
2. Active caregivers will report a greater number of physical health problems than non-caregivers.
3. Past caregivers will report a greater number of physical health problems than non-caregivers.

Physical health was measured by the number of health activites of the parents, number of items on the Physical Diagnosis, Depressed Mood, and Health Diagnosis Indices. A statistically significant difference was found between the groups on two of the four measures. Differences between groups were determined by the Scheffe multiple ranges test (alpha=.05).

The two differences were on the number of Physical Symptoms and Depressed Mood items. Active caregivers reported a greater number of health symptoms (_M_ =2.9) than the non-caregivers (_M_ =1.9) (F ratio=4.17, _df_ =2,207, _p_ =.02). A second difference was that non-caregivers reported fewer depressed mood items (_M_ =1.0) than past (_M_ =1.8) or active (_M_ =1.8) caregivers (F ratio=4.47, _df_ =2,207, _p_ =.01).

The final indicators of physical health were the Physical Diagnosis Index and five activities which either positively or negatively affect health status. No statistically significant differences were found when the three groups were compared the number of health diagnoses reported. The health activities also revealed no statistically significant differences between the groups.

Personal Time

The number of hours of free time available to the respondents was a second hypotheses. The personal time dimension was a measure of stress was specified in three sub-hypotheses. These were:

1. Active caregivers will report fewer hours available for personal time than past caregivers.
2. Active caregivers will report fewer hours available

for personal time than non-caregivers.

3. Past caregivers will report fewer hours available for personal time than non-caregivers.

Respondents were asked to report on the amount of personal time available within a week. Active caregivers reported significantly fewer hours of free time than the non-caregivers (F ratio=3.70, _df_ =2,183, _p_ =.03) based upon the Scheffe multiple ranges test (alpha=.05). The average hours per week for active caregivers was 17.2 (_SD_ = 17.0) hours, compared to 20.54 (_SD_ =20.1) for past, and 26.15 (_SD_ = 14.4) for non-caregivers. However, no difference existed between the parents on the degree of satisfaction they felt with this amount of time.

Life Change Events

The degree of life change for the three groups was measured by the Life Event Index. The overall number of changes were tabulated and events were classified into either positive, negative or equivocal categories depending upon the outcome of the event for an individual. The classification of life events into the three categories has been performed in other studies on life events (Moos et al., 1985). The three sub-hypotheses for life change were:

1. Active caregivers will report a greater number of life changes than past caregivers.
2. Active caregivers will report a greater number of life changes than non-caregivers.

3. Past caregivers will report a greater number of life changes than non-caregivers.

No statistically significant difference was found between the three groups on the total number of life events experienced within the past year. However, when events were classified into positive, negative or equivocal effects, one difference approached significance. Non-caregivers reported a greater number of positive life events than the other groups (F ratio=2.98, *df* =2,207, *p* =.053). Non-caregivers reported an average of 1.05 (*SD* = 1.0) of these events compared to .70 (*SD* =.79) for active and .67 (*SD* =.88) for past caregivers. No differences were found between the groups on the number of negative or equivocal events.

In summary, the stress hypotheses which predicted differences between the three caregiver groups were partially supported. Differences tended to be between the two groups of parents with a mentally retarded adult child and the non-caregiver group. Active caregivers reported a greater number of health symptoms than non-caregivers, and non-caregivers reported fewer mood disturbances than the other groups. Active caregivers reported fewer hours of free time than the non-caregivers. Non-caregivers experienced a greater number of positive life changes than the other two groups. Table 10 summarizes the statistically significant differences between the caregiver groups.

Insert Table 10 here

Social Support Hypotheses

The social support hypotheses predicted that the three parent groups would report different social support constellations. The social support hypotheses are listed below:

HYPOTHESIS 2: Active caregivers will report a different social support constellation than past caregivers.

HYPOTHESIS 4: Active caregivers will report a different social support constellation than non-caregivers.

HYPOTHESIS 6: Past caregivers will report a different social support constellation than non-caregivers.

These three hypotheses were further specified by identifying three dimensions of social support. These were: social relation, social network, and functional content dimensions. Sub-hypotheses for each dimension are listed in the following section.

Social Relation Dimension

One dimension of social support was the social relation dimension. Two variables were included. The first was the number of supports identified in the social support network of the parents. The second variable was the contact between the parents and their supports. Each

Table 10

Statistically Significant Differences by Caregiver Group on Stress Variables

	Stress Variable		
	# Health Symptoms	# Mood Disturbances	Hours of Free Time
Mean Per Group			
Active	*M*=2.9	*M*=1.8	*M*=17.2
Past	*M*=2.0	*M*=1.8	*M*=20.5
Non	*M*=1.9	*M*=1.0	*M*=26.1
F Ratio	4.17 *df*=2,207	4.47 *df*=2,207	3.70 *df*=2,182
Significance	*p*=.02	*p*=.01	*p*=.03
Differences Between Groups	1 & 3	(1,2) & 3	1 & 3
Scheffe Alpha	.05	.01	.05

of the sub-hypotheses are summarized below:

1. Active caregivers will report fewer people in a social support network than past caregivers.
2. Active caregivers will report fewer people in a social support network than non-caregivers.
3. Past caregivers will report fewer people in a social support network than non-caregivers.

The number of people named as supports did not differ significantly between the three groups. The average number of supports identified were 3.8 for active caregivers, 3.6 for past caregivers, and 3.9 for non-caregivers. A chi-square test of significance was used to determine if differences existed between the caregiver groups on the number who had empty grids. An empty grid indicated that the respondent did not name any person as a support. Although the average number of network members was not different between the groups, fewer non-caregiver parents (7%) had empty networks than either active (15%) or past (16%) caregivers (X^2=5.82, <u>df</u> =2, <u>p</u> =.054). In addition to the overall support network, membership in each sub-network was analyzed. No statistically significant difference was present in the number of supports identified in any of the four sub-networks when the groups of caregivers were compared.

The second variable in the social relation dimension was the contact between caregivers and their supports. The sub-hypotheses predicted that active caregivers would have fewer contacts with supports and non-caregivers would have the greatest number of contacts.

1. Active caregivers will report fewer contacts with supports than past caregivers.
2. Active caregivers will report fewer contacts with supports than non-caregivers.
3. Past caregivers will report fewer contacts with supports than non-caregivers.

Parents were asked to report how frequently they had received seven types of support. The respondents reported whether they had received no support at all, a little, some or a lot of support for each of seven support items. A one-way analysis of variance was used to determine differences between the average amount of contact for each group. The mean scores indicated that the groups averaged a little support within the past month. Non-caregivers had the highest average score (*M* = 1.5, *SD* =.56) compared to active (*M* = 1.47, *SD* = 1.47) and past caregivers (*M* = 1.45, *SD* = 1.45). No statistically significant difference was found among the groups on their contact with supports (F ratio =.109, *df* =2,207, *p* =.896).

The sub-hypotheses of differences about the social relations of the respondents to members of their support network were not supported. The three groups of caregivers reported social support networks of about equal sizes.

This finding was both in their overall support network and their four sub-networks of home and family, health, personal and social, and money and finances areas. No significant differences were found between the groups on the level of contact the caregivers had with their supports. All three groups received an average of a little support within the past month.

Social Network Dimension

The second dimension of support was the social network dimension. One variable which was included was the number of cohorts identified by the caregivers as supports. Supports were classified as five years or older, five years or younger, and the same age as the respondent. The sub-hypotheses are presented below:

1. Active caregivers will report fewer age cohorts as members of their social support network than past caregivers.
2. Active caregivers will report fewer age cohorts as members of their social support network than non-caregivers.
3. Past caregivers will report fewer age cohorts as members of their social support network than non-caregivers.

In the overall support network, the number of age cohorts did not differ between the three groups. Active caregivers had an average of .69 (*SD* =.94) network members their same age. Past caregivers reported an average of .78 (SD =1.15), and non-caregivers reported 1.07 (SD =1.29) supports who were within the 10 year age span of themselves.

Although there were no differences in the overall networks, differences in the number of age cohorts were found in the sub-networks of the respondents. Non-caregivers identified a greater number of individuals of the same age than either active or past caregivers in their health sub-network (F ratio=3.74, df =2, 187, p =.025). The money and finances sub-network contained similar differences (F ratio=5.97, df =2,184, p =.003). The Scheffe post hoc test was run with an alpha of .05 to determine differences between the groups. Non-caregivers reported a greater number of same age supports compared to active and past caregivers. A third sub-network, personal and social issues, approached significance (F ratio=2.53, df =2,185, p =.082). The trend was in the same direction, where non-caregivers reported more same age cohorts than active and past caregivers.

The second variable of the social network dimension was the supports who held formal roles. The sub-hypotheses predicted that active caregivers would identify a greater number and non-caregivers would identify the fewest supports in formal roles. Formal roles were defined as helping professionals. The sub-hypotheses are summarized in the following section.

1. Active caregivers will identify a greater number of people in formal roles as supports than past caregivers.
2. Past caregivers will identify a greater number of people in formal roles as supports than non-caregivers.
3. Past caregivers will identify a greater number of people in formal roles as supports than past caregivers.

No significant differences were found between the parents in the number of people in formal roles who were identified in the overall support networks. When each of the sub-networks was decomposed by roles, however, differences were discovered in the number of individuals in formal roles. In home and family, health, personal and social, and money and finances sub-networks, non-caregivers identified a significantly greater number of helping professionals than the other two groups. This finding is directly opposite to the sub-hypotheses which predicted that the network of non-caregivers would contain the fewest number of people in formal roles. Table 11 summarizes these differences.

Insert Table 11 here

Table 11

Supports in Formal Roles by Caregiver Group for Sub-Networks

	Sub-Network			
	Home/ Family	Health	Personal/ Social	Money/ Finances
Average Number				
Active	.47	.35	.48	.40
Past	.53	.49	.35	.33
Non-caregivers	1.36	1.97	2.20	2.15
F Ratio	3.41	9.00	10.44	10.50
Significance	.035	.000	.000	.000
Differences Between Groups	1 & 3	(1,2) & 3	(1,2) & 3	(1,2) & 3
Scheffe Alpha	.05	.01	.01	.01

In summary, differences were found between the caregiver groups on the social network dimension of social support. No differences existed between the three groups in the number of same age cohorts or supports holding formal roles in the overall social support networks of the caregivers. However, differences existed in the four sub-networks. Non-caregivers identified a greater number of same age cohorts in the areas of health, and money and finances. The non-caregiver group tended to identify people of the same age as supports in their personal and social sub-networks. Non-caregivers also identified a greater number of people in formal roles than the other groups in each of their four sub-networks.

Functional Content Dimension

The final dimension of support was the functional content dimension. Three variables were measured. One variable was the degree of reciprocity in the social support networks of the caregivers. The sub-hypotheses predicted that active caregivers would have networks with lower degrees of reciprocity. Non-caregivers were predicted to have the greatest degree of reciprocity in their exchanges.

1. Active caregivers will report fewer reciprocal exchanges within the social support system than past caregivers.
2. Active caregivers will report fewer reciprocal

exchanges within the social support system than non-caregivers.

3. Past caregivers will report fewer reciprocal exchanges within the social support system than non-caregivers.

Reciprocity ratios were calculated for each of the four sub-networks. Two sub-networks had ratios which reached significance between the parent groups. Non-caregivers had higher ratios in home and family, and personal and social sub-networks than the other groups. Table 12 summarizes the reciprocity ratios among the three groups.

Insert Table 12 here

The second variable which was measured was the caregivers' degree of satisfaction with their support. The respondents stated whether they were very satisfied, satisfied, dissatisfied, or very dissatisfied with the supports they identified in the four sub-networks. The sub-hypotheses predicted that active caregivers would have the lowest degrees of satisfaction. Non-caregivers were predicted to report the highest satisfaction. The sub-hypotheses about satisfaction with support are summarized below:

1. Active caregivers will report lower degrees of satisfaction with their social support system than

Table 12

Reciprocity Ratios for Sub-Networks by Caregiver Group

	Sub-Network			
	Home/ Family	Health	Personal/ Social	Money/ Finances
Average Number				
Active	72.25	90.78	77.4	76.71
Past	68.46	103.38	56.01	65.34
Non-caregivers	124.08	128.87	124.22	101.52
F Ratio	8.43	1.57	7.96	2.06
Significance	.000	.21	.000	.13
Differences Between Groups	(1,2) & 3		(1,2) & 3	2 & 3
Scheffe Alpha	.01		.05	.01

past caregivers.

2. Active caregivers will report lower degrees of satisfaction with their social support system than non-caregivers.
3. Past caregivers will report lower degrees of satisfaction with their social support system than non-caregivers.

All the groups reported high degrees of satisfaction with their supports across all four sub-networks. A chi-square analysis was run to determine if differences existed between the groups on satisfaction with support. Differences between the groups in the home and family (X^2=44.79, df =2, p =.09), health (X^2=3.37, df =2, p =.19), personal and social (X^2=2.45, df =2, p =.29), and money and finances (X^2=3.98, df =2, p =.14) sub-networks were not found.

The final variable in the functional content dimension was the type of support received by the caregivers. The respondents reported on the types of support they had received within the past month. Through the factor analysis of the seven support items, each item was classified as either instrumental or expressive types. The sub-hypotheses listed below summarize the predicted differences by group.

1. Active caregivers will report fewer expressive and greater instrumental exchanges within their social

support system than past caregivers.

2. Active caregivers will report fewer expressive and greater instrumental exchanges within their social support system than non-caregivers.
3. Past caregivers will report fewer expressive greater instrumental exchanges within their social support system than non-caregivers.

No statistical significant differences were found between the three groups on the amount of expressive support they had received (F ratio=.067, df =2, 164, p =.94). Additionally, no statistical significance was found on the instrumental support received by the parents, although this amount approached significance (F ratio=2.953, df =2,160, p =.055).

In summarizing the finding on the functional content dimension of support, one statistically significant difference was discovered between the caregivers. In all four sub-network areas, non-caregivers reported higher levels of reciprocity in the exchanges with their supports. The groups did not differ on their satisfaction with their support systems nor the type of support received.

Overall, the social support hypotheses of differences in the social support constellations of the three groups received partial support. Non-caregivers differed from the other groups by having fewer empty networks, by identifying more supports filling formal roles in all four sub-network areas, by having higher reciprocity ratios in the home and family, and personal and social sub-networks, and by identifying more age cohorts in their sub-networks of health, and money and finances. The social support networks of the active and past caregiver groups did not differ significantly on any variable.

Discriminant Models

Single Construct Models

Three single construct models were run to see if a single set of variables would be the predictors of group membership for this sample. The characteristics model contained both individual and household variables. Since many of these variables were nominal level, dummy variables were constructed to enter into the model. The actual items which were included in the model were: being married, level of education, being white, being female, being employed, living in Richmond/Henrico District which were the two most populated areas, years in home and income. The stress model consisted of the number of physical symptoms, the number of depressed feelings, the amount of free time, the number of positive and number of negative life events experienced. The final model contained the eight social support variables which were the number of supports, degree of contact with supports, number of same aged cohorts, number of supports in formal roles, degree of reciprocity, satisfaction with support, and the number of instrumental and expressive exchanges. Table 13 summarizes the results of the three single construct models.

Insert Table 13 here

None of the single construct models were good predictors of group membership. The functions which were derived within each of the models did not reach significance. In discriminant analysis, the significance of a function is determined by converting Wilk's lambda to a chi-squared distribution (Norusis, 1985). A small value for lambda indicates that within group variability is small compared to the total variability within the entire sample. Within all the single construct models, the null hypothesis of no differences between the groups based upon the functions could not be rejected.

Multiple Construct Models

Three multiple construct models were also run using discriminant procedures. These models contained the same measures as the single models, however, multiple sets were entered simultaneously. Two models combined characteristic variables with either stress or social support and a final model contained all three sets of predictors. Table 14 summarizes the three multiple construct models.

Table 13

Single Construct Models

	Demographics	Stress	Social Supports
Function 1			
Eigenvalue	.06933	.10038	.10144
% Variance	56.73	78.81	82.83
Canonical Correlation	.26	.30	.30
Wilk's Lambda	.88	.89	.89
Significance	X^2=17.37 _p_=.36	X^2=18.09 _p_=.053	X^2=17.20 _p_=.37
Function 2			
Eigenvalue	.05289	.02699	.02102
% Variance	43.27	21.19	17.17
Canonical Correlation	.22	.16	.14
Wilk's Lambda	.95	.97	.97
Significance	X^2=7.55 _p_=.37	X^2=3.94 _p_=.41	X^2=3.05 _p_=.88

Insert Table 14 here

The only model which produced significant differences between the groups on the functions was the one containing characteristic variables, stress and social support. Eight variables were contained within the two functions of the model. Function 1 (p =.002) accounted for 66% while Function 2 (p =.069) accounted for the remaining 34% of the variance.

Function 1 contained six variables. The function combined the reciprocity ratio, the number of positive life events, the amount of free time, and white racial membership. Two additional measures had negative coefficients which were the number of depressed mood items and living in Richmond/Henrico.

The combination and coefficients of the variables are clues to the meaning of the function. The standardized canonical discriminant function coefficients estimate the relative importance of the individual variables within the overall function (Klecka, 1980). The variable in Function 1 which has the highest coefficient is experiencing depressive thoughts and is a negative coefficient. The other variable with the next largest coefficient is the ratio of reciprocity in the exchanges within the support network. Table 15 summarizes which variables entered into

Table 14

Multiple Construct Models

	Demographics & Stress	Demographics & Social Support	Demographics Stress & Social Support
Function 1			
Eigenvalue	.18520	.06933	.17797
% Variance	69.02	56.73	65.52
Canonical Correlation	.40	.25	.39
Wilk's Lambda	.77	.88	.78
Significance	$X^2=35.97$ $p=.09$	$X^2=17.37$ $p=.36$	$X^2=37.11$ $p=.002$
Function 2			
Eigenvalue	.08313	.05289	.09367
% Variance	30.98	43.27	34.48
Canonical Correlation	.277	.22	.29
Wilk's Lambda	.92	.95	.91
Significance	$X^2=11.49$ $p=.49$	$X^2=7.55$ $p=.37$	$X^2=13.12$ $p=.069$
% Cases Correct (Chance=33.33%)			47.14

Function 1.

Insert Table 15 here

An examination of the individual items reveals that Function 1 includes variables from the four levels of systems contained within the research model. The individual variables (microsystem) includes the depressed mood and life events variables. The reciprocity variables represents symmetry in exchanges which is an relationship variable (mesosystem). Two other variables are exosystem variables, meaning those which have an indirect effect on functioning. Those area the degree of free time and residence of the respondents. The final variable entered into Function 1 was being white, which may be a surrogate variable for the experience of prejudice and discrimination experienced by Blacks. The variables which combine in Function 1 suggest that classification into caregiver groups is increased if variables are included which represent multiple levels of functioning.

An examination of the group centroids for Function 1 clarify how the three groups differ. A group centroid is the mean of the group for all of the variables entered into the function (Klecka, 1980). The dispersion of the centroids for each group is in the direction predicted by the study hypotheses. Active caregivers have the lowest

Table 15

Standardized Canonical Function Coefficients for Demographic, Stress and Social Support Model

	Function 1	Function 2
Demographics		
Education Level		.84
Race--White	.31	
Location live-- Richmond/Henrico District	-.37	
Stress		
# Depressed Mood	-.56	
# Hours Personal Time	.30	
# Life Changes--Positive	.37	
Social Support		
Reciprocity in Exchanges	.56	
Satisfaction with Supports		-.55
Group Centroids		
Active Caregivers	-.30	-.23
Past Caregivers	-.14	.49
Non-Caregivers	.69	-.07

mean while the non-caregivers have the highest. Past caregivers have a mean score that falls between the two other groups.

Although Function 2 was not significant at alpha .05, the function did approach significance (p =.069). Function 2 contained two variables which were years of education of the repondents and their satisfaction with supports . Education had a positive standardized coefficient (.84) while satisfaction with supports had a negative one (.-54). This function is the combination of higher levels of education and lower levels of satisfaction with their support systems.

Group centroids for Function 2 revealed a different order of the groups than Function 1. Past caregivers had the highest mean (.50) with active caregivers having the lowest (-.23). Non-caregivers fell between the other groups (-.07).

In summary, six discriminant models were constructed to determine which variables would predict membership of the three parent groups over chance. Only one function, a combination of characteristics, stress and social support measures, reached significance. The second function contained within the model approached significance.

The model did improve the ability to classify cases into the correct group over chance alone. By chance, a correct classifaction rate was 33.3%. The model had a rate of 47.14% in correctly classifying the cases. However, the eigenvalue, which is an estimate of the explained variance, was low for both functions. Function 1 had an eigenvalue of .177. The value for Function 2 was .093. While the classification of cases improved, a large amount of the variance between groups remains unexplained by the model.

The parent role is performed within the context of a family system. To gain additional understanding about family functioning, interviews were conducted with five families where an adult with mental retardation lived in the same household. The context of the interviews was the family home. The interviews gathered data about activities, communication patterns, and changes in the family system. The data from the interviews are summarized in the next chapter.

CHAPTER 5

Results of Family Interviews

Five families were interviewed to gain an indepth understanding of family functioning in families with an adult mentally retarded son or daughter. One family was selected from each of the five geographic areas surveyed as part of this study. The families participating in this part of the research were identified by a casemanager. All families contacted agreed to participate in the study. The interviews were conducted in their homes.

The following sections summarize information from the family interviews. The first section describes the family by their activities, patterns of communication, and methods of processing changes. An eco-map is presented for each family. An eco-map is a visual representation of the family in their life space. This tool has been tested in a variety of settings with a range of clients and has been found to be an effective method of portraying client data (Beckett & Coley, 1987; Freeman, 1984; Hartman, 1987). The second section identifies themes across families which emerge from the data for the three areas.

Description of Families

Chesterfield County

The family from Chesterfield was white and resided in the eastern section of the county. The family consisted of the father who was in his early 50s, and two twin autistic sons who were 18 years of age. The parents are separated and the mother resides in another city about 100 miles away. The father is employed as an engineer and the sons attend a special education school. One daughter, aged 19, is in military training in another state. Due to the limited communication of the sons, the father provided information in the interview. Figure 6 presents an eco-map of the family.

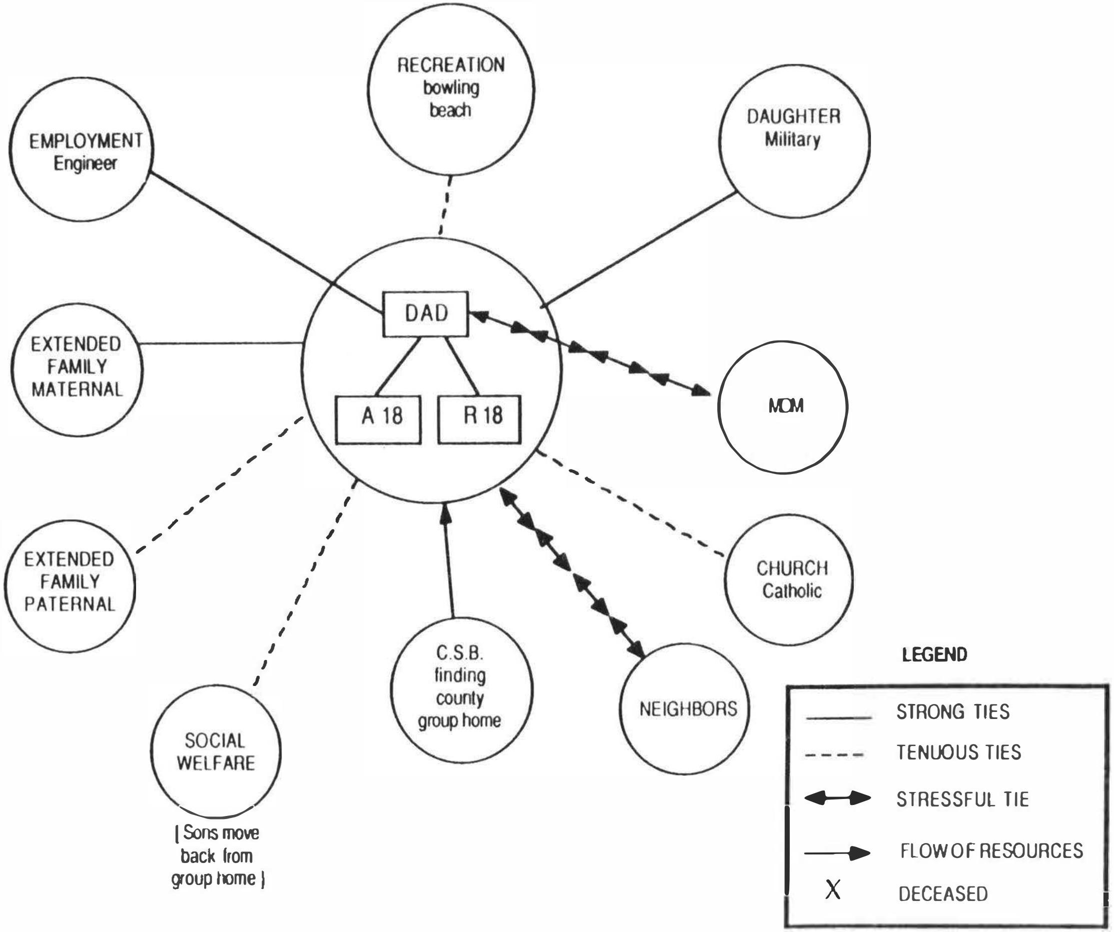
Insert Figure 6 here

Family Activities

Within the past two years, the family has experienced changes in household composition which affected the activities the family performs together. The parents have recently separated and the daughter has entered a military training program. The mother has only minimal contact with the sons.

When the family lived together, they attempted outings in the community. They would go to amusement parks, the

Figure 6. Eco-Map of Family in Chesterfield



beach, or church services. The father described these outings as stressful events. The twin sons would walk away or were socially inappropriate in their behaviors, for example, perform spontaneous vocalizations. The father stated that he did not perceive that his sons were accepted by some members of their extended family or the community.

The activities of the parents as a couple were explored. When they were together, the parents did not have many opportunities to spend time alone. The father reported that it was difficult finding care for their two sons, and their daughter would care for both of her brothers. He described one instance when one of the twins wandered onto a busy highway when the parents were away. On the way home from their outing, the parents saw their son riding his bicycle down the side of a heavily travelled road. This incident was frightening for the family and decreased the outings planned by the parents.

Activities between parent-child dyads were also discussed. Currently, the father takes the sons bowling as a weekly outing. He reports difficulty in supervising both of them together, as one frequently wanders away while the other is bowling.

The siblings do not have regular interactions. Since the daughter moved away, she has limited opportunity to return to the family home. Although the sons share a bedroom, they do not interact with each other. The father states that they frequently act as if the other did not exist.

The father does maintain ties away from the family unit. He is employed as an engineer and reports that he is satisfied with his job. He socializes with others from work. For example, he and a friend were going to a baseball game following the interview. He reports that he has always been more social than his wife, who did not maintain many connections outside the family.

Communication

The twin sons have minimal communication skills. Only one of the sons is verbal. He has minimal language skills and resists speaking even when directly addressed. The other son has no verbal skills and relates via gestures and minimal signing. The sons have virtually no input into family decision-making.

The father states that he has assumed the role of spokesperson for the family with other systems. For example, he was the liaison with his sons' school, and joined a support network for parents of mentally retarded children. He has also intervened with neighbors in situations involving his sons when on a few occassions, they have wandered onto other's property, upsetting the neighbors. He stated that he never told his wife about these incidents, as she would have become very hostile toward the neighbors.

Family Change

This family has recently experienced dramatic changes in the composition of household membership. Within the past two years, both the daughter and mother have moved out of the household. The sons are moving into a group home in the very near future. The father stated that the children's moves were planned and expected. He did not expect the separation from his wife. He expressed confusion and uncertainty about the reasons for her decision to separate.

The family has had to make changes in an attempt to assimilate into their neighborhood. The father describes the frustration felt by the parents in trying to maintain a household with autistic twins. He reported an incident where they purchased new carpet and shortly afterwards one son set it on fire. At other times, the sons would have temper tantrums and knock plaster from the walls. In an attempt to maintain the standards of the community, the parents became skillful at and spent a considerable amount of money on home maintainance.

The father also spoke of opportunities which were missed due to the disability of their sons. He has had to decline job promotions out of the community so the sons' school and services would not be disrupted. He also spoke of plans he and his wife were unable to implement because of expense and caregiving responsibilites.

Summary

In summary, the family from Chesterfield County consisted of three members. The father was employed and the autistic twin sons were in school programs. Recently, the mother and father separated and the daughter moved out of state. The family has had difficulty integrating into the community. The father was the parent connected with other systems in the environment. One son has limited verbal skills and the other son knows minimal signs. The family has been able to engage in only limited family activities because of problems in supervising two autistic children. Currently, the father is the family member with whom the sons have the most contact.

Hanover County

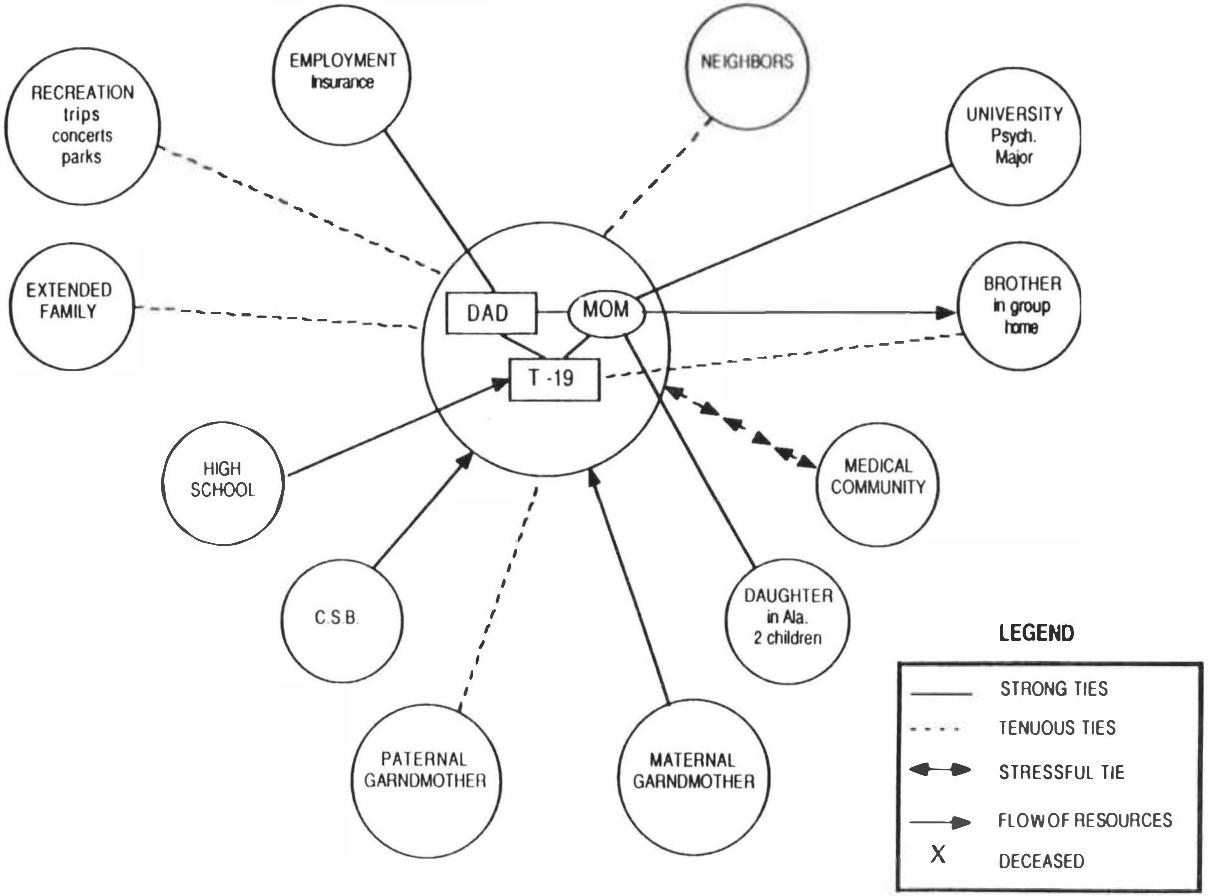
The family in Hanover County was white and lived in a sub-division in the northern section of the county. Three members live in the household, the parents who are in their mid-fifties, and a 19 year old son. The son is mentally retarded with autistic-like behaviors, and attends a special education class in the local high school. A second son, aged 30 years, is also mentally retarded and resides in a group home in the county. This son is part of a supported employment program and has a food service job at a local college. The family has one other member, a daughter who is married and lives out of state. She has two young children, both of whom have been diagnosed with the same genetic defect as her brothers. The father is employed in the insurance industry and has served as an elected official in local government. The mother is a student in a local university and expects to graduate this year. The family has lived in their current residence for five years, re-locating from the eastern shore of Virginia. The mother and 19 year old son provided information in the interview. See Figure 7 for the eco-map of the family from Hanover County.

Insert Figure 7 here

Family Activities

The mother reported that as a unit, the family does attempt outings together. Every Sunday the son from the group home attends church and has dinner with his brother and parents. The family travels to visit the daughter's family which is a few hundred miles away. These trips are limited, because the 19 year old son is jealous of his niece and nephew and is uncooperative during these visits. Other outings by the family include entertainment, such as amusement parks and concerts. The mother reported that these outings can be stressful because the son's behavior draws negative attention to the family. The son is physically unremarkable, which makes his tantrums or inappropriate verbalizations unexpected to others. In the

Figure 7. Eco-Map of Family in Hanover



past, the parents received comments about the lack of control of their child on several occassions.

Activities of the sub-groups of the family were also discussed. The activities of the parents as a couple are limited. Their son is able to stay home for two or three hours spans, which limits their activities to this time frame. The maternal grandmother who lives in the area has cared for the son when the parents need to be gone for longer periods. However, this resource is becoming less of an option as the son and grandmother age.

Most parent-child interactions are between the mother and sons. Both sons are high functioning intellectually and assert some independence in their living situation. The mother is the parent who routinely assists the sons with tasks, such as teaching them how to iron a shirt or taking them to buy clothes. During football season, the sons and father typically watch the games on television together. This activity typifies father-sons activities.

Sibling interactions are limited. When the daughter was living with the family, she provided care for her brothers. The mother reported that the daughter was helpful and when she left for college, she was missed. The sons have limited interaction with each other and do not engage in many activities together.

One activity which the family members have as individuals is at worship services. The sons sit away from their parents during church, as one is an usher and the other sits with an elderly member of the congregation. The father is in the choir and the mother teaches a Sunday School class.

The mother is currently a psychology student at a local university. She decided to pursue a degree after her oldest son moved away and the younger son began a medication to decrease aggressive behaviors. She stated that she needed to use her energy away from the household or "else I would have gone crazy." Her goal is to work with families who have a disabled son or daughter within a school system setting.

Communication

Both sons in this family have good verbal skills. The mother states that that her 19 year old son is very expressive and she is the parent to whom he turns. She was responsible for conveying information to the son, for example, she was the parent who had a discussion about sexuality with him.

One topic is not part of the family's communication. Although the term "mental retardation" is used as a descriptor of events (for example, going to a mental retardation association meeting), it is not used as a label for their son. The parents feel that the use of this term hampered their older son's development of self esteem and they resist using this term with the younger son.

In addition to being responsible for messages within the family, the mother states that she is typically the liasion to other environmental systems. She expressed worry over finding employment because she is frequently involved in dealing with professionals connected to her sons. At one point she left the university because of conflicts with her youngest son's school system. She has also assumed responsibility for making medical arrangements when her oldest son required emergency dental care. She states that her husband will take time off of work if necessary, however, she is the parent who has the most interaction with external systems.

Family Change

The family had controlled the degree of change experienced by their youngest son because he becomes upset by unexpected events. The morning of the interview, for example, he was unable to locate a shirt which he wanted to wear and had a tantrum. During the interview, which was much later in the day, he was still upset by the incident. He is now taking a new medication to decrease his acting out behaviors. The family was very careful in locating of their house when they moved to the county. They selected a home which was distanced from the neighbors so that the son's tantrums would not be heard by others.

The son's inability to handle new events has had an impact on the way the parents are preparing for his future.

Although his older brother lives in a group home and is doing well, the younger son is very resistant to discussing a move to a group home. Since their daughter also has two children with a disability, the son will probably live in a group home situation. The mother is currently working on independence skills with her youngest son, giving him greater autonomy in selecting clothes, and making him responsible for some household maintenance. These changes are calculated and planned to increase his competence and confidence that someday he will be able to live away from his parents.

Summary

The family in Hanover County has three members in the household. Additionally, another adult child has mental retardation and lives in a group home in the community. The daughter has two children who have been diagnosed with the same genetic defect as her brothers. The youngest son lives in the home and attends a special education program in an integrated school setting. The mother is a university student and the father is employed. The youngest son's disruptive behavior is a problem in integration into the neighborhood. The church is an important source of support for this family. Within the family system, the mother assumes most of the caregiving responsibility for the two sons. There is minimal involvement with members of the extended family, which is compounded by the aging process of the maternal grandmother who is no longer able to provide substitute care.

Henrico District

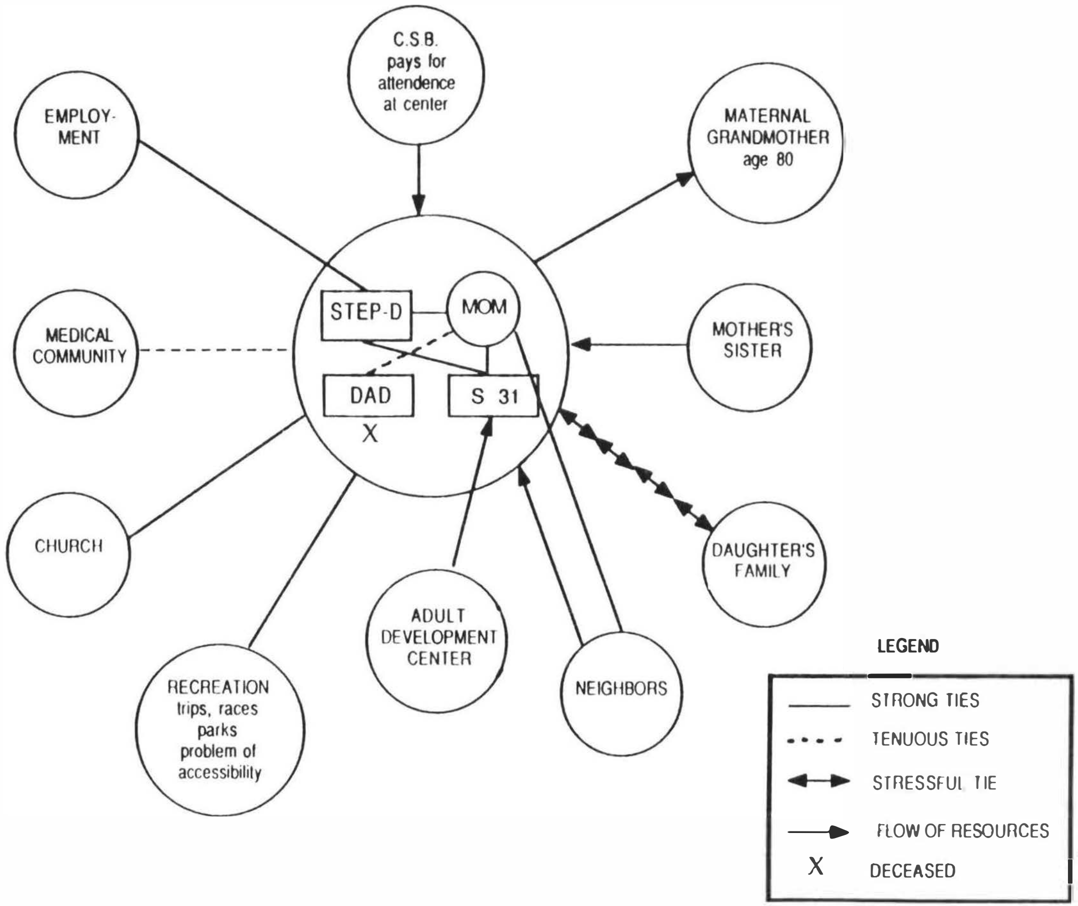
The family identified from this area was white and lived in a sub-division in western Henrico County. Three family members live in the household, the mother and step-father who were in their mid-fifties, and a 31 year old son. The parents have been married for 12 years. The son is multiply impaired, having mental retardation, cerebal palsy, deafness and asthma. He is a wheelchair user. The home is a single story building and is completely barrier-free, including widened doorways, ramps and grab-bars. The home was custom-designed to accomodate the son's physical needs. There is one other family member, a daughter who lives in the community with her husband and two young children. Since the son's disability makes communication difficult, the mother provided the information in the interview. The casemanager from the CSB was also present during the family interview. Figure 8 is the eco-map for the family in Henrico District.

Insert Figure 8 here

Family Activities

The mother reported that the family engages in a number of activities together. They attend worship

Figure 8. Eco-Map of Family in Henrico



services on a weekly basis and are involved in special events sponsored through their church. They also go to amusement parks, and to their daughter's home. They take family vacations, such as the beach or racetrack. These trips involve overnight stays, which can be difficult. She reported that their last stay at the beach was in a non-barrier free residence. They were forced to carry their son and his wheelchair in and out of the house and down to the beach.

The mother reports that she and her husband make time to do things together. She stated that they prioritize time together and make opportunities for activities. The son cannot stay alone and usually the daughter or an aunt comes into the home to stay with him.

The parents also participate in activities with their children. The step-father and son share a warm relationship and go on outings together. Besides doing things with her son, the mother also stressed the importance of including the daughter and her family in activities. She and her daughter regularly schedule outings together.

The son and daughter are reported to have a close relationship. During adolescence, she would include her brother in activities with her friends. She still lives in the same community and maintains close ties to her brother.

As individuals, the family members maintain relationships with others. The mother is not employed outside the home but is involved in community activities. She has friends in the neighborhood with whom she exercises and visits during the day. The son has an out-going personality and forms positive relationships with others. However, his friendships are limited to the activity center which he attends. He is integrated well into his neighborhood and church. Some neighbors have learned some basic signs in an attempt to communicate with him.

Communication

One problem faced by the family is the son's inability to communicate. Both parents sign and can communicate with the son. Due to his cerebal palsy, his signing is not easily understandable. The dual situation of deafness and a mobility impairment has caused problems in communication within the family. The mother gives the example of always having to drop what she is doing and phyically move to another room if her son needs something from her. The son appears to be creative in his effort to communicate with others. He will point, gesture or retrieve a picture to demonstrate the meaning he is trying to convey.

The responsibility in communicating with external systems is shared by the parents. When the issue is connected to the son, the mother is the one to become involved since she is the biological parent. Due to her son's level of disability, she is frequently placed in a decision-making role. She cited a recent situation where a physician believed that her son needed to undergo a serious surgical procedure. She stated that one of the most stressful parts of her role as a parent is decision-making and communicating for her adult son.

Family Change

The family has changed as a result of changed membership in the household. The mother described how the death of her husband precipitated a number of problems for the family. She took a full-time job for economic reasons, which caused problems in finding care for her son. After the daughter left for college, the mother re-married which has worked out well for the family.

The mother described the developmental changes in her parenting role. She credits her second husband with helping her appreciate her son as a functioning adult. Her attitude has evolved from feelings of self-pity and guilt to acceptance and belief in her son's worth as an individual. She stated that her son's disability was part of a master plan and not a mistake for which she is being punished.

The mother spent considerable time discussing plans for residential care of her son. She explained that a reason for building their current house was to provide him a secure environment for his future where he can function as independently as possible. She fears that his severe physical disabilities will restrict his group home options.

Summary

The family in Henrico County lives in a barrier-free home to accomodate the physical disabilites of their son. He uses a wheelchair, has cerebal palsy, is deaf, and has asthma. The other members of the household are his biological mother and step-father. The son is described as having a pleasant personality but interaction with others is limited by his multiple disabilities. He currently attends a day activity program for individuals with cerebal palsy.

Petersburg District

The family from this area was black and lived in the City of Petersburg. Three members lived in the household, the parents in their early 60s, and a son who is 38 years old. The son is mentally retarded, has a seizure disorder and limited motor skills. His disabilities were a result of an illness in infancy. Although the family is in one household, the mother and son live in the upstairs floors and the father lives in the basement. He is reported to be alcoholic and does not currently work. The mother is employed part-time at a laundry service. The son was enrolled in a day activity program sponsored by the CSB but was not attending the program because of a recent surgery. There are four other children in the family. Only one lives in the area. The mother and son participated in the interview. Figure 9 is an eco-map of this family.

Insert Figure 9 here

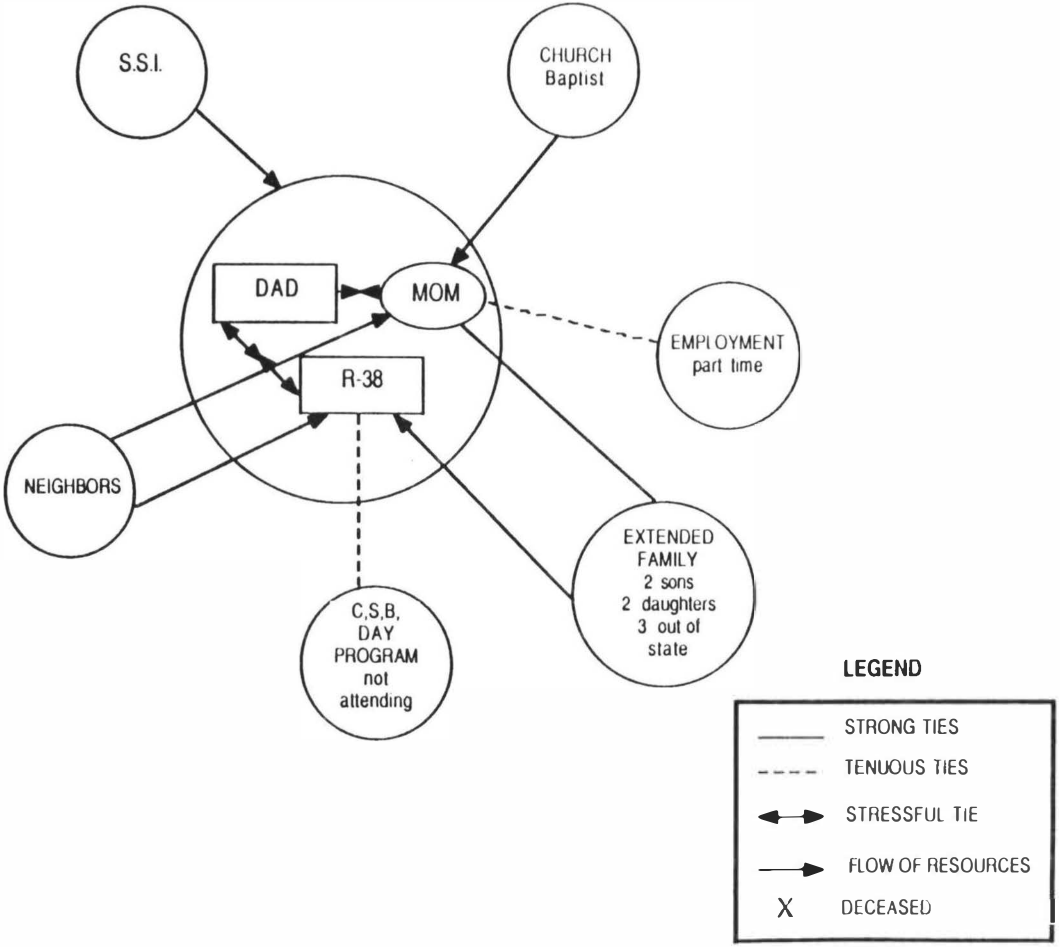
Family Activities

The mother reported that the family does not participate in any activities together. The mother and son have very limited interaction with the father. The mother also stated that her husband has a difficult time accepting his son's disability and has distanced himself from the son. Although they live at the same address, the impression is that the household contains two different residences.

The mother and son do engage in some activities together. They have weekly outings, such as shopping, and occassionally visit one of the other children. Their financial situation limits the type of activities they can undertake. Their usual past-time, both together and separately, is watching television.

The mother states that she has few friends. During the interview, she became tearful when she described her lack of a peer group. When she becomes very lonely, she will speak with her minister. The son has no friends and is not attending a day program. Although he gets along well with his other siblings, they do not maintain regular contact with him.

Figure 9. Eco-Map of Family in Petersburg District



Communication

The mother assumes the responsibility for communication between family members. She relays any messages between the father and son, and between the son and his siblings. She plans all the trips to visit relatives without input from her son. She described a recent situation involving information about the son's future residential plans. The four children outside the household conferred and decided where their brother will live in the future. They called their mother and informed her of the decision. The son with the disability was neither a member of this conference nor informed about the outcome.

Besides having responsibility for relaying messages within the family, the mother is the spokesperson with external systems. She described the process of deciding whether her son should have the most recent operation. The son is verbal but his speech is impaired and difficult to understand. During the course of the interview with the family, the mother would re-state some of his remarks which were incomprehensible.

Family Change

The mother expressed uncertainty about how to deal with some different behaviors which her son is beginning to demonstrate. On occassion, the son chooses to dress in clothes other than those which his mother selected for him.

She was concerned about having him seen in clothes that were not coordinated. She has consulted the family physician who advised her to allow her son some additional independence in dressing, even if the clothes were not to her standards. Her son has also stopped attending church with her. Although he is able to stay home alone, she is concerned about him becoming isolated from others.

The mother and son evidence a degree of a mutually beneficial relationship. The son performs various household tasks which helps the mother because she suffers from various health ailments. The mother also expressed her desire to have the son remain in the home, stating that she does not know what she would do if he was not there. While this relationship is currently beneficial, her remarks may indicate resistance to changing the household situation, even if the need became critical.

Summary

The family in Petersburg has three members, although the father occupies a different part of the house than the mother and son. The son's impairments are a result of an illness during infancy. The mother works part-time and suffers from various health impairments. Finances are an issue in this family and have an effect on the number and type of activities they perform. The son is currently not attending his day program due to recent surgery. The mother expressed loneliness and limited interaction with peers. She also described her son as isolated from others. There are four other siblings in the family, and they have planned that their brother will live with one of them in the future.

City of Richmond

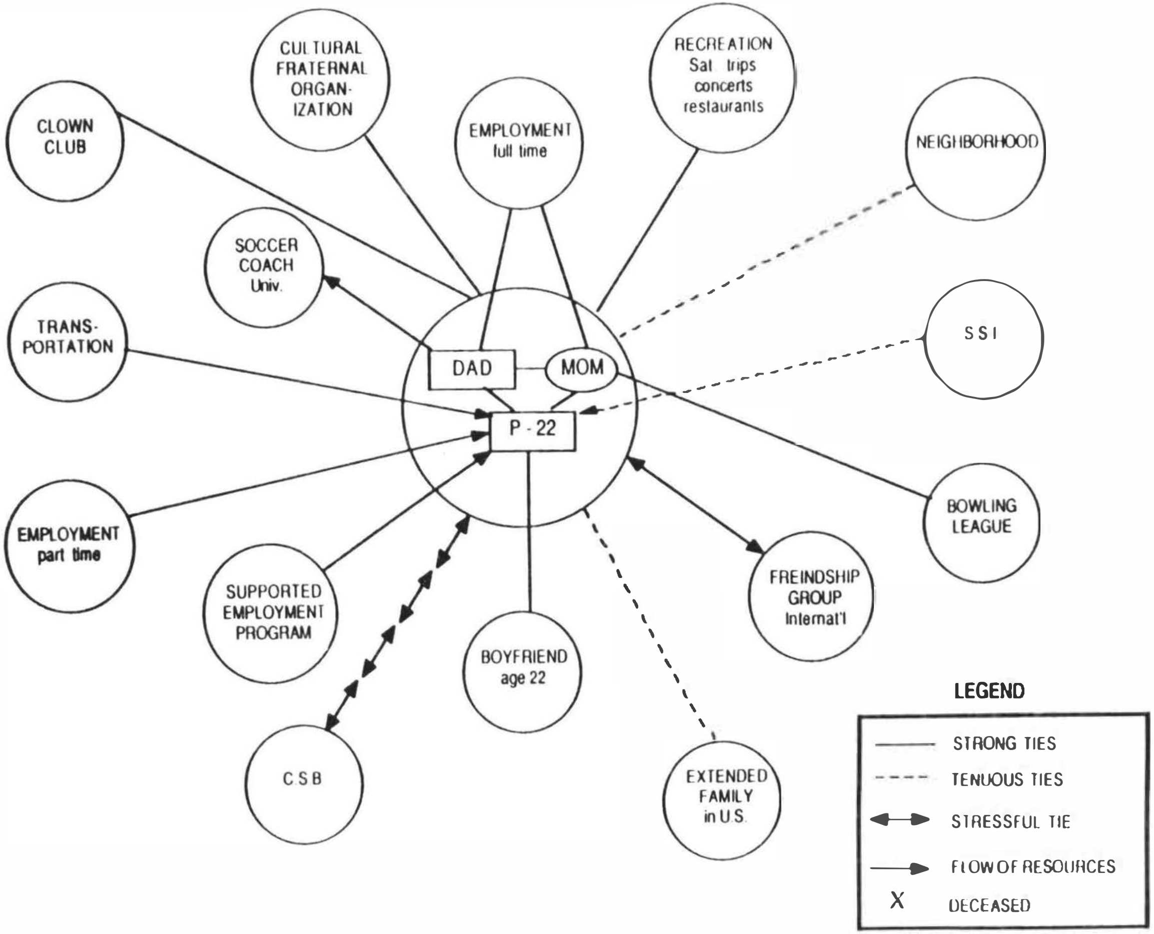
The family from Richmond are white and live in the southside of the city. Their house is located on a major traffic route, and the street is heavily travelled. Three people live in the household, the parents who are in their late 40s, and a daughter who is 22. The parents were born in Central Africa and came to this country in the 1960s. The daughter was born in Richmond. She graduated from a segregated special education school setting, and was placed in a job through a supported employment program for individuals with severe or profound mental retardation. She also has a seizure disorder which is under control, a visual impairment, and mild cerebal palsy. There are no other children in the family. Both parents have full-time employment outside the home. Both parents and the daughter participated in the interview. Figure 10 is an eco-map of this family.

Insert Figure 10 here

Family Activities

The family maintains a high level of activity, in

Figure 10. Eco-Map of Family in Richmond



which they participate together and individually. As a family unit, they have gone on a cruise, and are planning on attending a family reunion in Great Britain this summer. They belong to various community clubs and organizations. The three belong to a clown club and participate in parades and other special events. They report other outings together, including dining out or going to movies. Since they have no other family in the United States, they have become part of an international friendship network and they celebrate holidays and cultural events with this group of people. The daughter seems well integrated into family events, and shares in part of the decision-making process.

As a couple, the parents are involved in a number of activities. Two or three times per year, they plan a small vacation together. For example, during the trip to Great Britain, they are planning a week vacation while their daughter stays with relatives. They also report having evenings out together on a regular basis. The parents were satisfied with the amount of time they spend together.

The daughter is involved in activities with both parents. She and her mother spend time together in the home, such as cleaning and cooking. They join community groups together, such as a woman's auxilary. The father and daughter also spend time together on a weekly basis. One night per week, he assumes responsibility for caring for the daughter, so the mother has free time. Father and daughter engage in various activities, such as eating out, attending concerts, or cultural events. The daughter expressed excitement at spending time with her father.

The parents maintain ties to the community on an individual level. The mother is a member of a weekly bowling league. She also has a full-time job, which has held for a number of years. Even when the daughter was young, the mother continued in her job on a part-time basis. The father is an athletic coach for a local university and attends parctices and games weekly during the season. He is also a member of a fraternal organization.

The daugher maintains connections to others independent of her parents. She reports getting along well with co-workers at her job and is not currently being assisted by a job coach. She takes special transportation to and from the work site, and is responsible for purchasing her own tickets. She also reports that she has a boyfriend whom she met at school. While they do not see each other much, they maintain telephone contact on a regular basis. She is unable to stay at home alone, and after her work shift she is dropped off at a neighbor's home. She also stays with this woman when the parents go away, and reports that these outings are her vacation too. She is eager to stay with her aunt in Great Britain when her parents take their trip to Europe.

Communication

The family maintains direct verbal interaction between the members and each person is responsible for maintaining his or her own communication. During the interview, the daughter was an active participant in describing the family life. The parents did little interpretation for her, although her speech was unclear at times. The parents would direct questions to her, asking about her thoughts and perceptions. For example, the daughter had misunderstood the purpose of the interview and had thought we would be discussing group homes. The parents clarified the purpose, but asked her how she felt about living in a group home one day. From this example, it appeared that subjects were discussed openly between the family members and input from from everyone was valued in decision-making.

All three family members take responsibility for communicating with non-family systems. Both parents described their involvement with their daughter's programs. For example, the father discussed his disagreement with the CSB over budgetary decisions and his part in attempting to change funding priorities. The mother described her involvement with the school counselors in planning for the daughter's supported employment program.

The daughter has been part of various community systems. She was a participant in a national conference on supported employment where she described the program from a consumer's perspective. She also initiates contact with others, such as telephoning friends from work or school. She appears to be active in her involvement with non-family relationships.

Family Change

The family in Richmond has been very active in promoting change within the family unit. They include their daughter in the decision-making process in matters which involve her functioning. For example, she had input into whether she wanted to become part of a supported employment program. During the interview, she was receptive to the possibility of moving into a group home in the future. Shared decision-making appears to be the method used by the family when contemplating changes.

The family also seems have a structured schedule which allows the family time together and individually. Their schedules rotate so all dyads in the system have time to spend together. These times are planned so individuals know when they will spend time together. This situation is true for both the parents as a couple and the parent-child relationships.

Summary

The family in Richmond has three members in the household. The parents are from South Africa and came to this country in the 1960s. Their one daughter has a visual impairment, cerebal palsy and a seizure disorder. The active in their community, and have active schedules both as a family and individuals. All members of the family communicate directly with each other. The parents asked their daughter for input and are interested in her perceptions of situations. This family does not have relatives in this country but are members of a support network of others from different cultural backgrounds.

Themes Across Families

The five families all had an adult mentally retarded child residing with them. The functional status of the son or daughter varied from mild to severe impairment. Some of the families had an adult child with physical limitations in addition to mental retardation.

Although differences were apparent across the families, similar themes emereged from the interviews. Three were common to all the families. These themes are discussed in the following section.

Unpredictability

All five families spoke about the unpredictability in their lives as a consequence of caregiving for their adult child. One dimension addressed included factors associated with the child, such as disruptive behaviors. A second dimension included environmental factors, such as shifts in funding priorities. Both dimensions were described as frustrating for the family system.

Two families described the unpredictable behavior of their children. The Chesterfield family, with autistic twins, experienced disruptive behavior from their sons both inside and outside their household. The sons would tantrum and knock in walls, set fires, tear apart their bedroom. They would also wander onto the property of others, including roaming through neighbors' homes. The family in Hanover also had to deal with disruptive behaviors in their youngest son, who would tantrum. He would also wander into neighbors' yards. Both families described their personal fears resulting from their children's disruptive behaviors.

Factors in the environment can be unpredictable for these families. The Henrico family experienced problems in finding barrier-free facilities for their son who uses a wheelchair. This family also discussed the lack of residential options for a physically disabled adult. The family in Petersburg was uncertain about the son's return to the day activity program, since his recent surgery. The Richmond family also discussed the uncertainty they had prior to their daughter's graduation from school. They did not know whether she would be employable. This fear was reinforced after she lost her first job placement due to staffing changes in her place of employment.

The parents of an adult mentally retarded child face unpredictability in their lives due to caregiving responsibilities. This situation is associated both with characteristics of the child and environmental factors.

Parents express frustration and fear of the future not knowing what they can expect for their child. They also express fear for themselves as aging individuals and their ability to plan for the future is affected. As one parent stated, she and her husband resist thinking about retirement because it is impossible to make plans. Another parent stated that regardless the employment or residential arrangements for her son, she is his parent and will have the final responsibility for his well-being.

Vulnerability to Changes

The second theme which emerged across families was the vulnerability of the family system to changes in relationships. These could be within the household unit, such as changes in family composition, or external changes, such as service providers. Both types of relationship changes can mean a loss of support for the family.

Three families described how changes in household membership affected functioning of the system. Families in Chesterfield and Hanover described the degree to which they depended on a non-disabled sibling to provide substitute care for the adult child with mental retardation. When the sibling left the household, the families had difficulty finding or affording substitute care. The Henrico family experienced the death of a parent, which had an extreme impact upon the family system. The mother described this time as the "nightmarish time of her life." Economic losses forced her into the labor force which created a gap in care for her son.

While these situations involved the loss of a family member, the change can also be due to an additional member. Two families described the burden of additional caregiving. The Henrico family had occassional caregiving responsibility for an 80 year old family member. The Hanover family had their oldest mentally retarded son move back into the household for a time when a residential placement ended. In both situations, an addition to the household created extra caregiving responsibility for the family.

Three parents discussed changes in relationships external to the household and the impact upon family functioning. The families in Petersburg, Hanover, and Henrico all reported problems in finding physicians who were knowledgeable about their child's disabilities. They reported that they resisted changing physicians, even if they had to travel to communities where they had lived previously to continue care with a health care provider who understood the special needs of their son or daughter. The family in Richmond experienced changes in their daughter's employment situation due to changes in management in her workplace. The new managers were not invested in supported employment which left the daughter out of a job.

Families with a mentally retarded member are vulnerable to relationship changes. Internal changes in the household can mean a loss of support in caregiving or an additional caregiving responsibility. Changes in relationships with non-family members also have an impact on family functioning. Changes in other systems, such as health care or employment, can have a dramatic affect on how the family is able to function.

Role Conflict

A third theme which emerged from these interviews was the conflict performing multiple roles. The parents all identified problems with employment and caregiving responsibilities. The reasons for employment varied between the parents with one group reporting intrinsic motivation while others reported economic needs. In both situations, however, the parents discussed the problems in simultaneously enacting the roles of worker and parent.

Parents in two families described a motivation to work based upon personal desire. At the time of the interview, the mother in Hanover was completing a bachelor's degree. Her decision to pursue a degree to was based on a desire to make connections with other adults. She was a part-time student for many years and had to quit a university program at one point when her son was having difficulties in his own school system. While this parent was excited about starting her career, she also expressed concern in finding a job which would permit scheduling flexibility to accomodate parental demands. The mother in Richmond described her employment history as a parent of a mentally retarded adult. When her daughter was a child, she was forced to take part-time employment in her work setting. The job change allowed her to spend time at home but also kept her from having to abandon her position at work

The other three parents reported economic necessities for employment. The mother in Petersburg described her physically demanding job, yet the family continued to experience periods when they had no money. She expressed regret that she had to continue to work and leave her son at home alone during the day. The mother in Henrico was forced to work after her husband died. She described this time as "nightmarish" since she had difficulty finding care for her son. The father in Chesterfield described a situation where he declined a job promotion because he did not want to move his sons to a new community.

The parents in this study described conflicts between work and family roles. Motivation for work varied between personal desire and economic necessity. However, all five parents described conflict between balancing caregiving demands with employment responsibilities.

In summary, the five families who participated in the interviews all lived in households which included an adult with mental retardation. Although the functional status of the adult mentally retarded child varied, common themes emerged across the five interviews. All families discussed the unpredictability, vulnerability, and role overload in caregiving for the son or daughter.

The next chapter discusses the implications and recommendations from the survey and interview data.

CHAPTER 6

Interpretations, Limitations, and Recommendations for Additional Research about Parents with an Adult Mentally Retarded Child

This study has compared stress and social support of parents providing caregiving for an adult mentally retarded child with parents in two different caregiving roles. The framework of the study combined role theory, and social support literature based upon social exchange and ecological theory. The literature review included stress and social support variables from the two other ambiguous caregiving roles: caring for an impaired elder, and caring for a handicapped child. The results of this study are discussed in the context of the theoretical, empirical and practice literature on the caregiving role.

Review of the Research

A role is defined as identities which include a set of expectations that guide the behaviors performed by an actor (Biddle, 1979; Biddle & Thomas, 1966). Roles that contain behaviors where there is a low degree of consensus are classified as ambiguous (Biddle, 1979). Ambiguous roles create stress for an actor since there is little guidance to determine the behaviors the actor should perform to satisfactorily complete their role (Perlman, 1968; Ursprung, 1986).

The social support literature was reviewed to gain understanding about the transactions between an actor and other systems in the environment. Social support is based on the concepts of social exchange theory. In social exchange theory, interactions between actors are predicted to exist if the exchange maximizes profits and minimizes costs (Blau, 1964; Dowd, 1975, 1980; Homans, 1961). The exchanges which enhance well-being for an actor are classified as social support (Cook, 1987; Schilling et al., 1984; Simons & West, 1984-85). Environmental variables can enhance or inhibit the exchanges between actors and other systems (Beckett & Coley, 1987; Caplin, 1974).

The literature suggests that care of an adult mentally retarded child is an ambiguous caregiving role. This role combines the situation of caring for an adult and a person with mental retardation. However, this group of parents is virtually ignored within the literature (Jennings, 1987). Currently, the stress experienced by these caregivers and the supports they employ to perform their caregiving behaviors are unexplored areas.

Interpretation of Findings in the Study

Comparisons were made between parents who care for an adult mentally retarded child and two other groups of parents. The hypotheses predicted that the active caregivers would report higher levels of stress and smaller social support networks than the caregivers in other roles. Partial support was found for the major hypotheses of stress and social support. Significant differences between the groups on the characteristic variables and the hypotheses are summarized in Table 16.

Insert Table 16 here

To increase knowledge building about caregiving, the findings from this study are presented in the context of the caregiving literature.

Parental Stress

The stress hypotheses predicted that differences would be found between the three groups of parents on stress variables. Stress included health, free time, and life event variables. The sub-hypotheses predicted that active caregivers would report the highest degrees of stress on all three dimensions when compared to the other groups. Non-caregivers were predicted to report the lowest degrees of stress on the dimensions. Three statistically significant differences were found between caregiver groups. Differences were on the Depressed Mood Index, Physical Symptom Index, and the hours of free time. The stress variables are discussed in the following sections.

Table 16:

Summary of Statistically Significant Differences Between Groups

Variable	Caregiver Groups			Statistically Significant Differences
	Active	Past	Non	
Age (Yrs.)	M=56.7	M=58.1	M=63.7	(Active & Past) & Non
Characteristic Variables				
Current Employment				
In Labor Force	48.9%	58.2%	25.5%	
Not in Labor Force	26.6	20.0	49.1	
Homemaker	24.5	21.8	25.1	
Religious Affiliation				
Baptist	54.2%	44.9%	58.9%	
Methodist	18.1	12.1	17.9	
Catholic	7.2	22.4	21.4	
Other Protestant	20.5	20.4	1.8	
Years in Home	M=16.9	M=13.7	M=20.9	Past & Non
Stress Variables				
Health Symptoms	M=2.9	M=2.0	M=1.9	Active& Non
Depressed Mood	M=1.8	M=1.8	M=1.0	(Active & Past) & Non
Free Time Hours	M=17.2	M=20.5	M=26.1	Active & Non
Social Support Variables				
Age Cohort Supports				
Sub-networks				
Money/Finances	M=.26	M=.23	M=.58	(Active & Past) & Non
Formal Role Supports				
Sub-networks				
Home/Family	M=.47	M=.53	M=1.36	Active & Non
Health	M=.35	M=.49	M=1.97	(Active & Past) & Non
Personal/Social	M=.48	M=.35	M=2.20	(Active & Past) & Non
Money/Finances	M=.40	M=.33	M=2.15	(Active & Past) & Non
Reciprocity Ratio				
Sub-networks				
Home/Family	M=72.25	M=68.46	M=124.08	(Active & Past) & Non
Personal/Social	M=77.40	M=56.01	M=124.22	(Active & Past) & Non
Money/Finances	M=76.71	M=65.34	M=101.82	Past & Non

Health Variables

Two differences on health variables were found between the three caregiver groups. One difference between the three groups was the number of health symptoms on the Physical Symptoms Index. Active caregivers reported a greater number (*M* =2.9) than the non-caregivers (*M* =1.9). This difference is interesting since the non-caregiver group was significantly older than the other groups. Although age may increase physical symptoms, this variable does not explain the variance between the groups.

Other studies on health status have reported that the number of health ailments in caregivers increases with the length of caregiving (Cantor, 1983; Johnson & Catalano, 1983). Although the present study was cross-sectional, the distribution of health symptom scores across the three groups suggests that the parents who are currently enacting caregiving roles have the greatest number of health symptoms.

The data from this study were compared to two other studies which have used the Physical Symptom Index. The active caregivers reported about half the number of symptoms experienced by a group of depressed patients. This group reported an average of 5 - 6 of these symptoms (Billings & Moos, 1984a). However, active caregivers reported a greater number of symptoms than the non-depressed controls (*M* =2). Active caregivers also reported a greater number of symptoms than a community sample (*M* =1.7 for men and *M* =2.3 for women) (Billings & Moos, 1982). The past and non-caregivers (*M* =2.0 and *M* =1.9 respectively) groups compare favorably with the community and control groups.

An examination of the activities of daily living (ADLs) of the mentally retarded sons and daughters reveal some level of independence in functioning. Both active and past caregivers reported their adult children could perform five out of eight ADLs independently. Since the mentally retarded adults do not represent a highly impaired group, strenuous tasks of caregiving, such as transferring or lifting, do not appear to be part of the physical demands of the adult child's care. Therefore, the physical demands of caregiving do not explain the higher number of physical symptoms in the active caregiver group.

A possible explanation is the interaction of employment and caregiving roles held by active caregivers. Significantly more of the non-caregivers were out of the workforce; however, the past caregivers were employed. The difference between the active and past caregivers did not reach statistical significance. However, the number of symptoms reported by past caregivers (*M* =2.0) was similar to non-caregivers.

The overload between caregiving and employment roles is supported by family interview data. All the parents described difficulty in juggling demands from work and home. Other studies on adult caregiving report the stress involved in competing role demands in these areas (Brody, 1981; Cantor, 1983). These dual roles appear to be a source of stress for the caregivers, which may become manifested in physical symptomalogy.

A second difference was on the Depressed Mood Index. Non-caregivers reported fewer items (_M_ = 1.0) than either the past (_M_ = 1.8) or active caregivers (_M_ =1.8). Other studies on caregiving have found that caregivers reported worries, fears, and other mental health problems (Cantor, 1983; Gold et al., 1987; Goodman, 1978; Lichtenberg, 1988). However, the finding from this study suggests that this score is not dependent upon whether the parents are actively performing in a caregiving role. The scores between the active and past caregivers did not differ. From a role theory perspective, the ambiguous quality of this caregiving role appears to be emotionally stressful even after the mentally retarded child has left the home.

While differences between the groups reached significance in this sample, a comparison to another study that has used this instrument suggest that none of the three groups scored higher than a community sample. In a community sample in San Francisco, women reported an average of 2.3 of these items and the average for men was 1.6 items (Cronkite & Moos, 1984). Scores of the active and past caregivers appear similiar to this sample.

A question regarding the community study is the external validity. San Francisco is one of the most densely populated urban areas of the nation, and the landscape is geographically unstable. Fears, nervousness, and worries about the future may be a natural reaction to this environment which would inflate the scores of the community sample. The extent to which this sample is representative of other locations is not known.

A possible explanation of the differences between the groups in this study on the depressed mood items is due to the sampling process. Non-caregivers were selected through area churches which suggests they may be a more religious group. The effect of religiosity on a perceptions of depression is not known. However, the three groups did not differ on either their perceived religiosity or the number of religious activities attended per week. While religiosity is a possible explanatory variable, the measures used in this study did not support this explanation.

Two health variables did not differ between the three groups. All three groups reported an average of one health condition on the Health Diagnosis Index. This finding differed from the Gold et al. (1987) study that reported problematic health conditions in caregivers of mentally retarded adults. The difference in findings may be explained by the difference in definitions of health conditions used in the two studies. The variable in the Gold et al. (1987) study was a self report of parents' perceptions of their health. This may be a measure of symptoms instead of actual diagnoses. In this study, a diagnosis was defined as conditions diagnosed by a physician.

The lack of difference between the three groups is interesting for two reasons. First, the number of chronic ailments increases with age (Harkins, 1981; Harrigan & Farmer, 1989). However, the non-caregivers who were older than the other groups did not report a greater number of symptoms. Second, a study using a younger community sample and a control group of a clinical sample ($\underline{M}$ =39 to 44 years of age) reported lower incidences (.28 to .60) of these conditions (Billings et al., 1983; Mitchell et al., 1983; Mitchell & Moos, 1984). Replications of the finding in the present study are needed to determine the effects of caregiving status with age. A possible explanation of why the groups did not differ is the senescence of the older non-caregivers.

The final health variable was the health activities performed by the parents. This study found no differences between the number of activities reported by the three groups of parents. The three groups did not report differences in the number of health activities, either health promotion or negative health habits.

This finding does not support findings of Snyder and Keefe (1987). Their research on caregivers of impaired elderly reported that caregivers decreased the number of health activities in which they participated as a consequence of performing caregiving tasks. The lack of support for the finding in the current study could be attributed to the age range in the Snyder and Keefe (1987) research. The average age of the respondents in their study was 60 years, however, the minimum age of the caregivers was 28 years. Their study did not control for age of caregiver. The extent to which the variance in their study is due to divergent lifestyles between older and younger caregivers is not known.

In summary, two statistically significant differences were found between the three caregiver groups on the Physical Symptom Index and Depressed Mood Index. The combination of these findings suggests that the physical stress of parenting a mentally retarded adult may be minimized by a change in role status, from active to past caregiver. However, this change does not necessarily diminish the emotional components of caregiving, since these two groups did not differ on the Depressed Mood Index. Although the difference in scores between the three groups on this index could be a result of the sample selection of non-caregivers, the religiosity measures of the survey do not support this hypothesis.

Personal Time Variables

The second dimension of stress was the amount of personal time available to respondents. In the caregiving literature, the lack of free time for personal issues has been identified as stressful for caregivers (Clark & Rakowski, 1983; Zarit et al., 1980). A statistically significant difference was found between the hours available to active caregivers (*M* = 17.2) and non-caregivers (*M* =26.15). The past caregiver group (*M* =20.54) did not differ significantly from the other groups.

While the difference between groups reached statistical significance, the finding may partially be explained by labor force participation. More of the non-caregivers were not employed than the other groups. The non-caregivers may have more free time because they do not have employment schedules. Although the difference between the active and past caregivers did not reach significance, the trend is in the direction predicted by the hypothesis.

Although the active caregivers have fewest hours of free time, they did not report dissatisfaction with the amount available to them. In other caregiving studies, the number of free time hours has been a predictor of caregiver stress. Frequently, caregivers for the impaired elderly need to accomodate existing lifestyle patterns to perform the caregiving tasks (Montgomery et al., 1985). The marginal activities, often those which are individual activities of the caregiver, are the first to be relinquished when a caregiving role is assumed (Cantor, 1983). Caregivers of the impaired elderly may be more sensitive to the loss of free time than parents who have assumed caregiving for many years.

Data from the family interviews support this explanation. One mother stated that she wished she had more time to spend with her husband but she is accustomed to her present schedule. Another mother stated that she has been a parent so long, she would not know what to do with additional time for herself. For caregivers who have performed their role for years, the number of personal hours may not be a predictor of stress. This variable may be a more valid for measuring stress when caregivers are just beginning to perform caregiving tasks.

Life Change Events

The final stress variable was the life events experienced by the respondents. This study found that the three groups experienced about the same number of events. However, when the events were classified into outcomes on individuals, a trend was the active (M =.70) and past (M =.67) caregivers reported fewer events which have positive effects than did the non-caregivers (M =1.4). Examples of positive events are taking a vacation, increasing an income, and receiving a job promotion. No difference was found between the groups on negative events.

This finding differs from a study on life change in families with mentally retarded children. In a comparison of families with younger and older mentally retarded children, Tausig (1985) found high degrees of life changes in both groups of families. His sample was selected from a waiting list for residential placement of the mentally retarded family member. The difference between his finding, and this study may be attributed to differences in the sample selection. The amount of change taking place may be a predictor of families needing residential placement and not all families with a mentally retarded member. The other studies involving life change events did not categorize events into the effects for the caregiver (Clark & Rakowski, 1983; Jenkins, 1985; Lichtenberg, 1988).

While no difference was found on the negative events, the incidence of positive life events in caregiving families has been unexplored. In other studies, the experience of positive events have been associated with decreased depression (Finney et al., 1982), an increased sense of competence, mastery and social support (Mitchell & Moos, 1984). The absence of positive events in families of mentally retarded adults may be a result of a number of factors. For example, the parents in the family interviews identified a lack of finances, lack of friends, lack of time, and environmental barriers as reasons they did not participate in activities or events.

In summary, the three caregiver groups did report differences on some of the stress variables included in this study. However, there is no indication that any of these groups is experiencing an unusually high degree of stress. Some variables did not differ between the groups, and compared favorably to non-clinical samples in other studies.

A distinction is made in the literature between stress and strain. Most studies on life stress use instruments which measure acute stress, however, strain has also been found to affect functioning levels. Strains have been defined as the stress associated with on-going roles and daily living (Billings & Moos, 1984b). The lack of difference between the three groups in this study may be a result of the inability of the stress instruments to measure the rountine strains faced by caregiving parents.

Data from the family interviews reveal that active caregivers experience frequent strains. One mother described how she had to stop tasks she was performing, walk to another room, and position herself to sign with her deaf, non-ambulatory son. Other parents discussed the problems in finding respite providers, even to go shopping with their spouse. These incidents are a sample of the types of strains present in caregiving families. While these are not equal to a serious illness, divorce or bankrupcy, the accumulation of these daily inconveniences may affect functioning.

Social Support of Parents

In addition to the stress experienced by the caregivers, the social support systems of the parents were measured. Three dimensions of support were included. These were the social relations, social network and functional content dimensions. The social network contained differences in the ages and roles of the caregivers' social support constellations. The functional content contained differences between the groups on the reciprocity of their exchange relationships. Findings for each of these dimensions are discussed in the context of the caregiving literature.

Social Relation

The first dimension of social support was the social relation dimension. The parents all identified about three or four supports in their overall support grid. Contrary to the conceptual review on parenting by Byrne and Cunningham (1985), the parents of an adult mentally retarded child did not identify fewer people in their networks. The parents in this study did report established support systems.

No difference was found on the degree of contact with supports as reported by the three groups. All the groups had received a little support within the past month. Dunst et al. (1986) reported that over time, parents who formed supports and used support systems had mentally retarded children with fewer behavior problems than families lacking support. The presence and contact with supports by parents may be a coping mechanism which contributes to the ability to maintain a mentally retarded child in the household over time.

The lack of difference between the groups on this dimension is notable. Although the literature predicted fewer supports, parents of mentally retarded adults did identify established support systems. Since this study is cross-sectional, the degree of change in these networks over time cannot be evaluated. Although more of the non-caregivers were not working, the effect of being out of the labor force on this group's social support network can not be determined. However, the groups did not differ in the amount of contacts with their supports. Replication between groups of similar labor force status would help determine whether this finding is due to the loss of support by the non-caregivers.

Social Network

The second dimension of social support was the social network dimension. The hypotheses predicted differences by ages and roles of the supports identified by the three groups. The study found differences in the number of professionals identified by the groups as their supports. Non-caregivers identified significantly more than either other caregiver group in home and family, health, personal and social, and money and finances sub-networks.

This finding was in direct opposition to the prediction of the hypotheses. The data from this study do not support the Suezle and Keenan (1981) finding on the interaction of parents with professionals. Their study reported that parents of both mentally retarded children and young adults had interactions with numerous professionals. The differences between the Suezle and Keenan (1981) and this study may be explained by a different conceptualization between social network and social support network. A lack of conceptual clarity has been identified as a methodological problem in social support literature, specifically imprecise definitions of social network and social support network (Barrera & Ainlay, 1983; House & Kahn, 1985; Wilcox & Vernberg, 1983). Social network is a more diffuse construct which includes all interactions between actors and members of a role set. Social support network is a more specific construct which includes only those exchanges which are beneficial for the actor (Cook, 1981; Schilling et al., 1984; Simons & West, 1984-5).

Data from the family interviews support the explanation that interactions with professionals are not necessarily helpful for the parents. Parents reported problems in interactions with school, medical, and community support service personnel. Although parents with a mentally retarded adult have interactions with a number of professionals, the relationships are not necessarily beneficial.

An alternative explanation for this finding is the non-caregivers differed from the other groups because of the sampling method for this group. A possibility exists that religious professionals are more highly reported in the non-caregiver group. The consistency with which helping professionals were identified in all four sub-networks challenges this interpretation. Are clergy more likely to be identified as a support in health or financial matters over physicians or attorneys? While the likelihood exists that church members turn to their clergy in family and personal matters, it is questionable whether these professionals would explain the total variance of the groups especially since the religiosity variables did not reach statistical significance.

A second variable of a social network is the age homogeneity of an actor with members of a support system. In this study, non-caregivers reported a greater number of age cohorts as supports in their money and finances sub-networks. This finding may be attributed to the income structure shared by the non-caregivers. Since many of this group are retired, they may be receiving pension and Social Security benefits. Non-caregivers may share information about the Social Security system, investment programs for retirees, and other information affecting this age group.

This explanation is interesting since mentally retarded adults often receive Social Security benefits. One parent in the interviews specifically mentioned this area as a source of stress. However, parents of mentally retarded adults do not have a cohort to whom they can turn with financial questions, since many people do not have children who receive these payments. From a role theory perspective, the non-caregivers have a cohort that shares similar roles to which they can turn for information and expection about finances. The active and past caregivers do not necessarily have that resource.

No differences were found among the three groups on satisfaction with their support system in any sub-network area. This finding suggests that chronological age may not be a good predictor of satisfaction without controlling for the roles of the support system members. Rosow (1967) and Osgood (1982) reported that high rates of satisfaction were found among the elderly with same age cohorts. This study suggests that there was not a difference in satisfaction in one sub-network even when non-caregivers reported more age cohorts as supports. Both of the previous studies were conducted in age segregated living environments where the elderly were in a similar role status. The present study suggests that further research on the interaction of age and roles of support with satisfaction level should be conducted.

Differences among the caregiver groups were found in the composition of their social support system. Non-caregivers were more likely to report professionals as supports than the other groups. While this finding may be attributed to the sample selection process, an alternative hypothesis supported by the family interviews was the poor quality of prior relationships with professionals on the part of parents with an adult mentally retarded child.

Functional Content

The last dimension of social support was the functional content of the support provided to an actor. No differences were found on the level of satisfaction or the type of support received by the three groups. Because of the high levels of satisfaction reported, the validity of this measure is questionable.

On the final support variable, non-caregivers reported higher degrees of reciprocity in their home and family, and personal and social sub-networks. Reciprocity is the degree of symmetry involved in the exchange between members of a network (Goodman, 1985). This finding suggests that non-caregivers provide more support in home and family, and personal and social sub-networks than the other groups.

A possible explanation is that parents of mentally retarded adults have less energy to expend with others in these areas, regardless of the living arrangements of the son or daughter. The past caregivers report a number of contacts with their adult child per month. On the average, these parents had seven phone converations, visited twice, and had one overnight visit together. This degree of contact is fairly high, since the adult child lived an average of 44 miles from the parents. Parents with mentally retarded adults may spend family, and social energy with their son or daughter, regardless of living arrangement, which affords little opportunity to exchange with others.

A rival explanation is that the non-caregivers have a greater number of hours per week which they devote to family and social functions. Because of the flexibility of post-retirement schedules, this group may be more readily available, for example, to volunteer or watch a grandchild. The higher rate of exchange by this group may be a function of flexibility in their schedules.

In summary, the social support findings suggest that all the groups have established support networks. However, the composition of these networks, and the way the networks are utilized is different between the groups. All the differences appeared in the sub-networks, not the overall support grid of the parents.

The social support literature describes the two functions of support as moderating and buffering stress. Stress is buffered when support is an antecedent to an event. The moderating effect is when support is an intervening variable between stress and coping. The fact that differences were not found in the overall grids while differences did appear in the sub-networks suggests that active and past caregivers use their supports as a potential moderator of stress. One mother described this pattern in the family interviews. She stated that there are people to whom she can turn, if there is an emergency. While further research on the effects of social support is needed, there is some indication that the actualization of support may be different in the active and past caregiver groups.

Discriminant Model

The one function of the discriminant analysis which was significant combined stress, social support, and demographic variables. These included being white (.31), living in Richmond/Henrico (-.37), depressed mood (-.56), hours of personal time (.30), number of positive life events (.37), and the reciprocity ratio (.56). This model had a correct classification rate of 47.14%.

Two features of this model are noteworthy. First, the highest two loadings, depressed mood and reciprocity, are in opposite directions. Together, these two variables appear to describe the developmental task of generativity versus stagnation. This task has been defined as the feeling of being connected with others and of being productive in guiding future generations (Ward, 1984). Successful mastery of this task involves feeling one is a resource to others and feeling secure in past accomplishments. The direction of group centroids for this function reveals that the both groups of parents with an adult mentally retarded child are lower on this function (active = -.30 and past = -.14) than the non-caregivers (.69). This suggests that having a dependent adult child may inhibit the developmental process for the parents as they age.

A second aspect of the discriminant model is the multidimensional quality of the function. The variables which were entered into the function include internal process variables, such as depressed mood; personal resources, such as free time hours; social resources, such as reciprocity in support systems; and structural variables, such as being white, which is membership in the cultural majority. Differences between the groups reflect multi-level variables which were depicted in the theoretical and empirical models of the study.

Limitations of the Study

Research on parents of mentally retarded adults is still in the beginning stages. While this study has contributed to increased understanding of these caregivers, it contains limitations in the areas of sampling and design. Both of these limitations are discussed in the following sections.

Sampling

A limitation in sampling is related to the lack of representativeness of the parent group. The parents of an adult mentally retarded child were identified by casemanagers in five community services boards. Estimates on the number of mentally retarded adults in service delivery systems reflect usage rates of 10% to 40% of the total population size (Seltzer, 1989; Stokesberry, 1989). These statistics indicate that over one-half of mentally retarded individuals are not receiving any formal services through developmental disability networks. One hypothesis is that families outside the service delivery network are extreme cases. At one extreme, the non-identified families may function on a level which does not require any formal services. The other extreme contains those families who may be isolated from resources in the community. This issue restricts generalizability of the findings to families who are connected to developmental disability services.

A second issue pertains to the external validity of this research. The sample was selected from an area in east-central Virginia. Historical and regional factors of may differ from other parts of the country. The degree to which this area is representative of parents in other locations is not known.

A third sampling issue concerns identification of the parents for the study. Although efforts were made to minimize the selection of "ideal" parents by the casemanagers, those who were identified may be individuals who have positive relationships with community service agencies. Since the method of identification was based on recall and not random selection, the casemanagers could have selected those parents who were most the memorable.

A fourth issue deals with the non-respondent group. The response rate for active and past caregivers combined was 47%. Over one-half of the parents who were mailed the survey did not return it. Certain characteristics may be associated with this group that differ from the respondents. Non-respondents may lack literacy or comprehension skills. Physical limitations such as visual, gross or fine motor skills, and lack of endurance may have prohibited some parents from participating. A third problem may have been a recording-keeping problem. Some parents may not have received the survey due to address changes or errors in the CSBs. Three percent (3%) of the surveys were returned due to address-related problems.

The selection of the non-caregiver group is an additional issue. These parents were identified through religious, not community, systems. Although this group did not differ from the other groups on measures of religiosity, the extent to which their religious affiliation biased the findings is not known.

Design

A second limitation of the study is a design issue. Currently, no other study has compared parents with an adult mentally retarded child to parents of non-disabled adult children. While the cross-sectional design provides information about current differences between the caregivers, no conclusions can be made about changes in stress and social support over time. Lacking a longitudinal design, conclusions about changes in stress levels and support constellations within and between the caregiving roles cannot be determined.

Implications for Social Work

This study increases understanding in social work about parental caregiving for an adult mentally retarded child. A greater number of parents perform this role as a consequence of community based services and longer lifespans for both the disabled and non-disabled populations. Since social workers are members of both aging and developmental disability services, they will become increasingly involved with these two-generation adult families. Implications from this study for social work practice, policy and education are discussed in the following sections.

Social Work Practice

An important finding of this study is the relationship between parents of a mentally retarded adult and professionals. The hypotheses of this study predicted that non-caregivers would identify fewer people in formal roles as supports. The opposite situation was found. Non-caregivers reported a greater number of professionals in their home and family, health, personal and social, and money and finances sub-networks. Family interview data included information about problems encountered with school, medical, and social service personnel.

In dealing with families of an adult mentally retarded child, social work practitioners need to be sensitive to the parents' past and present relationships with professionals. The major shift from institutional to community based services has taken place within the last twenty five years. Previously, parents and professionals maintained adversarial relationships which have foster distrust among parents. While current service models emphasize support and collaboration between the two groups, parents and professionals still maintain hostile relations. Parents also have negative experiences with medical professionals who are unfamiliar with mental retardation. Older families may be wary or guarded with social work practitioners due to historical patterns of relationships with professionals in general. Practitioners working with these families need to be sensitive to previous and current relationships with professionals. Attention to building a relationship and fostering trust are essential components of effective practice with this group of parents.

A second implication for practice is related to programmatic decisions about services to older families. The number of supports reported by parents in all three study groups of did not differ statistically. Parents of an adult mentally retarded child have established supports within their families and their community. However, caregivers of mentally retarded adults reported different membership composition and exchanges in their sub-networks. Data from the family interviews highlighted the vulnerability of these caregiving families when support is lost. Interventions with caregiving parents should assist them in utilizing and maintaining established supportive relationships. Programs to meet this goal include funding and training respite providers who are identified by family members, such as relatives, friends or neighbors. Social work practitioners who work with families of a mentally retarded adult should structure interventions with a goal to preserving and enhancing the supports established by the family. Training and paying family members as respite providers is one way of meeting this goal.

A third practice implication is in transitional planning for the mentally retarded person's future. The concept of transition is prominent in the mental retardation literature, most frequently involving changes in the role of the mentally retarded person as student to worker (Hill & Morton, 1988; McCarty, Everson, Moon & Barcus, 1985; Wehman, Moon, Everson, Wood & Barcus, 1988). Additional emphasis has been placed on assisting parents with the concomitant transitions which they must make to accompany the role change in their mentally retarded child (Ossofsky, 1989). As educational, vocational, and residential options for people with disabilities increase, social work practitioners need to assist parents in making adjustments to their expectations of the potential for their son or daughter to assume another role status. In assisting a mentally retarded adult to assume an additional role in society, a practitioner should also provide services to parents who are transitioning out of the caregiving role.

Findings from the study have implications for assessment with parents of mentally retarded adults. The results of the discrminant analysis suggest that differences between the caregiver groups were based upon multi-system variables. Assessment of this parent group needs to reflect multidimensional areas of functioning.

Policy

One dimension of role strain for caregivers of the impaired elderly is the competition between employment and family demands. In this study, parents who care for an mentally retarded child also reported this source of strain. The provision of care to another adult is a financial burden (Zimmer & Mellor, 1982). People with mental retardation do not have the same resources to build assets such as savings, pension plans, or home ownership. Unlike the elderly whose impairments are a consequence of the aging process, the cost of care for a mentally retarded adult is a life-long family expense. The cost and demands of multiple roles suggest increased sensitivity to employed caregivers. Changes to promote flexibility in work hours and leave of absence policies would allow workers to attend to family demands. Responsiveness in the social welfare system would include increased availability of respite and adult day care for workers who are caregivers. For example, programs could include weekend and evening hours for workers with non-traditional employment schedules.

A second policy issue relates to the division between aging and developmentally disability service sectors. Collaboration between these historically separate networks is currently being advocated as a method of supporting both mentally retarded adults and their families (Gettings, 1989; Rose, 1987; Rose & Janicki, 1986; Seltzer &

Krause, 1987). Increasing options to families for day care, household assistance programs, and other services could be facilitated by greater cooperation and linkages between services for the elderly and developmentally disabled populations.

A third policy issue relates to the long-term care system available to disabled and non-disabled elderly. Long-term care includes institutional, community based, and in-home services. The cost for care, especially nursing homes, continues to escalate. A greater array of services, such as homemaker, meal programs, and transportation services need to be available and affordable for all elderly persons. Two dependent families, which includes aged parents and mentally retarded adults, may especially benefit from community support services.

Education

Social work educators hold a responsibility for shaping future practitioners. As the size of the older population continues to increase, social workers in all practice settings will be exposed to elderly clients. Information from this research and similar studies help dispel ageist myths which exist in society.

An important characteristic of the elderly population is diversity. Older people are more heterogenous than other age groups (Zarit, 1980). Students may not realize that many parents continue to actively perform the caregiving role into their elderly years. The social work curriculum should include information about older people in a variety of roles to sensitize students to the diversity of the elderly population.

A second implication for social work education is to demonstrate the importance of clients' social support networks. The informal support network accounts for about 80% of the care to the elderly (Hooyman, 1983). Families of a mentally retarded member also assume the majority of responsibility for financial, social and emotional support. Families are often heroic in efforts to maintain care of a disabled member both in situations of a life-long or age-related disability. Social work students need to be sensitive to the importance families, friends, and neighbors as support to many disabled adults.

Recommendations for Additional Research

While the results of this study have provided additional insight into the role of caregiving for a mentally retarded adult, a need exists for additional knowledge building. Recommendations for further research are presented in this section.

One area of needed research is the support provided to the family by an adult with mental retardation. Reconsideration of the productivity of mentally retarded individuals is being advocated instead of the currently assumption of this group as "throw away adults" (McDowell, 1989, p. 63) who are helpless and dependent (Elder, 1989). These assumptions discredit the contributions made by mentally retarded family members. In the family interviews conducted for this study, parents described contributions made by their sons or daughters. These included assistance with household maintenance, companionship, and financial assistance. As supported employment of people with disabilities continues to expand, even individuals with severe and profound retardation are earning competitive wages (Moon et al., 1990). The financial contributions of mentally retarded individuals will become a vital part of many household budgets. The support provided by a mentally retarded adult to the household is an area of needed research.

A second area needing further research is in the relationships between non-disabled family members in caregiving families. Byrne and Cunningham (1985) report the effects of a mentally retarded child upon siblings. However, studies have not been expanded to include adult relations, such as a parent and adult child, or between grandparents and grandchildren. In the family interviews, one mother described her abandonment of the grandmother role because of the jealousy of her mentally retarded son. While some research has included the dyadic relations, studies have not explored the effect on adult relations in families with a mentally retarded member.

A third area for additional research is on models of functioning in families with an adult mentally retarded child. Wikler (1981) has developed and empirically tested (Wikler, 1986; Wikler et al., 1981) the chronic sorrow model which identifies periods during the development of a mentally retarded child when the parents are at risk to re-experience a sense of loss. This model, however, is not expanded to include adult developmental issues. Models which relate to adult functioning need to be proposed and tested. Divorce, retirement, or marriages of non-disabled children are all adult events which can precipitate feelings of loss resulting from prolonged caregiving roles. Identification of high-risk developmental periods for caregiving parents would add adult events to the chronic sorrow model.

Besides the major stress points, the strains experienced by caregivers of mentally retarded adults need further investigation. The findings of this study suggest that these caregivers are exposed to numerous daily strains and struggles. Chronic, low-level stress may affect physical and mental functioning. This study suggests that the emotional aspects of caregiving may continue after the mentally retarded child has left the household.

Additional research is needed on availability and utilization of resources of parents with an adult mentally retarded child. The literature suggests that families with handicapped children who use supports to buffer stress increase coping patterns (Dunst et al., 1986; Mink et al., 1983). Less is known about the ways older families use support systems and the effect of use over time. Do parents over-tax resources which diminishes availability over time? Can parents establish additional supports in later life when greater resources are needed? Are informal supports less available when a mentally retarded child assumes adult traits, features, and behaviors? Answers to these questions provide additional insight into the extent and quality of the support systems of older parents.

A final recommendation is to replicate this research using a large probability sample. This research was exploratory, with the goal of identifying relationships between variables. Replication would increase the probability that the findings were not due to chance or sample selection. A large study would also permit sub-group investigation. Some evidence suggests that people of color have different patterns of caregiving than white families (Eyman et al., 1977; Meyers, et al., 1985). Research which includes racial and ethnic samples would increase understanding about caregiving in all population groups. The use of a large probability sample would add support to the findings and increase population diversity.

In summary, parents of an adult mentally retarded child are a little researched group of caregivers. This study focused on ways parents differed from parents in other caregiving roles. While this study has increased understanding about parents in the caregiver role, additional research on the continuation of the parent-child caregiving situation is needed.

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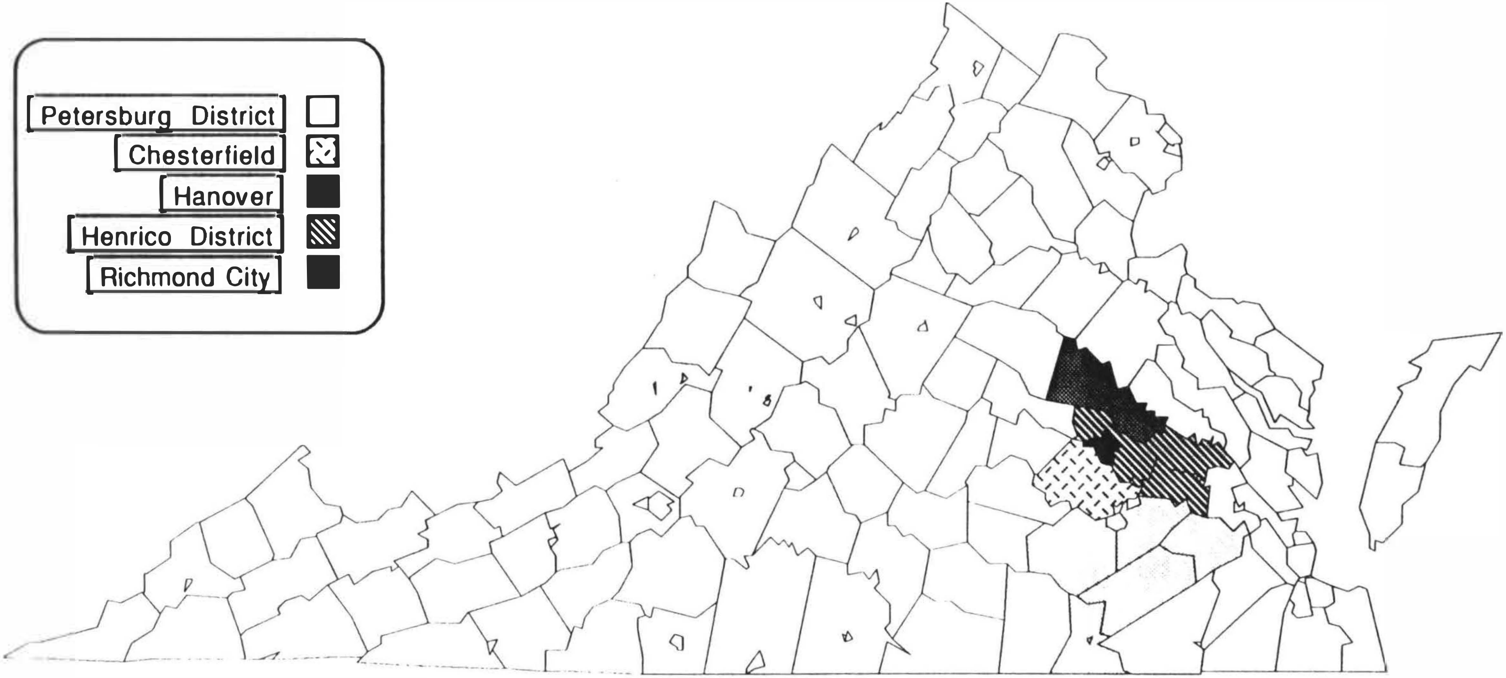
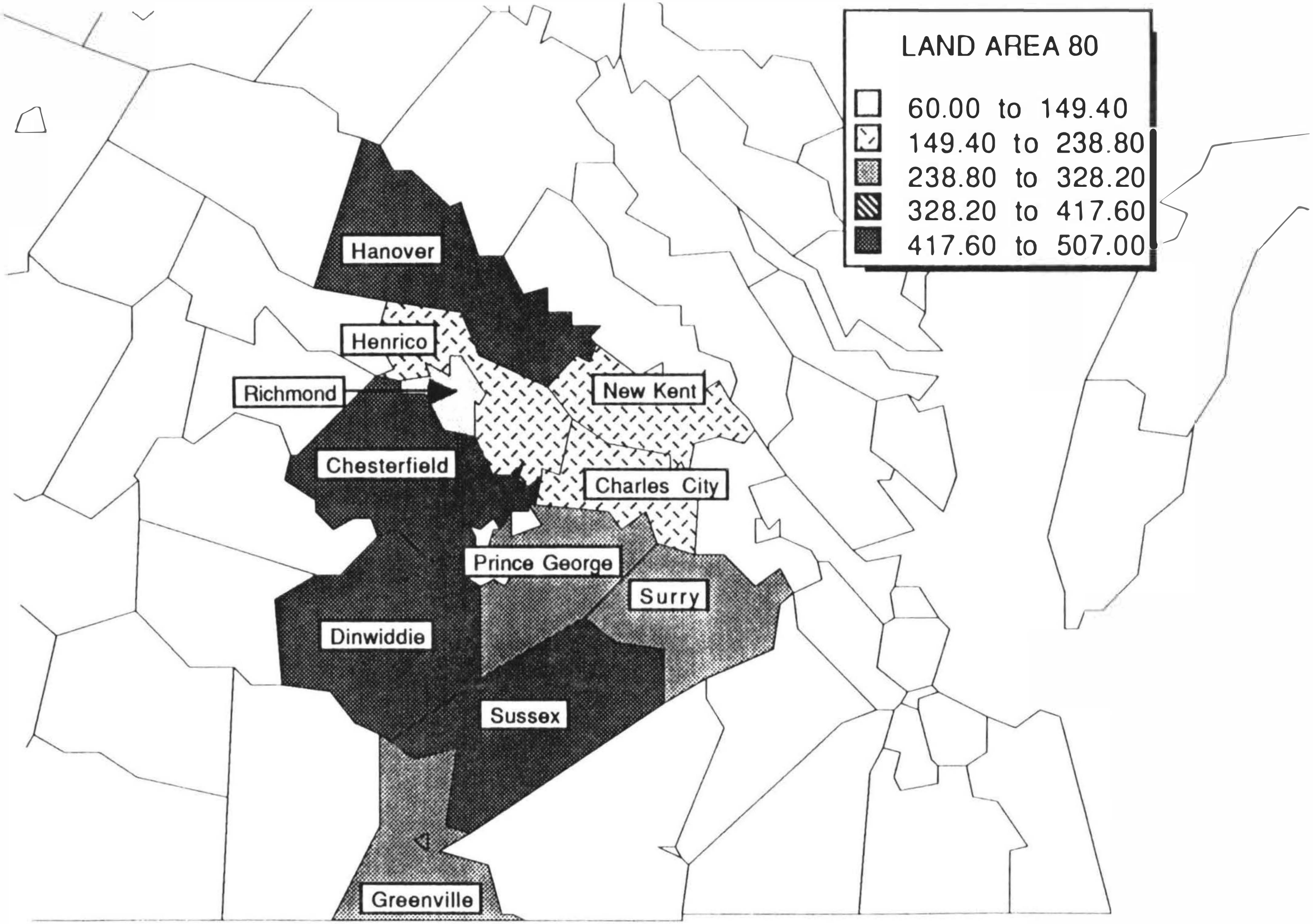
Appendices

APPENDIX A

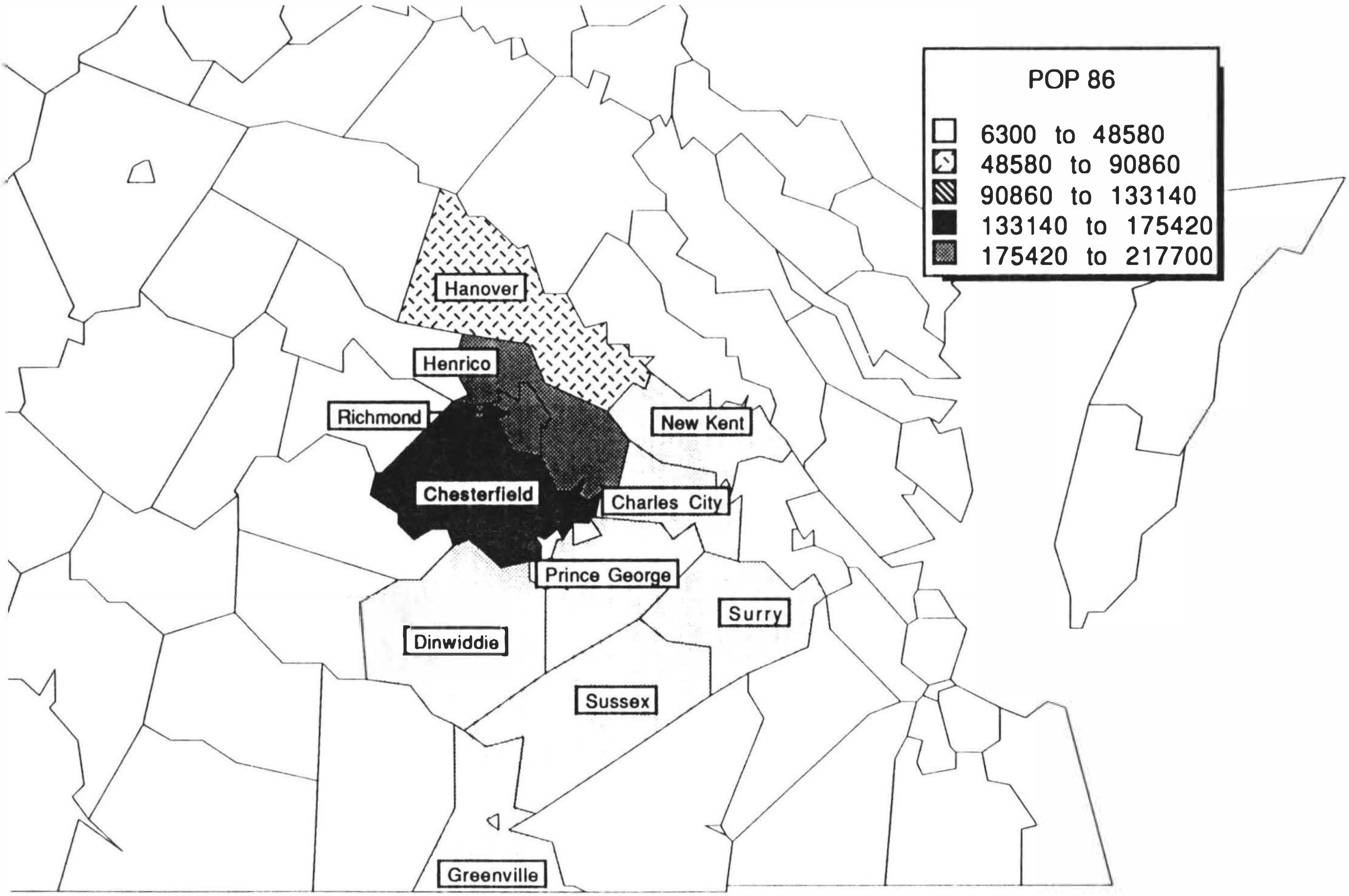
Participating Community Services Boards



Land Area by Community Services Boards (1980)



Population by Community Services Boards (1986)



APPENDIX C

Question & Answer Sheet:

Stress and Social Support of Parents with an Adult Mentally Retarded Child

WHO IS SPONSORING THIS RESEARCH? The proposed research project is the doctoral dissertation of Nancy Kropf in the School of Social Work, Virginia Commonwealth University. (See curriculum vita for more information about the researcher.)

WHAT IS THE STUDY ABOUT? This research is about caregiving in families where an adult-child is diagnosed as mentally retarded. As our population continues to stay alive longer, greater information is needed about caregiving of mentally retarded adults and the effects of caregiving upon the parents.

WHAT VARIABLES WILL BE MEASURED IN THIS STUDY? One variable of the study is the type of caregiving situation. The sample will contain three groups of caregivers:

> ACTIVE CAREGIVERS: Those parents who currently provide care to a mentally retarded adult son or daughter with their home.
>
> PAST CAREGIVERS: Those parents whose mentally retarded adult son or daughter currently resides outside the parental home.
>
> NON-CAREGIVERS: Those parents who had parenting responsibilities for non-handicapped children.

Both stress and social support variables will be measured. (See Variable Measurement and Research Model sheets.)

WHAT ARE THE PREDICTIONS ABOUT THE RELATIONSHIP BETWEEN CAREGIVING, STRESS AND SOCIAL SUPPORT? The hypotheses of the study predict that the ACTIVE CAREGIVER group will report higher degrees of stress and a smaller social support network than the other two groups. Additionally, the NON-CAREGIVER group is predicted to report lower degrees of stress and a larger social support network than the other groups.

WHY USE THE COMMUNITY SERVICE BOARDS? So far, the few studies on older families have used some service delivery system to identify the sample. Sampling from other community organizations, such as the Association for Retarded Citizens, would bias the sample for this research since that type of organization is established to provide social support to families.

WHAT WILL BE THE ROLE OF THE CSBs? The CSBs have important information for this research. The casemanagers have been selected as a point of access for the mentally retarded adult population served through the CSB. EACH casemanager within the CSB would be asked to assist with three tasks:

TASK 1:
Identify the names/address of 15 parents (one per family) who meet these criteria:

1. a mentally retarded son or daughter has an open file through the CSB
2. the son or daughter is 18 years of age or above
3. the parent is the birth parent of the son or daughter
4. the son or daughter <u>currently lives</u> with the parent

TASK 2:
Identify the names/addresses of 15 parents (one per family) who meet these criteria:

1. a mentally retarded son or daughter has an open file through the CSB
2. the son or daughter is at least 18 years of age or above
3. the parent is the birth parent of the son or daughter
4. the son or daughter <u>does not currently live</u> with the parent

TASK 3:
Co-sign a letter enclosed with the survey to the parents which he or she has nominated. This letter will explain the purpose of the research and directions about how to complete the questionnaire.

WILL THE CSBs BE RESPONSIBLE FOR ANY COSTS ASSOCIATED WITH THE RESEARCH? No, the CSB is not responsible for any costs. The cost of mailing, printing, computer and clerical time will be provided by the researcher.

WHY IS THIS RESEARCH IMPORTANT FOR THE CSB? Parenting any child is a stressful job. Parenting a child with a disability increases the stress parents experience. However, most research to date has used families with a mentally retarded child, not an adult. Little is known about the stress of caring for a mentally retarded person who reaches adulthood. Additionally, the effect of caregiving upon the family's ability to build and maintain social support networks is lacking. This research will examine both stress levels and the social support constellation between three different caregiving groups. Practice and policy implications will be proposed and discussed.

APPENDIX D

Pre-Test Cover Letter and Form

Dear Parents:

I am a doctoral student and instructor in the School of Social Work at Virginia Commonwealth University. I am doing my dissertation research on caregiving in families with a mentally retarded adult-child. From my own experience as a respite care casemanager in Michigan, and research studies which are being done currently, I believe that human service workers need to have a better understanding about parents who are caring for a person who is both an adult AND a mentally retarded person. My research is studying the amount of stress experienced by parents of a mentally retarded adult, and the type and number of people these parents turn to when they need assistance.

As parents of a mentally retarded child, you are a valuable resource in this piece of research. By volunteering to pre-test this survey, I am able to get feedback about my questionnaire to increase its accuracy. Please follow the instructions below.

1. Answer the questions contained in the survey, as if this was a real situation. Read all the directions carefully, as I am interested in determining whether you think any are unclear or confusing. I DO NOT KNOW YOUR NAMES AND WILL NOT BE ANALYZING THE SURVEYS YOU COMPLETE. Remember that a pre-test is a practice run--I am only interesting in finding out whether you have any difficulty in completing the survey and where the trouble spots are. I will DESTROY your surveys after I have read your responses.

2. Fill out the Pre-Test Information Sheet (Pink form). This form is for your feedback about the survey and informs me of any problems.

3. Mail BOTH the survey AND the Information Sheet back to me in the pre-addressed and pre-stamped envelope by April 6.

Again, I appreciate your willingness to contribute to my research. I believe that caregiving of an adult with mental retardation is an important area for research and that this dissertation will produce some valuable information about this type of caregiving. Please contact me at [redacted] if you want to discuss any issues further. I look forward to your feedba

Sincerely,

Nancy P. Kropf

Pilot Test--Information Form

1. How long did it take you to complete this survey?

_______ Hours _______ Minutes

2. Please rate each of the following about the survey.

a. PRINT SIZE: Is the size of the printed letters too large or small?

Too large O.K. Too small

b. READING LEVEL: Is the vocabulary too easy or difficult?

Too easy O.K. Too difficult

c. INSTRUCTIONS: Are instructions to the questions clear enough?

Clear Some are unclear All are unclear

———-> WHICH?

Page: ________________
Page: ________________
Page: ________________

d. LENGTH: Is the survey too long or too short?

Too long O.K. Too short

e. If you received this survey with a cover letter which explained the purpose of this research and assured you that your identity is unknown to the researcher, would you have completed and returned it in a pre-stamped envelope?

1. Yes
2. No: Why not? ____

PARENT SURVEY

The goal of this survey is to better understand the effect of parenting after children have left home. Have only one parent answer the questions, either the mother or father. Please answer all questions and return the survey in the envelope which is provided.

Thank you for taking time to be a part of this study.

School of Social Work
Virginia Commonwealth University

A. THE FOLLOWING QUESTIONS ARE ABOUT YOU PERSONALLY. ANSWER EACH QUESTION BY CIRCLING THE NUMBER NEXT TO THE BEST ANSWER OR FILLING IN THE BLANK.

1. Your sex is:

   1. Female
   2. Male

2. Your race/ethnic group is:

   1. Black
   2. White
   3. Hispanic
   4. Other (Specify) ____________________

3. How many years of school have you finished? (Circle the number)

0 1 2 3 4 5 6	7 8 9	10 11 12	13 14 15 16	17 18 19 20+
Elementary School	Jr. HS	High School	College	Graduate School

4. What is your age, as of your last birthday? ________ (Years)

5. Which answer <u>best describes</u> your <u>current</u> work situation? (Circle the single best answer)

   1. Retired
   2. Employed -- Full time (32 or more hours per week)
   3. Employed -- Part time (less than 32 hours per week)
   4. Unemployed
   5. Not employed --Laid-off
   6. Full-time homemaker
   7. Not employed -- Student

6. Which answer <u>best describes</u> your <u>past</u> work situation? (Circle the single best answer)

   1. Employed full-time (32 or more hours per week)
   2. Employed part-time (32 or less hours per week)
   3. Full-time homemaker
   4. Other (Specify) __________________________

7. What is your religion? (Circle one)

   1. Catholic
   2. Jewish
   3. Protestant (Specify) _____________________
   4. Other (Specify) __________________________
   5. None

8. How many church activities do you usually attend in a week? These can include worship services, social clubs, choir practices, etc.

   _______ Number of activities within a usual week

9. How religious you are?

   1. I am more religious than most people
   2. I am about as religious as most people
   3. I am less religious than most people

10. Circle the category which best describes your marital status. Fill in the blank next to the category with the number of years.

    1. Never married
    2. Married (how long? ____________)
    3. Widowed (how long? ____________)
    4. Divorced (how long? ____________)
    5. Separated (how long? ____________)
    6. Other (how long? ____________)

11. How many children do you have? ________ (number)

12. How many of your children live in your home with you now?

    a. Number of children living in home _______

    b. Ages of your children in home _____ _____ _____ _____

13. How many people live in your home now?

    _______ Total number in home

14. How many years have you lived in your current home?

    _______ Years in home

15. In which location do you live now? (Circle one).

    1. City of Richmond
    2. Henrico County
    3. Hanover County
    4. Chesterfield County
    5. Charles City County
    6. New Kent County
    7. Petersburg
    8. Hopewell
    9. Emporia
    10. Colonial Heights
    11. Dinwiddie County
    12. Greensville County
    13. Prince George County
    14. Surry County
    15. Sussex County
    16. Other ______________

16. Do any family members who live in your home have any of the following? (Circle all that apply).

    1. Brain injury from an accident
    2. Mental retardation
    3. Mental illness
    4. Physical disability
    5. Other handicapping condition: Specify ______________________

17. What is the total income of your household? Add the income of everyone living with you <u>before</u> taxes are taken out.

    1. less than $5,000
    2. $ 5,001 - $10,000
    3. $10,001 - $15,000
    4. $15,001 - $20,000
    5. $20,001 - $25,000
    6. $25,001 - $30,000
    7. $30,001 - $35,000
    8. $35,001 - $40,000
    9. $40,001 - $50,000
    10. $50,001 - $60,000
    11. $60,001 $70,000
    12. More than $70,000

INCLUDED FOR ACTIVE AND PAST CAREGIVERS ONLY

THE NEXT SERIES OF QUESTIONS ARE ABOUT YOUR SON OR DAUGHTER WHO IS MENTALLY RETARDED AND RECEIVES SERVICES THROUGH THE COUNTY.

18. This person is my:

    1. Daughter
    2. Son

19. How old is your son or daughter? _______ (Years)

20. How independent is your son or daughter in each of the following activities NOW? Circle one number for each activity.

ACTIVITY	**DOES TOTALLY BY HIMSELF OR HERSELF**	**NEEDS SOME ASSISTANCE**	**NEEDS TOTAL ASSISTANCE**
	1	2	3
Walking	1	2	3
Dressing	1	2	3
Bathing	1	2	3
Feeding self	1	2	3
Going to the bathroom	1	2	3
Preparing simple meals (i.e.--sandwiches)	1	2	3
Using public transportation	1	2	3
Getting around the neighborhood	1	2	3

INCLUDED FOR PAST CAREGIVERS ONLY

21. How many years has it been since your son or daughter last lived with you?

    _______ (Years)

22. What is your son's or daughter's current living arrangement? (Circle the best answer).

    1. Lives by himself/herself or with a roommate
    2. Group home
    3. Adult foster care home
    4. Residential institution
    5. Nursing home
    6. Supervised apartments
    7. Other (Specify) ______________________

23. About how many times a month do you and this son or daughter:

    Talk on the phone ________
    Visit together (not overnight) ________
    Visit together overnight _______

24. About how many miles are there between your home and your son's or daughter's residence? ________

A. LISTED BELOW ARE A NUMBER OF EVENTS WHICH HAPPEN TO SOME PEOPLE. READ EACH OF THE FOLLOWING EVENTS. THINK OF WHETHER YOU, YOUR SPOUSE OR AN ADULT CHILD LIVING IN YOUR HOME HAS HAD THIS EVENT HAPPEN WITHIN THE LAST 12 MONTHS. IF THE ANSWER IS "NO," CIRCLE THE "N." IF THE ANSWER IS "YES," CIRCLE THE "Y" AND CIRCLE WHETHER YOU, YOUR SPOUSE OR AN ADULT CHILD LIVING IN YOUR HOME HAD EXPERIENCED THE EVENT.

	NO This event did not happen	**YES** This event did happen	**WHO** This event happened to 1 = Me 2 = Spouse 3 = Adult Child		
1. lost something of value	N	Y ---->	1	2	3
2. death of a close friend	N	Y ---->	1	2	3
3. trouble with friends or neighbors	N	Y ---->	1	2	3
4. separation	N	Y ---->	1	2	3
5. divorce	N	Y ---->	1	2	3
6. trouble with in-laws	N	Y ---->	1	2	3
7. trouble with boss at work	N	Y ---->	1	2	3
8. retired	N	Y ---->	1	2	3
9. laid off or fired from a job	N	Y ---->	1	2	3
10. unemployed for a month or more	N	Y ---->	1	2	3
11. large decrease in income	N	Y ---->	1	2	3
12. legal problems	N	Y ---->	1	2	3
13. assaulted or robbed	N	Y ---->	1	2	3
14. raped or sexually assaulted	N	Y ---->	1	2	3
15. death of a spouse	N	Y ---->	1	2	3
16. death of close family member	N	Y ---->	1	2	3
17. child left home	N	Y ---->	1	2	3
18. started new job, school or training program	N	Y ---->	1	2	3
19. graduation from school or training program	N	Y ---->	1	2	3
20. engagement	N	Y ---->	1	2	3
21. marriage	N	Y ---->	1	2	3
22. got back together with spouse	N	Y ---->	1	2	3
23. birth of a child in your close family	N	Y ---->	1	2	3
24. promotion at work	N	Y ---->	1	2	3
25. took a new job	N	Y ---->	1	2	3
26. income increased a lot	N	Y ---->	1	2	3
27. took a vacation	N	Y ---->	1	2	3
28. had to cancel vacation plans	N	Y ---->	1	2	3
29. moved to a new home	N	Y ---->	1	2	3
30. someone moved into the home	N	Y ---->	1	2	3

B. THE NEXT SECTION IS ABOUT YOUR PERSONAL HEALTH AND ROUTINE. THESE QUESTIONS ARE ABOUT WHAT YOU HAVE BEEN DOING AND HOW YOU HAVE BEEN FEELING WITHIN THE LAST 12 MONTHS.

1. About how many hours per week do you usually have for free time to do whatever you want?

   _____ Total number of hours per week

2. Which of the following statements best describes how satisfied you currently are with the free time you have for yourself each week. (Circle the one best answer).

   1. I am very satisfied with the number of hours I have for myself.
   2. I am satisfied with the number of hours I have for myself.
   3. I am dissatisfied because I have too many hours for myself.
   4. I am dissatisfied because I have too few hours for myself.

3. Listed below are some activities which some people do. Circle all those activities which have been a part of your routine within the last 12 months. (Circle all that apply).

   1. Eating 3 meals a day
   2. Sleeping 6 - 8 hours a night
   3. Exercising 2 - 3 hours a week
   4. Smoking cigarettes daily
   5. Drinking more than 2 alcoholic beverages a day
   6. Drinking more than 2 cups of coffee and/or cola a day
   7. Visiting a doctor for regular medical check-ups
   8. I don't do any of these activities.

4. Which of the following feelings have you had within the last 12 months? (Circle all that apply to you).

   1. Felt that you just couldn't get going
   2. Felt that you were a worrier?
   3. Felt that your memory wasn't all right?
   4. Had personal worries that made you feel sick?
   5. Felt that nothing turned out right for you?
   6. Wondered if anything was worthwhile anymore?
   7. I haven't had any of these feelings within the last 12 months.

5. Circle any of the health problems that you have had within the last 12 months. (Circle all that apply).

   1. Felt weak all over
   2. Suddenly felt hot all over
   3. Felt your heart was pounding or beating hard
   4. Did not feel like eating
   5. Felt nervous, fidgety or tense
   6. Had constipation
   7. Had "cold sweats"
   8. Had an acidy stomach or indigestion
   9. Had trembling hands
   10. Had frequent or severe headaches
   11. Had problems falling or staying asleep
   12. I haven't had any of these problems in the last 12 months.

6. Circle any of the following health problems which a doctor has told you that you have and have bothered you within the last 12 months. (Circle all that apply).

   1. Anemia
   2. Asthma
   3. Arthritis
   4. Bronchitis
   5. Cancer
   6. Chronic liver trouble
   7. Diabetes
   8. Serious back trouble
   9. Heart trouble
   10. High blood pressure
   11. Kidney trouble
   12. Stroke
   13. Tuberculosis
   14. Ulcers

7. Compared to other people your same age, how would you rate your physical health? Circle the best answer.

MUCH BETTER	BETTER	SAME	WORSE	MUCH WORSE
1	2	3	4	5

ON THE NEXT PAGE, THERE ARE QUESTIONS ABOUT THOSE PEOPLE WHO ARE YOUR SUPPORTS. AT THIS TIME, THINK ABOUT THE PEOPLE IN YOUR LIFE WHO YOU TALK TO ABOUT IMPORTANT THINGS AND TURN TO WHEN YOU NEED HELP. IN THE LEFT-HAND COLUMN LABELLED "INITIALS," LIST THE INITIALS OF THOSE PEOPLE WHO COME TO MIND. TRY AND MAKE EACH SET OF INITIALS DIFFERENT, THAT IS, USE SETS WHICH ARE NOT THE SAME FOR TWO PEOPLE. FOR EXAMPLE, IF TWO PEOPLE HAVE INITIALS OF "NPK," LIST ONE PERSON AS "NPK" AND THE OTHER PERSON AS "NK". AFTER YOU HAVE LISTED THOSE PEOPLE YOU TURN TO IN THE "INITIAL" COLUMN, MOVE ACROSS THE PAGE TO THE CENTER COLUMN "RELATIONSHIP". FOR EACH PERSON IDENTIFIED IN THE "INITIAL" COLUMN, CIRCLE THE WORD WHICH BEST DESCRIBES YOUR RELATIONSHIP TO THAT PERSON. FINALLY, IN THE RIGHT-HAND COLUMN, CIRCLE THE CLOSENESS IN AGE BETWEEN YOU AND EACH PERSON IDENTIFIED IN THE "INITIAL" COLUMN.

DO NOT FEEL THAT YOU MUST FILL IN ALL THE BLANK LINES. YOU DO NOT HAVE TO IDENTIFY A CERTAIN NUMBER OF PEOPLE IN THIS SECTION. AN EXAMPLE IS GIVEN TO SHOW HOW TO COMPLETE THIS SECTION.

EXAMPLES:

INITIALS	RELATIONSHIP	AGE
NPK	[✓ Spouse] Child Other Family Member Neighbor Helping Professional Friend Other	Younger [✓ Same Age] Older
NK	Spouse Child [✓ Other Family Member] Neighbor Helping Professional Friend Other	Younger Same Age [✓ Older]

Follow the examples above when filling in your supports on the following page.

YOUR SUPPORTS

INITIALS

List one person's set
of Initials on one line.

RELATIONSHIP

Please indicate for each
his or her relationship to you.

AGE

Please indicate for each whether
he or she is older (by 5+ yrs.),
younger (by 5+ yrs.) or about
the same age as you are.

___ ___ ___	Spouse	Child	Other Family Member	Neighbor	Helping Professional	Friend	Other	Younger	Same Age	Older
___ ___ ___	Spouse	Child	Other Family Member	Neighbor	Helping Professional	Friend	Other	Younger	Same Age	Older
___ ___ ___	Spouse	Child	Other Family Member	Neighbor	Helping Professional	Friend	Other	Younger	Same Age	Older
___ ___ ___	Spouse	Child	Other Family Member	Neighbor	Helping Professional	Friend	Other	Younger	Same Age	Older
___ ___ ___	Spouse	Child	Other Family Member	Neighbor	Helping Professional	Friend	Other	Younger	Same Age	Older
___ ___ ___	Spouse	Child	Other Family Member	Neighbor	Helping Professional	Friend	Other	Younger	Same Age	Older
___ ___ ___	Spouse	Child	Other Family Member	Neighbor	Helping Professional	Friend	Other	Younger	Same Age	Older
___ ___ ___	Spouse	Child	Other Family Member	Neighbor	Helping Professional	Friend	Other	Younger	Same Age	Older

QUESTIONS ABOUT YOUR SUPPORTS

THE NEXT QUESTIONS ARE ABOUT THOSE PEOPLE YOU HAVE JUST IDENTIFIED AS SUPPORTS. MANY TIMES, PEOPLE WILL TURN TO A PERSON FOR SUPPORT WITH ONE PROBLEM BUT NOT WITH ANOTHER PROBLEM. THIS PART IS ABOUT WHO YOU TURN TO WITH DIFFERENT PROBLEMS. FOR THE FOLLOWING SET OF QUESTIONS, USE ONLY THE INITIALS OF THOSE PEOPLE YOU HAVE ALREADY IDENTIFIED AS YOUR SUPPORTS.

A. HOME AND FAMILY

1. The first question is about things that happen with your home and family. In the blanks below, fill in the initials of those people you have identified as your supports who you turn to when you need to discuss or receive help with problems about your <u>home and family</u>. Do not feel you must fill in all blanks.

________ ________ ________
________ ________ ________
________ ________

2. Within this group of people, how many come to you to discuss or receive help with problems about their home and family?

_____ Number of people who also discuss their home and family with me

3. How satisfied are you with those people who you turn to with problems about your home and family? (Circle the best answer)

VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED
1	2	3	4

B. HEALTH

1. The second question is about things that happen with your health. In the blanks below, fill in the initials of those people you have identified as your supports who you turn to when you need to discuss or receive help with problems about your <u>health</u>. Do not feel you must fill in all blanks.

________ ________ ________
________ ________ ________
________ ________

2. Within this group of people, how many come to you to discuss or receive help with problems about their health?

______ Number of people who also discuss their health with me

3. How satisfied are you with those people who you turn to with problems about your health? (Circle the best answer)

VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED
1	2	3	4

C. PERSONAL/SOCIAL ISSUES

1. The third question is about things that happen with you personally and socially. In the blanks below, fill in the initials of those people you have identified as your supports who you turn to when you need to discuss or receive help you personally and socially. Do not feel you must fill in all blanks.

______ ______ ______

______ ______ ______

______ ______

2. Within this group of people, how many come to you to discuss or receive help with problems about them personally and socially?

______ Number of people who also discuss their personal and social issues with me

3. How satisfied are you with those people who you turn to with problems about you personally and socially? Circle the best answer.

VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED
1	2	3	4

D. MONEY MATTERS

1. The fourth question is about money matters. In the blanks below, fill in the initials of those people you have identified as your supports who you turn to when you need to discuss or receive help with problems about money. Do not feel you must fill in all blanks.

______ ______ ______

______ ______ ______

______ ______

2. Within this group of people, how many come to you to discuss or receive assistance with problems about their money matters?

_______ Number of people who also discuss their money matters with me

3. How satisfied are you with those people who you turn to with problems about your money matters? (Circle the best answer)

VERY SATISFIED	SATISFIED	DISSATISFIED	VERY DISSATISFIED
1	2	3	4

DURING THE <u>LAST MONTH</u>, HOW OFTEN DID YOU HAVE PEOPLE WHO HAVE DONE THE FOLLOWING WITH YOU:

	NOT AT ALL	A LITTLE BIT	SOME	QUITE A BIT
1. a. Talked about things which are personal or private	1	2	3	4
b. Loaned you things that you needed but couldn't get for yourself	1	2	3	4
c. Given you important advice	1	2	3	4
d. Told you they liked the things that you did	1	2	3	4
e. Helped you take care of something you needed to do (i.e.--go to store, move a heavy object)	1	2	3	4
f. Gotten together with you for fun and to relax	1	2	3	4
g. Given you comfort by showing physical affection	1	2	3	4

2. Who helped you fill out these questions? (Circle the best answer)

   a. No one helped me.
   b. My spouse
   c. Another family member
   d. A friend
   e. A neighbor
   f. Someone who volunteers to help me
   g. Someone I pay to help me
   h. Another person who is ____________________

APPENDIX F

Data Collection Schedule

TIME	EVENT
March-April 1989	Initial contact with CSBs Substitute one CSB for a location which chose not to participate
March 1989	Survey instrument pre-tested by parent support group in Hanover County and Chesterfield Human Subject Committee
April-May 1989	Casemanagers of CSBs given instructional packet to identify parents from their caseloads. Casemanagers co-signed cover letters to parent son their caseloads.
May 1989	Packets containing survey were distributed to CSBs for mailing through the agency. One week follow-up postcards mailed through CSBs.
May-June 1989	Surveys were returned by respondents in active and past caregiver groups. Data were coded and initial analyses were run on demographic variables to select churches which would identify parents in the non-caregiver group.
June-August 1989	Churches were selected from denominational rosters. Meetings were conducted with the clergy from each church to discuss the study.
July-September 1989	Surveys and follow-up postcards were mailed to non-caregivers.
September 1989	Casemanager supervisors from the five CSBs were contacted to identify an active caregiving family from their jurisdiction to participate in the study.
September-October 1989	Conducted family interviews with in the homes of five families.

APPENDIX G

Cover Letter to Parents

«Date»

Dear Parent:

PARENTS ARE PEOPLE TOO! Being a parent is tough at times. As part of my Ph.D. in social work, I am studying how a parent's life is affected by having an adult son or daughter who is mentally retarded. Your answers to questions in the enclosed survey are important to better understand the needs of parents with mentally retarded adult-children.

You were identified as a parent by ((a casemanager in «CSB»)) ((the pastor of «church»)). However, I do not know your name or address and your participation in this study is optional. To preserve your identity, the mailing label on the enveloped was attached by «county staff» «church staff», not by the researcher. Parents from five counties are part of this study. Results from the study will be shared with staff in the «counties» «churches» to help them better understand the parenting role.

Only one parent in each family is asked to fill out the questions. If two parents are in the home, either can complete them. «However, if only one is the birth-parent of the son or daughter who is mentally retarded, have the parent answer the questions.»

Please return the finished survey in the pre-addressed envelope that is included. Postage is already paid so you do not need to attach a stamp. Please mail back the finished survey within a week. Keep the stickers that are enclosed to remind others that PARENTS ARE PEOPLE TOO!

Sincerely,

Nancy P. Kropf and «Casemanager»
Instructor «Community Services Board»
OR
«Pastor»
«Church»

Vita

[redacted]