DEINSTITUTIONALIZATION: THE CONSEQUENCES
FOR THE PRIMARY CAREGIVER

by

JENNIFER PETTIT

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Dedicated to my grandparents

C.T. Mann and Leona Mann

Joseph V. Pettit and Doris A. Pettit
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ABSTRACT

DEI NSTITUTIONALIZATION: THE CONSEQUENCES

FOR THE PRIMARY CAREGIVER

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Jennifer Pettit, MA

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Supervising Professor: Beth Anne Shelton, Ph. D.

This study examines the psychological well-being of the primary caregiver of a mentally-challenged individual. In this research, the primary caregiver is the person who has responsibility for the care of a mentally-challenged individual. The three main questions examined in this research are: Will caregiver’s socioeconomic status be associated with the reported stress level of the caregiver? Will the use of formal supports to the caregiver be associated with lower levels of caregiver stress? Will the use of informal supports be associated with lower levels of caregiver stress?

The study involved a quantative approach to examine 90 primary caregivers who live in the State of Texas, cares for only one mentally-challenged individual in
their natural home setting. The research was conducted for five months, August through December 2005. Data was collected through Texas Special Olympics, various support groups, and networking throughout the State of Texas. A portion of the Parenting Stress Inventory (PSI) developed by Terry (1991) was used in the survey. The Multiple Classification Analysis was used in this research. The findings show caregiver’s socioeconomic status is associated with the reported stress level of the caregiver but the use of formal supports and informal supports are not associated with lower levels of caregiver stress.
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Deinstitutionalization of the mentally-challenged has become a primary national trend in the last decade. Over sixty-one thousand individuals were on waiting lists for community-based services in the United States in 1990 (Drouty and Katina 1999). Options for those who require institutionalization are increasingly limited (Palley and Van Hollen 2000).

In 1995, the U.S. Congress defined a mentally-challenged individual as one who has chronic, severe disability attributed to a mental and/or physical impairment. Such impairment results in substantial functional limitations in major life activities (U.S. Congress 1995: 289).

In the United States, extensive deinstitutionalization of the mentally-challenged began in the mid 1960s. Individuals in large institutions were relocated to either smaller group homes, or back to a natural home setting with their families of origin. The justification for deinstitutionalization is that it provides individuals the right to “…live independently, enjoy self-determination, make choices, contribute to society, and experience full integration…” into society (U.S. Congress 1995: 285). Privacy laws limit access to literature on caregiving of mentally-challenged family members in their natural home setting. This study attempts to acknowledge the complexities of the
various needs and demands of the caregivers and their particular situations (Bernard, Andrew, and Luster 2002). This research identifies the primary caregiver as the person who has the primary and crucial responsibilities for the care of the mentally-challenged individual. Findings indicate that much more extensive research in this area is warranted. Such studies would significantly increase government awareness and lend advocacy to both the mentally-challenged and their caregivers in home and group home settings.

Families operate as an interactive unit and what affects one member affects all of the family (Garner and Chapman 1990). The deinstitutionalization of the mentally-challenged has transformed family dynamics and roles. Parents of families who have a mentally-challenged child now have the added responsibilities of caregiving in the home (Marks et al. 2002). A mentally-challenged family member in the home requires care twenty four hours a day, leaving many caretakers without any quality time for themselves. These families need additional support to provide quality care for their mentally-challenged family member’s needs. Unfortunately, many families caring for the mentally-challenged lack the developed networks and social services to help carry out their daily caretaking responsibilities (Moroney 1979).

Now, more than ever, families are being held solely responsible for the care of their mentally-challenged family member. Deinstitutionalization leaves the responsibility of socialization, and the provisions of both economic and emotional security of the mentally-challenged family member up to his/her primary caregiver. Families must now provide resources for these individuals for daily care, as well as
education and medical treatment. The family’s responsibility is to provide a safe, nurturing environment, as well as the socialization of each individual within the home. The family needs to encourage and foster the development, assimilation, and psychological well-being of all members (Cummings 2001). In some rare cases, parents may be in denial of their child’s disability. Professionals are then challenged with making such parents understand their child’s needs, so that they can move forward, and reach out to receive necessary help (Garica et al. 2000). Once the parents accept the disability, then the formal supports available to these families can be utilized to alleviate the parent’s increased stress levels. These supports include day programs, respite care, and some paid specialized child/adult care services.

There are many caregiving roles within the family unit, including, but not limited to, spousal, parental, other kin and children. The focus of this research paper will be on the primary caregiver of a mentally-challenged individual. This research will focus on how caring for mentally-challenged family members living at home affects the psychological well-being, specifically related to stress, of the primary caregivers. This research intends to educate others about caregiving of the mentally-challenged. It hopes to increase both awareness and advocacy for this specialized group.
CHAPTER 2
LITERATURE REVIEW

2.1 History of Deinstitutionalization in the United States

Until the mid-1800s, families with mentally-challenged individuals cared for them within their natural home setting (Cummings 2001). Institutionalization became an option to families beginning in the mid-1800s. It allowed families to place individuals in a state institution for what was perceived as more appropriate care. Yet, by the end of the twentieth-century, families were again caring for their family members at home and “families who might have chosen to institutionalize their family members in the past now keep them at home” (Griffiths and Unger 1994: 221).

“Decentralization” precipitated the movement toward deinstitutionalization in the United States in the mid-1900s. Erving Goffman’s (1961) Asylum also influenced the evolving trend toward deinstitutionalization. Goffman spent a year observing patients at St. Elizabeth’s Hospital in Washington, D.C. His writings contributed further rationale for the deinstitutionalization that patient advocates and government representatives now favored. In his observations, Goffman paid close attention to both the quality of the care, and the quality of the lives of institutionalized mentally-challenged patients. He characterized the institutions as dehumanizing, demoralizing, and humiliating, in stark contrast to how the institutions depicted themselves publicly.
(Johnson 1990). While the institutions portrayed themselves as well-run organizations, Goffman (1961) argued that, in reality, they were “dumping grounds” for the mentally-challenged. In *Asylum*, Goffman describes a “betrayal funnel” a system (perceived as normal) in which the institution’s employees conditioned the mentally-challenged residents to cooperate in order to avoid pain, discomfort, or embarrassment. Goffman asserted that institutionalized individuals gradually lost all, or most of the physical and social supports that once held them together and integrated them into society. In persuading both patient advocates and government agencies that the humanity of these patients was at stake, his writings notably contributed a great deal to the push for deinstitutionalization.

According to Durkheim, appetites and desires are regulated by society. Essentially, people are bonded together by their common morals and beliefs obtained primarily through family and community. Durkheim’s “theory of anomie” can be summed up when the “…deregulation of behavior exists, society is said to be characterized by a state of anomie” (Perrucci 1974: 130). This “state of anomie” is most apparent when individual’s actions are no longer within the ‘norms’. Durkheim also identifies “two conditions in the means-ends system of behavior that gives rise to a state of deregulations” (Perrucci 1974: 130). The first condition of anomie involves social changes and shifts in societal structure. A previously workable societal organization will no longer work in the present day. This is supported by changes in the philosophy of institutions. At the turn of the century, state institutions were thought of as “well-oiled machines” that could provide a better, more appropriate, and stable
environment for individuals outside of the ‘norms’ of society (i.e., the mentally-challenged). During the early 1900’s, American society wanted “insane” and mentally-challenged individuals to be protected from society and, perhaps more importantly, society protected from them. Today, our social structure more readily supports the change from large institutions to community-based care settings. Influenced by the writings of social scientists like Goffman, advocates pushed for these changes which eventually led to the mass deinstitutionalization of the mentally-challenged.

The second condition of “anomie”, according to Durkheim concerns the goals of action, focusing on goals that can never be achieved. For example, the assertion that mentally-challenged individuals in state institutions can never be independent enough to live on their own. As long as an individual depends on a ‘total institution’ they can never meet the goal of independence and caring for oneself completely. However, deinstitutionalization could allow mentally-challenged individuals a better opportunity to meet the goal.

Emile Durkheim’s theory of anomie and social structure clearly influenced sociologist Robert K. Merton. Merton (1938) described the United States, the American dream, and the search for prosperity as an example of this anomie and social structure. Deinstitutionalization may perhaps, inspire, the hope of acquiring the American dream for each family. Social networks, the development of social skills, and ambition may help a mentally-challenged individual gain the everyday rights and opportunities granted to all citizens of the United States (Perkins and Burns 2001).
However, the effects and challenges involved in caring for a mentally-challenged family member can also diminish the American dream for the primary caregiver.

In theory, deinstitutionalization provides mentally-challenged individuals with the opportunity to learn appropriate behaviors and interactions common to society. George Herbert Mead, father of “symbolic interaction theory”, explains that the self arises through social experience and activity. Mead contended that the individual mind and self arises out of social processes in which an individual acts according to societal views of the world, as well as what he/she’s taught. (Mulkey 1993). Thus, the self develops in each individual as a result of its relationship with others and its own growth. Individuals need role models to show, instruct, and teach what society expects of them, which strengthens the argument for deinstitutionalization and the importance of family-based care.

Current trends in deinstitutionalization “evolved out of the parent movement in the 1950s and 1960s” (Braddock 1991: 3). Parents of mentally-challenged individuals demanded greater opportunities for community-based living. Over the past twenty to thirty years, the emergence of arguments for normalization and socialization, and a weak economy has contributed to the closing of most state-funded institutions. The shift from state institutions to family-based community programs result in a significant change of environmental settings for the mentally-challenged. From limited access of services in state institutions to increased access to a variety of services offered in the community, society’s expectations about both the quality of care and the quality of life for the mentally-challenged are rapidly changing (Perkins and Burns 2001).
The process of deinstitutionalization officially began in the U. S. after Wyatt v. Stickney (1972). The court ruled that the Parlow State School and Hospital in Alabama did not provide quality care to mentally-challenged patients. This case established the right to habilitation when testimony indicated that institution was basically a warehouse for retardates. Testimony further revealed that the state school contributed to mentally-challenged individual’s deterioration of self-care and independent abilities (Stroman 1989). This well-known case was the beginning of a long line of court cases beginning in the early 1970s which led to the development of vast movement toward deinstitutionalization throughout the United States.

2.2 The Political and Economic Context of Deinstitutionalization

The parallel occurrences of the ideology of normalization, economic rationalism, and push for privatization in the past twenty years have been the fundamental justification for deinstitutionalization of the mentally-challenged (Cummings 2001). State governments have turned their focus to the “whole-scale closure” of institutions for the mentally-challenged, placing the care of the mentally-challenged in the hands of their families and their local communities (Cummings 2001). The main objective of community placement is to provide the greatest potential for growth, camaraderie, and happiness of the mentally-challenged individuals and their families. The government saves billions of dollars because deinstitutionalization transferred the burden of providing care to the families and away from the state (Cummings 2001). “Governments have saved billions of dollars through the utilization of free care provided by families” (Fadden et al. 1987: 97). In the 1980s, an economic
recession induced the need for cost cutting, which made community-based care of institutionalized Americans appealing to the government.

The history of funding and the care and treatment of the mentally-challenged has been complex and shifting. Presently, there are three primary sources of funding for the care of mentally-challenged individuals. If a mentally-challenged individual lives in a developmental center or state school, then the federal government pays, whereas, if he/she lives in a group residential home, then the state government pays (Bromley 2003). Financing for acute care is largely the province of Medicare and the federal government, while longer-term care is dominated by Medicaid and state governments (Weiner 1996, p. 47). Finally, if the individual lives in his/her natural family home, then the family pays for his/her care.

The dismantling of state institutions precipitated establishing community providers in which states can assign a central agency to oversee the welfare and programs provided for the mentally-challenged (MHMR 1986: 1). In 1965, House Bill 3 created the Texas Department of Mental Health Mental Retardation (TDMHMR). This agency is charged with the operating and networking of community and residential services for the mentally-challenged.

Unfortunately, funding for the care of the mentally-challenged is currently not increasing at a rate commensurate with the increases in the mentally-challenged population. The gradual (but steady) increase in the mentally-challenged population is based on several factors, including the overall increase of the world population and other external factors such as advances in health care technology (Palley and Van
Hollen 2000). Such advances in medical technology and drug treatment have saved the lives of people who would have not survived in the past. In Texas alone, almost 13,000 individuals are currently on waiting lists for home and community based services. These services include: respite services, home health care, family education and training, family counseling, and support groups (Freedman and Capobianco 2000).

The Texas Department of Mental Health and Mental Retardation is currently able to serve less than a third of the estimated priority population (Texas 2000 Annual Report). Mentally-challenged individuals and their families suffer because services and supports are inadequate to meet their needs (Schulman 1980). Along with the increasing demand is the increasing cost of services including medications, specialty equipment, and higher salaries for healthcare workers. The increased costs for some of these basic services have exceeded the economy’s average rate of inflation, further disintegrating the buying power of a publicly funded system (Texas 2000 Annual Report).

The 2000 Texas Mental Health Mental Retardation Annual Report notes that in Texas, thousands of people are on waiting lists for services and supports, and many more thousands are ready to add their names to waiting lists if services seem likely. Throughout the annual report is mention of community based service programs, such as respite services, family counseling, and support groups that are severely restricted due to insufficient funding. Many budget constraints are imposed by the general state revenue needed necessary to match the Title XIX and XX funds, Medicaid and Medicare. These waiting lists only account for persons who have applied for services. The difficulties with funding and deinstitutionalization are not a new but, an ongoing
dilemma. As far back as 1977, the General Accounting Office reported that federal, state, and local level agencies that are responsible for the mentally-disabled lacked the funds needed to develop adequate community-based care systems. Today, most of these agencies cannot meet the standards of care in communities; therefore, they must rely on existing social programs, welfare, and other resources available to the aged and/or disabled. According to the 1995 Annual Report from Texas Mental Health and Mental Retardation (TXMHMR), the Texas Legislature was looking for ways to cut cost in various programs.

2.3 Theoretical Approach

The largest single providers of support for deinstitutionalized mentally-challenged individuals are their families (Freedman and Capobianco 2000). “The evidence is strong that caregiving is a family affair” (Pilisuk and Parks 1988: 437), and the availability of family-based supports depends on the number of caregivers within the household, ideally, with a two parent household sharing the responsibilities of the caring for the mentally-challenged family member. Also significant is the number of extended family members and close friends of the primary caregivers. Providing care for a disabled family member, typically reduces the caregivers’ social and leisure activities, and increases the potential for added financial strain (Fadden et al 1987). Caregivers must learn to cope with the stress, and simultaneously reassure other family members understand that the mentally-challenged individual is getting better care at home rather than he/she would get in an institution (Fadden et al. 1987). “These parents also have to cope with the normative stressors associated with their own aging along
with the challenges of their continued parenting responsibilities” (Griffiths and Unger 1994: 221).

Before the industrial revolution, families were typically larger and included extended family. These family members lived together and worked the land. Today, families are smaller, with fewer older children available to help care for mentally-challenged family members. Adult members of families are no longer working at home but rather working outside the home to help provide the necessities needed to survive, resulting in fewer prospective caregivers within the family unit (Cummings 2001). The “social forces encouraging families to be responsible for the care of their own family members with a disability have not been shaped by considerations of life quality for the families concerned” (Cummings 2001: 85).

2.4 Stress

According to Kuster and Merkle (2004), society impacts healthcare advances and the resulting decisions and actions related to these advances. Furthermore, Goode (1966) maintained that many changes in society are due to “urbanization and industrialization” and are, therefore, a primary source of stress and strain (Goode 1966). However, role conflict can lead to role strain. Role conflict is when a person assumes two conflicting roles, in this case, caregiver and professional (Thio 1992). The caregiver is expected to provide care and nurture while that same person is also a professional who must be successful. Being a caregiver and a professional are demanding and can lead to role strain. According to Goode (1960), external forces that influences an individual are stressors, whereas, internal factors such as physiological
factors and cognitive impairments are indicated by strain. The theory of “role strain” explains individuals who take on their perceived societal roles, but later discover that one or more roles are incompatible with each other (Katz and Kahn 1978). Society places expectations on a number of different roles (Goode 1966). An individual who assumes several different roles, for instance, mother to wife to nurse usually cannot meet all of the assigned expectations. In the case of parents raising a mentally-challenged individual, multiple roles are inevitable. For example, if a woman embraces her roles as a mother and nurse for her special needs child, the incompatibility of both roles may strain her interactions with other siblings and her spouse. The demand on her as the primary caregiver as a mother to her other children can place additional stress because of the expectations associated with her roles as a wife and as a mother to her other children. Time constraints further contribute to a decline in spousal and family interactions and communication. In most cases, these and other stressors inevitably result in the imbalance of the family’s normal demand capabilities, which can cause adaptive family behavior (McCubbin and Patterson 1983). Britner, et al. (2003) adds further support to what McCubbin and Patterson defined as “family stress”. Britner’s (and his colleagues’ findings) indicate that stress levels among parents of mentally individuals were higher than parents of typical children (2003).

A greater risk of additional stress, social isolation, and decreased feelings of autonomy exists for families involved in the caregiving of a mentally-challenged individual (Slater and Wikler 1986). There is a significant relation between social supports and the adjustment to stress (Britner et al. 2003). The parental stresses
typically accompanying the adjustment to having a new child are much more evident if the child is mentally-challenged. Such parents must first absorb usually unexpected news about their child. They must then quickly adapt to the overwhelming tasks of collecting information about their child’s condition so they may better understand the special long-term care that their child will need (Britner et al. 2003). The most difficult time for the parents of a mentally-challenged individual is generally the weeks and months following the birth of their child (Kerr and McIntosh 1999). The parents, who displayed a helpful relationship with their child, were the ones who obtained the additional supports needed to help with the daily stress that comes from caring for a mentally-challenged individual (Boyd 2002).

Role strain is increasingly common in today’s society. “The values, ideals, and role obligations of every individual are at times in conflict” and thus, maintaining society in a strain equilibrium (Goode 1973: 102). Role strain is evident when caregivers are not able to perform multiple role obligations because of insufficient time and his/her resources (Mui 1990). A caregiver who has to make the decision of caring for his/her mentally-challenged family member and/or working outside the home can encounter role strain. According to Goode (1960), a caregivers role includes obligations driven by both external forces such as the family financial needs (i.e. the job, loss of another family member, etc) and internal ones (i.e. the caregivers personal ideology about family expectations, etc). The results of role strain affect internal and external factors. For example, a caregivers decision to resign from a career in order to
care for a mentally-challenged individual (based on an internal force) indirectly tied to the family’s financial strain (an external force) (Anderson, Towsley, and Gaugler 2003).

According to Walker and Walker (1988), a caregiver’s stress is a “subjective reaction to an appraisal of environmental demands” (p. 374). Holroyd and Lazarus (1982) state that psychological stress occurs when individual demands go beyond one’s resources and his/her ability to change the occurring circumstances. As such a dynamic is frequent for parents of mentally-challenged children; the difficulty of filling the role obligations of these parents is obvious. Some caregivers get stressed over the ‘burden’ of caring for mentally-challenged individual due to financial obligations, disorderly daily routine and emotional overload (Dwyer and Miller 1990). Slater and Wikler (1986) suggest that families can minimize stress associated with caring for a mentally-challenged family member by maintaining a normal daily routine along with scheduling vacations regularly. This includes the need for normal employment opportunities and social relationships outside of the home. Mentally-challenged individuals should have the same opportunities as the general population, known as “normalization” (DeWeaver 1983). Normalization requires the alienation and abandonment of formal institutionalization (Wikler 1986). “The best alternative to institutions, for children, is the family (Wikler 1986:167)”. However, families of mentally-challenged-individuals often face stress, social isolation, and financial strains while providing family-based care. According to Sheehan and Nuttall (1988) the caregiver’s own health may be in jeopardy due to physical exhaustion and illness. Many factors will affect the family’s ability to adjust to stressful events related to the care of the mentally-challenged. Such
factors include individual personal resources, finances, education, health, and family internal resources similar to extended family resources and social supports. Social supports have a positive effect on a child’s behaviors and development by increasing parental well-being and improving family function and interaction between family members.

2.5 Socioeconomic Status

Morell (1979) emphasizes that family additional financial strain caused by extra medical expenses accrued by the mentally-challenged family member, can increase family stress. Middle and upper social class families have the financial resources and ability to identify and create needed services (Justice, O’Conner, and Warren 1971; Stone 1967). They often organize formal support networks to help minimize stress levels (NARC 1975; Waskowitz 1959). Families with mentally-challenged individuals tend to be less upwardly mobile. In fact the financial stress of raising a mentally-challenged individual can actually result in the downward mobility of the fathers’ career (Farber 1960; Holt 1958; Waisbern 1980). These family members usually must spend more time and energy raising a mentally-challenged individual than on career advancement (Slater and Wikler 1986). Families with disabled children tend to earn less money, with an average household income of $15,000-$20,000 per year (Hodapp and Krasner 1994). Medicaid and Medicare are financial supports available to families with financial need. These financial services help protect lower income families against high medical costs needed for caregiving tasks of
the family. These services are intended to assist low-income families.

However, the eligibility standards of such financial support are determined by the level of family income, which results in many families who struggle financially but are just above the income cutoff required to receive government help. These families are left with few or no outside resources to cover needed medical expenses for the mentally-challenged family member.

Mentally-challenged individuals and their families often need additional financial support from the government in order to obtain the same quality of life that is available to families without disabled family members. Families have to attend to the daily processes that families without mentally-challenged individuals go through plus any additional duties required to care for their disabled family member. The acuity of a disability directly impacts the level of care required and any expense involved. Such situations typically place added stress on the family unit; families of mentally-challenged individuals often acquire debt in order to get the appropriate care for their loved ones. Morell (1979) emphasizes that the disability level of the mentally-challenged individual is proportionate to the ability of the family to care for the child. The mental and/or physical severity of the mentally-challenged individual coincides with other severe impairments which puts more stress on the primary caregiver (Slater and Wikler 1986). Furthermore, an individual’s disability is not measured by the illness per se, but rather the functional limitations caused by the illness (Milosfsky 1980).
Bass (1990) reports that the general public acknowledge the additional costs related to caring for someone with a chronic and/or incapacitating illness. These costs include, but are not limited to, medical, therapeutic, and equipment costs. Many of these additional items and services are not adequately covered by insurances and other resources. Families may become disillusioned, e.g., they lose hope, dreams, and goals because they lack the funding needed to provide safe, secure, and happy life for their mentally-challenged loved ones.

Leicester (2001) asserts that education about the mentally-challenged is vital for both caregivers, and society at large. A caregiver who is educated about disabilities and caregiving will typically have increased self-esteem and self confidence. Education of family members also aids in the care of the mentally-challenged individual. Leicester’s findings support the need to educate the general population as well. He found that people who aren’t educated about this population think that the mentally-challenged individuals are “missing the point. In actuality, mentally-challenged individuals have a different way of seeing situations (Leicester 2001, p. 257). Educating others about the mentally-challenged can mitigate many of these prejudices and presumptions. The more educated the community and the primary caregivers are, the better they can serve the mentally challenged.

2.6 Resources

Support resources can reduce the stress levels of caregivers who care for their mentally challenged (loved ones/family members) at home. Family resources can be classified as “informal supports networks” and “formal supports networks” (McCubbin,
Joy, Cauble, Comeau, Paterson, and Needle 1980). Caregiving is the primary responsibility of any parents; however it tends to decrease as their children age. Such a dynamic is typically not the case for families who care for mentally-challenged individuals. Caring for a mentally challenged family member is long-term, tough, and time consuming. Tasks are unlike those of families with no mentally challenged family member. For example, many parents have difficulty finding babysitters to come to their home to care for the mentally-challenged individual (Slater and Wikler 1986), the need for babysitters does not end with age. Jackson (1993) discusses the ‘team’ needed to care for an institutionalized individual, including medical doctors and nurses, administrative staff, and the many support staff including janitorial, dietary, and laundry workers. Today, the caregiving family is held responsible to provide all the same services that the ‘team’ formerly provided. Therefore, the family, and specifically, the caregiver, needs to have a supportive family and community environment. External resources help reduce stress in families with a child with disabilities (Duis and Summers 1997, p.60).

The primary caregiver is the connection between the community-based support services and the mentally-challenged individual. The primary caregiver’s role includes tending to the daily living tasks of the mentally-challenged individual. Milofsky (1980) describes the different tasks that are placed on a mentally-challenged individual’s caregiver; they include but are not limited to “autonomous tasks, social tasks, and impersonal tasks” (p.150).
2.7 Formal Supports

Formal supports consist of professionals and agencies within the community used by the family to help alleviate stress (Vincent 1983). Formal supports help parents by providing additional help in coping with the daily care of their child. These programs and supports include paid services such as day programs, respite care, and specialized child care (Heller and Hsieh 1997). Formal supports are specialized and segregated to care for the mentally-challenged individual and not for the rest of the family members (Robinson et al. 2001).

Morell (1979) notes that institutional supports are needed for families with mentally-challenged individuals to help ensure a sufficient level of care. These families need access to organized formal supports to help them cope with their unique situation. Deinstitutionalization has drastically increased the financial burden on the family, primarily due to the different specialized services needed to care for these individuals at home. One remedy available is the case management system, which assists families in locating, and participating in these different support agencies. The case management model, which includes family centered and community based alternatives, is today’s link to adequately serving the needs of the mentally-challenged individual and their family (Fiene and Taylor 1991). Case management is viewed as “family focus, systematic planning, and community coordination, concern for continuity of care, counseling services, and cost-effectiveness” (Feine and Taylor 1991, p.325). Case managers help locate and search for agencies while the family focuses on the caregiving needs of the mentally-challenged individual. Increased access to case management
would provide the families with additional options of resources. Milofsky (1980) emphasizes the primary caregiver’s role; “the goal is to help the disabled help themselves” (p. 150).

Bromley (2003) notes that access to formal supports is often limited because of high turnover rates among case managers. Therefore, some families view a service provider as inexperienced, and yet another person for the family to train to care for that individual (Seltzer 1992; Robinson et al. 2001). Another concern regarding case managers is the large caseload that each case coordinator is responsible to assist in locating specialized services for the mentally-challenged individual and his/her family (Seltzer 1992). Robinson et al. (2001) documented that the greater the severity of the individual’s disability, the more likely the parents are to want qualified professionals to work with their child. Families are also more likely to become involved in formal intervention programs if they have had positive feedback, showing that these programs were approachable and receptive to the needs of the family caring for their mentally-challenged family member (Unger et al. 2001).

2.8 Informal Support

Informal supports are essential in caring for a mentally-challenged individual. These supports provide the much needed reassurance, encouragement, and emotional support to help parents get through daily routines (Kerr and McIntosh 1999). Britner et al. (2003) describes social supports as a buffer for stressful life events that also helps parents avoid social isolation. Informal support may come from parents of other mentally-challenged individuals, who can relate to one another’s situation, and can help
provide additional social, emotional, and physical support (Kerr and McIntosh 1999). The informal support from other families can help by comparing and sharing experiences of similar situations (Matloff and Zimmerman 1996). Informal supports may help when the formal, professional supports are not enough for the caregiver or families to maintain daily life caring for a mentally-challenged individual. Informal supports are defined as supports that provide assistance without pay.

Usually friends, family members, co-workers, neighbors, and people at a house of worship make up a circle of support for a family. The people in this circle of support are not paid to help, but do so out of care and concern for the individual or family (Bradley 2000). The emphasis on caring for the elderly has the same basis as caregiving of a mentally-challenged individual today. However, the concept of community based home care is less expensive than institutionalization (Dwyer and Miller 1990). Dwyer and Miller (1990) further state the community-based home care is more stressful for the caregiver but the mentally-challenged individual has a more normative atmosphere, therefore, the benefits outweigh the negative effects of the large institutions.

Church communities can provide families with various coping skills to help alleviate stress in the parents with its emotional support. The extent of personal faith, indicated by such things as church attendance, has shown decreased stress levels for families with a mentally-challenged individual (Farber 1960; Levinson 1975; Saenger 1960; Zuk, Miller, Barham, Kling 1961). Different denominations have dissimilarity in
the approach to caregiving. A family that believes in the power of prayer can integrate this source into a survival strategy (Hossiotis 1996).

A family’s locale also clearly has an impact on access to services available for the family and the mentally-challenged individual. Families residing in rural areas tend to rely more on informal relationships with the people within the community, as they come to know and care about each other (Milofsky 1980). The government has attempted to transfer the urban model of assistance programs to fit the needs of the rural communities (Templeton and Mitchell 2002). However, rural communities do not fit the mold of the urban model due to the distances, time, and costs of accessing the social services. Rural families tend to have a lower socioeconomic status than urban or suburban families. However, the providers of limited specialized services often are not located in or near the rural areas. This is due, in part to the high costs of such services, which many rural families are unable to pay (Templeton and Mitchell 2002). Furthermore, public transportation is not readily available for these rural families to seek such services. According to Kuipers et al. (2000), comparative to urban families, rural families have access to fewer resources and are less likely to seek external resources until economically convenient.

While limited, the research available shows a notable difference between rural and urban families (Dwyer and Miller 1990). Caregiving in rural areas have lower income levels, much fewer social networks for support, and lack transportation as well as newer technology compared to their urban equivalents (Dwyer and Miller 1990).
Hossiotis (1996) determined that the impact of having a mentally-challenged family member differs according to the ethnic and cultural background of each individual family. Families from different cultures, who follow norms different than those of U.S. society, are perceived as part of the problem, rather than as supportive of developing a plan for the mentally-challenged individual (Garcia et al. 2000). While some (or most) parents will eventually come to realize that their child has a disability, other parents will continue to struggle over what went “wrong” with their child. These parents typically continue with unsolved anguish, pain, guilt, and unhappiness towards their situation (Hossiotis 1996). Each family will develop an understanding and coping mechanisms needed that are consistent with their ethnic and cultural background and values (Begay et al 1999). Begay et al. (1999) notes that some families (immediate, extended, and/or non-related) move in with one another to help with caregiving responsibilities of the mentally-challenged family member, while other families depend on non-resident, extended family members to help with caregiving responsibilities. Cultural differences and misunderstanding can adversely affect the use of formal supports available to a family (Hossiotis 1996, Begay et al. 1999). The family’s connection to the formal support services is the most influential factor of providing support to these families caring for the mentally-challenged in the United States (Begay et al 1999). The values, beliefs and attitudes of family members are invariably influenced by culture and other related factors. Therefore, service providers must consider and respect cultural differences in order to ensure adequate delivery of interventions (Allison and Vining 1999).
2.9 Control Variables

The demands of a caregiver are usually proportionate to the level of the mentally-challenged individual’s impairment(s), thus affecting the degree of responsibility and amount of assistance needed (Johnson-Welch and Strickland 2001). Boyd (2002) found higher stress scores in mothers with more severely impaired children than in the fathers of the same children. In addition to the stress levels of each individual parent, the extent of a mentally-challenged individual’s is found to have an effect on the parent’s marriage (Britner et al. 2003). Other factors that may be related to stress within a family caring for a mentally-challenged individual, would include life changing transitions (Britner et al. 2003). The caregiver’s dependence on extended family, friends, and acquaintances to help with the caregiving tasks inevitably increases if the severity of the mentally-challenged individual’s disability increases (Natterlund et al. 2000). The out of pocket costs, both directly and indirectly related to the care of the child, or children with disabilities in a household had an impact on the family’s finances and solvency, in some cases affecting the family’s overall well-being (Meyers et al. 1998). However, the degree of disability of a mentally-challenged individual does factor into determination of financial help the government is likely to offer to the family. The length of actual time the caregiver must spend helping the individual with his/her everyday living skills is also significant in deciding on the appropriation of these funds.

According to Vadasy (1986), a caregiver from a dual income family is more likely to have the funds needed to provide adequate resources than a caregiver from a
single income family. Marital status is another important variable. In married couples, there is an increased possibility of more people to help with care giving and provide support. There is the mother, father, siblings, extended family members, and friends of both parents. According to Marsh (1992), informal support networks i.e., friends, church, and neighbors provide the place needed for the caregiver to vent, share, and obtain validation and advice. These informal support networks and their function are essential to the psychological well-being of the caregiver.

Marital status can also affect the psychological well-being of the caregiver. Married caregivers will usually have more available support from extended family support and a greater earning potential than a single caregiver. The two-parent household can offer two ‘primary caregivers’ verses one ‘primary caregiver’ in a single-parent home. The two-parent household is also more likely to have extended family members who can help with the caregiving of a mentally-challenged individual. The two-parent family would also have an increased opportunity to provide financial and emotional stability. Vadasy (1986) argues that the two-parent family is also more stable, and therefore, more likely than a single-parent household to provide care for other family members, financial supports for the entire family, as well as the daily caregiving to the mentally-challenged individual. The two-parent family sometimes has the option of being a dual income family where the mother and father both work and contribute to the financial obligations of a mentally-challenged individual. The two-parent family may also allow for the option of one of the parents staying home,
depending on the financial situation, and caring for the mentally-challenged individual while the other parent works (Vadas 1986).

The single parent family caring for a mentally-challenged individual is more complicated. The stressors facing such a single-parent family are immense compared to the two-parent family. The single parent may be less likely than the two-parent family to provide adequate services because of financial constraints. There also tends to be a decrease in informal social support networks, fewer primary caregivers, and fewer extended caregivers in a single parent family.

Gottlieb (1997) evaluated single mothers caring for children with disabilities in order to determine the importance of employment, as well as the affects of no partner. The likelihood that these families were at, or below, the poverty levels was significantly influenced by the years of education, marital status, number of children, and employment. Single mothers with lower education levels, who worked only part-time or were unemployed, and had more than one child were more commonly below the poverty level, and required more government assistance (Meyers et al. 1998). Frequently, role strain, social isolation, poverty, and social stigma negatively often affect single mothers (Gottlieb 1997). Increased financial costs, caregiving burdens, missed career opportunities, and restrictions on family lifestyles may also result from the long term care of children with special needs (Allard, Gottlieb, & Hart 1993).

Elevated levels of depression, increased parenting stress, and overall lower psychological well-being is often experienced by unemployed, non partnered women. In comparison, unemployed, partnered mothers reported higher levels of psychological
well being and lower depression, although they generally also had low family incomes (Gottlieb 1997). Primary financial providing mothers who were lacking in the support of a partner experienced greater depression and lower psychological well-being when compared to their partnered counterparts, as well as when compared to non-partnered mothers whose employment was less critical to their families’ financial well-being (Gottlieb 1997). The presence of a chronically disabled child within an impoverished family leaves minimal opportunities to rise out of poverty (Meyers, Lukemeyer & Smeeding 1998). The reduction in work hours, changing schedules, and taking too much time off to meet caregiving demands and obligations can lead to loss of employment (Pilisuk and Parks 1988).

Fadden and associates (1987) noted that the government has saved billions of dollars with families now caring for their family members at home. However, the economic and emotional costs to the families have been ignored, the predominant costs being the well-being of mother “who is commonly the primary caregiver in such circumstances” (Fadden et al. 1987: 97). The mother is the likely parent to care for the child(ren) after a divorce, separation, or out of wedlock child birth (Seltzer et al. 1989). According to the U.S. Bureau of the Census, (1998) single mothers with children “are more likely to be poor” (Seltzer et al. 1989, p. 1013). But it is poor, single caregivers who are caring for a mentally-challenged individual that are more likely to need additional formal and informal supports (Unger et al. 2001).

Numerous studies show that women are the primary caregiver of a disabled relative (Heller and Hsieh 1997; Boyd 2002). Women are often viewed as natural
caregivers, however, they do also often experience and express dissatisfaction with both limited access to resources and additional help and their disadvantage in the economic realm i.e., career opportunities (Johnson-Welch and Strickland 2001). Female caregivers usually find their options in employment significantly reduced because of the level of assistance that their caregiving roles require (Heller and Hsieh 1997). Some women may take on flex-time jobs, part-time jobs, or even home-based work to help supplement the household income (Johnson-Welch and Strickland 2001). Johnson-Welch and Strickland (2001) note that female caregivers who overload themselves with both caregiving responsibilities, and working outside the home, jeopardize their own health and the family’s psychological well-being. Boyd (2002) found that the female caregivers of mentally-challenged individuals experienced less involvement in social activities, including recreational, cultural, and other stress-reducing activities than mothers of typical children. Previous research finds mothers of mentally-challenged individuals to be more outspoken than fathers when discussing formal supports, probably due to the more direct contact they have with the support professionals. Mothers are also more likely to seek social supports than fathers because of the increased levels of stress (Boyd 2002). According to Marks, Lambert, and Choi (2002), mothers who are caregivers of mentally-challenged individuals show much greater levels of stress, loneliness, and isolation than mothers of non-mentally-challenged individuals. Mothers of mentally-challenged individuals acting as primary caregivers who report more help from their spouses do experience higher marital satisfaction and less distress (Britner et al. 2003). Furthermore, wives who report supportive marriages
are better able to cope with stress and ultimately have lower stress levels (Friedrich 1979).

Caregiver’s health symptoms are negatively affected by both the chronic and ongoing nature of care giving, and the disabled individual’s ability to perform daily living activities (Wallsten 2000). Becoming a new caregiver for a child with a disability had women and men reporting a significantly greater increase in depressive symptoms. Higher levels of hostility were also reported by women who began providing care for a child. Loneliness was noted by women who began providing care to a child (Marks et al 2002). Marks, Lukemeyer and Smeeding (1998) suggest that gender differences should be considered while looking at role responsibilities in caregiving.

However, fathers are found to be less likely to help with daily chores and caregiving activities for a mentally-challenged individual (Finley 1989; Willoughby and Glidden 1995; McConachie 1989). The increased number of work hours, related to financial provision for the family is one explanation for limited time available to care for the disabled (Heller and Hsieh 1997), as well as the decreased involvement in the caregiving responsibilities (Britner et al. 2003). Fathers who provide assistance with caregiving for a mentally-challenged child report having lower levels of happiness and personal success than men who have no caregiving responsibility (Marks, Lambert, and Choi 2002).

Past studies point out the high emotional and financial costs of caring for mentally-challenged individuals, as well as the intense difficulties involved in the stages
of caring for a disabled person (Lubetsky et al. 1995; Archbold 1980). The impact on the family and the caregiver(s) seem to go unnoticed by government representatives and agencies when determining the need for funding more public services (Meyers et al. 1998). The calculation of direct care costs of medical and other rehabilitative services (e.g. medications, hospital, rehabilitative services, and specialized devices) are seen as the human capital approach. Also, the indirect costs (e.g. loss of income) are thought of in the same way (Meyers et al. 1998). Indirect costs such as transportation to the hospital, pharmacy, or specialized services and the additional costs that do not include medical items like special food, clothing, or alterations to the home are typically not funded by any public or government agencies. Therefore, they seem to fall through the cracks as they are seldom seen within the human capital approach. Meyers, Lukemeyer, and Smeeding’s research finds that half of the families being studied acquired “direct, out-of-pocket costs for special medical expenses, food, transportation, or other goods and services related directly to their child’s special needs….and indirect costs in the form of forgone earnings” (1998: 229). It becomes evident that the lack of services and funding available to the mentally challenged affect not only these individuals and their families, but society overall.
CHAPTER 3

METHODS

3.1 Data Sources

Data was collected from 90 adults in Texas, who are caring for mentally-challenged family member in their natural home setting. Research involved a variety of ways to recruit families for the survey. The non-probability sample consists of both convenience sampling and snowball sampling. The convenience sample includes volunteers from Special Olympics and support groups; snowball sampling includes a “network” of caregivers located through friends, acquaintances, and other caregivers throughout Texas. Data collection consists of surveying the primary caregiver and includes a combination of closed-ended and open-ended questions. To ensure privacy, the survey was self-administered and unmonitored. Data collection was conducted over a five-month period, between August 2005 and December 2005. The unit of analysis is the household in which the caregiver and mentally-challenged individual reside.

Ethical considerations are imperative in this research. The ethical considerations involved in this research included: confidentiality, informed consent, and voluntary participation. The confidentiality of the mentally-challenged individuals and their families is of utmost importance. Caregivers who acted as respondents signed an informed consent form prior to completing the survey. Selection was strictly
voluntary and allowed the caregiver to withdraw at anytime. The researcher only surveyed non-mentally-challenged adult caregivers, not the mentally-challenged individuals. The collected surveys are kept in a secured, locked, file cabinet; the researcher compiling data is the only one to have access. To ensure confidentiality, the survey numbers, names of participants, and signed written informed consent forms are kept in a separate location from the survey data. A unique numeric unit for each participant was placed on a personal information form when the consent form was signed. The same numeric unit was entered on the survey given to the respondent to complete. The surveys are kept separate from any identifiable personal information, but are accounted for by this numeric system. Upon completion of the research, the personal identifying information was destroyed. The risk to the respondent is minimal.

3.2 Operationalization of Variables

This section will detail the Operationalization of the dependent, independent, and control variables used in the research. Each variable is summarized in Table 1.
<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>Metric</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>DEPENDENT VARIABLE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological well-being</td>
<td>Inventory</td>
<td>1=Have not experienced, 2=Experienced but not difficult, 3=Experienced and somewhat difficult, 4=Experienced and very difficult</td>
</tr>
<tr>
<td>of the caregiver (stress)</td>
<td>General &amp; Marital Financial Index</td>
<td>1=Strongly agree, 2=Agree, 3=Undecided, 4=Disagree, 5=Strongly Disagree</td>
</tr>
<tr>
<td><strong>INDEPENDENT VARIABLE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Socioeconomic Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver</td>
<td>Who does the caregiving</td>
<td>1=Father, 2=Mother, 3=Sister, 4=Brother, 5=Grandmother, 6=Grandfather, 7=Aunt, 8=Uncle, 9=Guardian, 0=Other</td>
</tr>
<tr>
<td>Caregiver's education</td>
<td>Years of formal education completed by caregiver</td>
<td>1=Less than High School, 2=High School, 3=Two-year college/tech, 4=Four-year college, 5=Graduate Degree, 6=PhD, 0=Other</td>
</tr>
<tr>
<td>Caregiver's occupation</td>
<td>Caregiver's paid employment</td>
<td>Nominal Level</td>
</tr>
<tr>
<td>Income</td>
<td>Annual household income (after taxes)</td>
<td>1=less than $10,000; 2=$10,000-$20,000; 3=$20,001-$30,000; 4=$30,001-$40,000; 5=$40,001-$50,000; 6=$50,001-$60,000; 7=$60,001-$70,000; 8=$70,001-$80,000; 9=More than $80,000</td>
</tr>
<tr>
<td>Age of mentally challenged individual</td>
<td>The chronological age of the mentally challenged individual</td>
<td>Interval Level</td>
</tr>
<tr>
<td>Residence</td>
<td>Caregiver's current residence</td>
<td>1=Rural, 2=Urban, 3=Suburban</td>
</tr>
<tr>
<td><strong>Formal supports</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Professional</td>
<td>Formal paid supports received</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Physician, Psychologist, Behavioral Support, Case Management, Respite In-home Training, Speech Therapy, Physical Therapy, Occupational Therapy Counseling, School Support, Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>School</td>
<td>Public school services received</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Behavioral Support, Counseling, Speech Therapy, Occupational Therapy, Physical Therapy, Other</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church</td>
<td>Caregiver receiving any financial support from church</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>0=No, 1=Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Church, Immediate Family, Extended Family, Friends, Co-workers, Neighbors, Others</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Informal supports</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver's supports</td>
<td>Unpaid supports received</td>
<td>0=No, 1=Yes</td>
</tr>
</tbody>
</table>
Table 1: cont’d.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Description</th>
<th>Metric</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td>Caregiver’s marital status at time of survey</td>
<td>1=Single, 2=Married, 3=Divorced, 4=Widowed, 5=Separated, 6=Cohabitating</td>
</tr>
<tr>
<td>MCI School</td>
<td>Does mentally challenged individual attend school?</td>
<td>0=No, 1=Yes</td>
</tr>
<tr>
<td>Level of Mental Retardation</td>
<td>IQ of Mentally challenged individual who is being cared for</td>
<td>1=Mild, 2= Moderate, 3=Severe/Profound</td>
</tr>
</tbody>
</table>

3.3 Dependent Variable

The dependent variable in this research is the stress level and psychological well-being of the primary caregiver. The survey includes fourteen items from the Parenting Stress Inventory (PSI) developed by Terry (1991). All respondents answered the first part which contained 8 items that focus on daily routine, time management, and overall socialization which give the general stress level. The first 8 items are as follows: “Not being able to manage and coordinate your daily routine at home”, “Receiving contradictory advice from other people”, “Less time with adults (other than partner)”, “Less time to do things you enjoy”, “Less freedom to do what you want when you want”, “Lack of intellectual stimulation”, “Changes to your work commitments”, and “Loss of independence”. The range of scores for general stress levels were from 8 to 32. Eight being the lowest and no general stress reported to 32 being the highest with the most general stress reported. Only married or cohabiting respondent answered the second part, which consists of 6 items that highlight marital relations and helps provide the marital stress level. Respondents, who were not currently married or cohabiting, skipped the last six items of this section of the survey.
The respondents who have partners were asked to respond to the last six items regarding their relationship and caregiving tasks. These items consist of the following: “Change to your marital relationship”, “Feeling more distant from your partner”, “Less time with your partner”, “Changes in you and your partner’s sexual relationship”, “Problems sharing child care tasks with your partner”, and “Problems sharing household tasks with your partner”. The range of scores for marital stress levels were from 6 to 24. Six being the lowest and no marital stress reported to 24 being the highest with the most marital stress reported. The data was collected at an ordinal level of measurement differentiated between four choices: 1=Have not experienced; 2=Experienced but not difficult; 3=Experienced and somewhat difficult; 4=Experienced and very difficult. These questions were used to determine the level of caregiver stress at the time of the survey. Higher scores indicate higher stress levels. There were eight additional items addressing financial stress that were measured at the ordinal level of measurement with five choices of the following: 1=Strongly Agree; 2=Agree; 3=Undecided; 4=Disagree; 5=Strongly Disagree. These items were selected from the Financial Impact Scale (FIS) by K. Todtman and A.W. Gustafson (1991). The questions for financial stress are as followed: “I feel that my family argues more about money now than we did before I was responsible for caregiving”, “I worry about my finances because I have had to pay for food for the person I care for”, “I feel that caregiving is a financial burden for me”, “I feel that I am unable to buy clothing for myself because of caregiving expenses”, “Overall, I feel that caregiving strains my family and social life”, “I feel guilty sometimes because I worry about caregiving costs”, “Overall, I feel that caregiving has
been a financial drain on me and/or my family” and “I worry about my finances because they are being used to pay for major living expenses for the person I take care of”. The range of scores for financial stress levels were from 8 to 40. Eight being the lowest and the most financial stress reported to 40 being the highest with the least financial stress reported. When calculated into the overall stress, this section had to be recoded to fit with the “larger the number, the more stress” and the “lower the number, the lower the stress”.

The dependent variable of stress is separated into smaller groupings of marital, general, financial, and overall stress. There were questions that all respondents answered which were coded for “general stress” and “financial stress” while a section of questions specifically directed toward married or cohabiting individuals was coded for “marital stress”. Each individual segment was examined apart from other data. Afterward the separate sections general, financial, and marital were added and examined collectively to obtain overall stress levels. The collection of scores for overall stress levels were broken down into two separate groups. The overall stress levels that included married respondents had a range from 22 to 96. Twenty-two is the lowest reported overall stress level for married couples whereas, ninety-six is the highest reported overall stress level. The overall stress levels that included single respondents had a range from 16 to 72. Sixteen is the lowest reported overall stress level for single respondents and seventy-two is the highest reported overall stress level (See appendix B).
3.4 Independent Variables

The independent variables are broken down into three sets of factors: socioeconomic status, formal supports, and informal supports. Socioeconomic background details the caregiver’s education level, occupation, income, and residence. Formal supports include caregiver’s contacts with paid professionals, school districts, and house of worship. The informal supports consist of caregiver’s unpaid supports such as extended family neighbors and friends. The independent variables of formal and informal supports were recoded into dummy variables where their possible values were either zero or one (0, 1). If the respondent received any of the formal supports, then the respondent received a numeric score of one, if not, then the respondent received a numeric score of zero. Informal supports were evaluated likewise.

**Hypothesis 1:** The higher the caregiver’s socioeconomic status, the lower the reported stress level of the caregiver.

Socioeconomic status is operationalized by five variables: education, income, occupation, and residence of the primary caregiver, and the age of the mentally-challenged individual. The caregiver’s education level was measured at the ordinal level by asking “What is the highest level of education, which you have completed?” Answers range from less than high school to post graduate level. The question(s) concerning the occupation(s) of the caregiver, and, if applicable, the spouse questions were open-ended while items addressing hours worked were measured at an ordinal level. Questions include: “Do you currently work for pay outside of the home?”, “What is your occupation?”, “How many hours do you work in an average week?”,
“Does your spouse or partner work for pay?”, and “What is your spouse’s or partner’s occupation?”. The caregiver’s “total household income, after taxes” was determined by an ordinal level of measurement ranging from less than $10,000 to more than $80,000 by asking “What was your total household income last year, after taxes?”. To fully gauge the family income, an item inquiring about “any additional monetary support during the year” was included as an open-ended question. The residence of the caregiver was measured with an ordinal level of measurement. The residence was limited to Texas residences. The nominal question, “Do you currently live in the State of Texas?” was coded with 0 for “Yes” and 1 for “No”. The city size was determined as follows: urban, population greater than 100,000; suburban, population between 25,000 and 99,999; and rural, and population under 25,000. The chronological age of the mentally-challenged individual was collected with an open-ended question, “What is the mentally-challenged individual’s age?”. The nominal question “Does your mentally-challenged individual currently attend school?” collected data about public school attendance was coded 0 for “No” and 1 for “Yes” (See Appendix B).

**Hypothesis 2:** The greater the utilization of formal caregiver supports, the lower the stress level of the caregiver.

Formal supports of the caregiver include details of the paid supports the caregiver receives to help with caregiving of the mentally-challenged individual through professionals, school districts, and place of worship. The formal supports were measured at the nominal level with the open-ended question of “how often they receive the professional supports”. The nominal question, “Which of the following formal,
paid, supports do you receive regularly for the mentally-challenged individual?“ and was coded 0 for “No” and 1 for “Yes”. The categories of formal supports include physician, psychologist, behavioral specialist, case management, respite, In-home training, speech therapy, physical therapy, occupational therapy, counseling, school support, childcare, and other. The above was recoded to 0 for “No” formal supports used and 1 for “Yes” formal supports used. There is one nominal question to determine the educational status of the mentally-challenged individual, “Does your mentally-challenged individual currently attend school?” and was coded 0 for “No” and 1 for “Yes”. To help measure school districts, the survey posed a nominal question concerning formal supports offered through the school district: “Please mark the formal supports that are available and provided by the school for your mentally-challenged individual”. This question was coded 0 for “No” and 1 for “Yes”. The school categories consist of behavioral support, counseling, speech therapy, occupational therapy, physical therapy, other, or none. The above was recoded to 0 for “No” school supports used and 1 for “Yes” school supports used. The formal supports and school supports were then recoded together. If the caregiver received either formal supports or school supports, they received a 1 for “Yes” or if they did not receive either supports a 0 for “No” was recorded. To help determine the current school level of the mentally-challenged individual, the survey posed the next open-ended question: “What is the highest grade level he/she has completed?” To examine the formal support of faith based institutions, the nominal question: “If you are a member of a religious community, do you receive any financial support from your religious community?”,
coded 0 for “yes” and 1 for “no”. Emphasis was placed on services and resources needed to deinstitutionalize these various individuals (See Appendix B).

**Hypothesis 3:** The greater the utilization of informal caregiver supports, the lower the stress level of the caregiver.

Informal supports of the caregiver can include his/her religion/faith and the assistance other caregivers provide. The caregiver’s religion/faith was collected by an open-ended question concerning the caregiver’s religious denomination: “What is your religion, if any?” collected information about the caregiver’s religion/beliefs. In addition, a nominal question, “How often, on average, would you say you attend religious services?” with responses ranging from “Never” to “More than once a week” obtained information about the respondent’s involvement in a faith-based community. There are several additional questions regarding the caregiver’s supports; these questions focus on identifying additional people to assist with caregiving responsibilities. There are several interval level questions to help identify the supports in place. They include: “How many children under the age of 18 do you have living in your household?”, “How many people total (adults and children) do you have living in your household?”, and “How many people within your household help on a daily basis with the caregiving of the mentally-challenged individual?”. Also included were nominal question to measure informal, unpaid, supports, and an additional open-ended question that determined how often they receive assistance with caregiving responsibilities from which include these informal supports; church, immediate family, extended family, friends, co-workers, neighbors, and/or others. The nominal question,
“From which of the following, if any, do you receive help like babysitting, transportation, etc?” was coded 0 for “No” and 1 for “Yes” (See Appendix B).

3.5 Control Variables

The control variables in this research consist of marital status, public school attendance, and the level of mental retardation of mentally-challenged individual. Marital status was collected at the nominal level of measurement by asking “What is your marital status?” and operationalized to determine between the possibilities of a single or double income within the household. A modified version of the Activities of Daily Living (ADL) scale (Lawton and Brody 1969, Katz et. al 1970) helped to determine the disability level of the mentally-challenged individual. The data was collected with the ordinal level of measurement and broken down as follows: severe/profound, the individual will depend on ‘a lot’ of help from caregiver as compared to other children of the same age; moderate, the individual will need ‘some’ assistance from the caregiver as compared to other children of the same age; mild, the individual will need ‘a little’ assistance from caregiver to perform their daily living skills. The modified version of the ADL selected consists of six questions: eating/nutrition, dressing, personal hygiene, toileting, mobility, and behavior management with a score range of 6-18. Six is the lowest score feasible and the mentally-challenged individual is independent and eighteen is the highest score possible and the mentally-challenged individual is completely dependent on the caregiver. The following question, “What is the mental retardation level of the mentally-challenged
individual for whom you care? (IQ)”, was collected at the ordinal level to aid the findings on the ADL scale (See Appendix B).

3.6 Characteristics of Sample

This study collected data from 90 primary caregivers in various venues across Texas including the Dallas, Fort Worth, Waco, Houston, and Austin areas. Volunteer service experience at the Special Olympics proved invaluable. In order to arrange volunteering for upcoming events, appropriate Special Olympic representatives had to grant approval. This process took several days, numerous several phone calls, and the faxing of multiple surveys to the Special Olympic headquarters in Austin, Texas. In the meantime, the search began for area support groups. The power of networking with friends and acquaintances guided me to a few support groups. Once all the contacts were made and appointments set, data collection began.

The ethnic allocation of respondents is predominately Caucasian, with 93% of the entire sample classified as Caucasian. Eighty percent of the sample is female. Eighty-four percent of the sample is married or cohabiting. The respondent’s age range is 28 years to 87 years with a mean age of 51.68 years. Sixty-two percent of the respondents, and 71% of their partners had paid, employment outside of the home. None of the respondents held advanced degrees, but 43% had attended college for two or more years, and 32% had attended some college. Twenty-four percent had only a high school diploma or less. The household annual income range averages between $50,001 through $60,000. Fifty-four percent of the respondents reside in suburban areas, while 24% live in rural areas and 21% live in urban areas. The mean
chronological age of the mentally-challenged individual involved is 23.49 years with a standard deviation of 10.66. The chronological age range of the mentally-challenged individual is 5 years to 55 years old. The levels of performance found in this research of the mentally-challenged individuals are 45% mild, 47% moderate, and 8% severe/profound.

3.7 Analytic Method

Multiple Classification Analysis (MCA), performed in SPSS, examined the patterns between SES, formal, and informal variables as related to stress. This research endeavors to answer three questions. Will a caregiver’s higher socioeconomic status result in his/her lower reported stress level? Will greater utilization of formal supports result in a lower reported stress level of the caregiver? Will greater utilization of informal supports result in a lower reported stress level of the caregiver?

One researcher collecting and coding all data provides consistency, which is essential to ensure reliability. The representation of this survey will provide a beginning look at the caregiver’s current needs and deinstitutionalization. The level of disability will be controlled to help better understand the caregiver’s needs for deinstitutionalization. Simple face validity is the basis of this topic being studied. Socioeconomic status is being studied through multiple aspects; therefore, good content validity and reliability. Content validity is exhibited by using a stress index, a financial strain index, and an activity of daily living index. Along with utilizing these indexes, we also include some additional questions throughout the survey.
3.8 Limitations Related to Data

Limitations of this research include a small sample size with limited generalizability towards the overall state population. The survey would consist mainly of caregivers who have reached out for support of help, thus, leaving a portion of the population unavailable to contact. Families who have sought support could be considered to have decreased stress levels due to them seeking additional assistance or the opposite could be found with them having increased stress levels. Laws designed to protect the mentally challenged unfortunately limit the potential for further research. These laws include Health Insurance Portability and Accountability Act of 1996 (HIPAA) and Family Educational Right to Privacy Act (FERBA). HIPPA protects health information on individuals which precludes access to confidential information from agencies who serve the mentally-challenged population. The FERBA law protects privacy rights in federally funded school districts. This law prevented the access to mentally-challenged students served in our local school districts. These two laws further limited data collection from Special Olympics, various support groups, and networking through friends and acquaintances. Data collection also considered the respondent’s potential to experience psychological stress while providing information needed from the caregiver. Psychological stress to the respondent could occur as the result of something as simple as interrupting their usual routine. To help reduce possible stress, factors, participants received handouts containing the contact information of various support groups to help minimize stress.
CHAPTER 4
RESULTS

Data analysis consists of two statistical parts. The first segment uses descriptive statistics to describe the sample and suggest traits that could potentially affect stress levels. The second segment uses Multiple Classification Analysis to examine the relationship between socioeconomic status, formal supports, informal supports, and caregiver psychological well-being. This analysis provides a degree of association (beta) that is similar to a correlation coefficient.

4.1 Descriptive Variables of Sample

Demographic characteristics of this sample are reported in Table 2. The majority of respondents were female (80%). The average age of the respondents was 52, ranging from 28 to 87 years old (SD=10.79). Eighty-four percent were married, while 15.6 percent (N=14) were single, divorced, or widowed. The mentally-challenged individuals were 53.3% male and 46.7% female. Exactly one-half (50%) of these individuals attended public school; 50% did not.
Table 2: Demographic characteristics of sample (n=90)

<table>
<thead>
<tr>
<th>Variable Name</th>
<th>Frequency</th>
<th>Percent of Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Respondents' gender</td>
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<td>20.0</td>
</tr>
<tr>
<td>Respondents' gender</td>
<td>72</td>
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<td>43.3</td>
</tr>
<tr>
<td>Respondents' annual household income</td>
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<td>31.1</td>
</tr>
<tr>
<td>Respondents' annual household income</td>
<td>29</td>
<td>32.2</td>
</tr>
<tr>
<td>Respondents' annual household income</td>
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<td>36.7</td>
</tr>
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<td>Respondents' work for pay</td>
<td>56</td>
<td>62.2</td>
</tr>
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<td>Respondents' work for pay</td>
<td>34</td>
<td>37.8</td>
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<tr>
<td>Mentally-challenged individuals' gender</td>
<td>48</td>
<td>53.3</td>
</tr>
<tr>
<td>Mentally-challenged individuals' gender</td>
<td>42</td>
<td>46.7</td>
</tr>
<tr>
<td>Mental retardation level</td>
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<td>45.6</td>
</tr>
<tr>
<td>Mental retardation level</td>
<td>42</td>
<td>46.7</td>
</tr>
<tr>
<td>Mental retardation level</td>
<td>7</td>
<td>7.8</td>
</tr>
<tr>
<td>Mentally-challenged individual attends public school</td>
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<td>50</td>
</tr>
<tr>
<td>Mentally-challenged individual attends public school</td>
<td>45</td>
<td>50</td>
</tr>
</tbody>
</table>

4.2 Socioeconomic Status Variables related to Marital, General, Financial, and Overall Stress

In Table 3, the relationship between socioeconomic status and marital stress is examined. The relationship between respondent’s educational level, annual household income, mentally-challenged individual’s age, residence and marital stress are all statistically significant at the .05 level. The participants who have “two-year college degrees or beyond”, report the highest level of marital stress while those who have a
high school diploma or below experience the lowest level of marital stress. As education levels rise, so does the level of marital stress. The annual household income that falls between $40,001 to $70,000 experience the highest level of marital stress compared to those that have annual incomes of $40,000 or below as well as those annual incomes of $70,001 or higher. The mentally-challenged individuals’ age has a strong relationship to marital stress: the older the mentally-challenged individual, the lower the marital stress reported. Where the caregiver resides shows statistical significance. Participants in rural areas show greater marital stress with an adjusted mean of 12.33 than those in urban areas, who show the lowest marital stress with an adjusted mean of 10.27. Whether the respondents’ “work for pay” is not statistically significant, however, the pattern is consistent with expectations.
Table 3: Marital Stress by respondents’ work for pay, respondents’ educational level, annual household income, mentally-challenged individuals’ age, and residence.

<table>
<thead>
<tr>
<th>Marital Stress</th>
<th>N=76</th>
<th>Adjusted Mean</th>
<th>Correlation Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Variable</strong></td>
<td><strong>N</strong></td>
<td><strong>Beta</strong></td>
<td></td>
</tr>
<tr>
<td>Respondents’ work for pay</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>48</td>
<td>12.02</td>
<td>.06</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>11.43</td>
<td></td>
</tr>
<tr>
<td>Respondents’ education level</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school or Below</td>
<td>17</td>
<td>9.29</td>
<td>.55 **</td>
</tr>
<tr>
<td>Some college</td>
<td>25</td>
<td>10.52</td>
<td></td>
</tr>
<tr>
<td>Two-year college degree of beyond</td>
<td>34</td>
<td>14.00</td>
<td></td>
</tr>
<tr>
<td>Household Income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>$40,000 or less</td>
<td>18</td>
<td>10.39</td>
<td>.27 *</td>
</tr>
<tr>
<td>$40,001 - $70,000</td>
<td>27</td>
<td>13.26</td>
<td></td>
</tr>
<tr>
<td>$70,001 or higher</td>
<td>31</td>
<td>11.26</td>
<td></td>
</tr>
<tr>
<td>Mentally-challenged individuals’ age</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17 years and below</td>
<td>30</td>
<td>12.50</td>
<td>.50 **</td>
</tr>
<tr>
<td>18-25 years old</td>
<td>23</td>
<td>12.39</td>
<td></td>
</tr>
<tr>
<td>26 years and older</td>
<td>23</td>
<td>10.30</td>
<td></td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>18</td>
<td>12.33</td>
<td>.29 *</td>
</tr>
<tr>
<td>Suburban</td>
<td>43</td>
<td>12.12</td>
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</tr>
<tr>
<td>Urban</td>
<td>15</td>
<td>10.27</td>
<td></td>
</tr>
</tbody>
</table>

Controlling for mental retardation level and mentally-challenged individual attends public school.
Missing cases due to marital status.
*.05, **.01

Table 4 reports the relationship between socioeconomic status and general stress. The relationships between respondents’ work for pay outside the home, respondents’ education level, and mentally-challenged individuals’ age are all statistically significant at the .05 level. The annual household income is statistically significant at the .10 level. The respondents who work for pay outside the home experience more stress with an adjusted mean of 19.61. The respondents who have
some or no college experience less stress than their counterparts with two years or more of college. There is a moderate correlation between respondents’ education level and general stress. The reported stress levels of respondents’ education level can possibly be clarified by saying the respondents who have some college or above may have more stressful careers and jobs than those that have high school or below. In addition, more educated caregivers likely to have higher expectations (reasonable or not) therefore, report higher stress levels when they are not met. The mentally-challenged individuals’ age has a strong correlation with general stress and the older the mentally-challenged individuals’ age, the lower the reported general stress. The respondents’ with an annual income between $40,001 and $70,000 report higher levels of general stress than those with incomes of $40,000 or below, and $70,001 or greater. The reported stress levels of respondents’ annual household income can possibly theorized that those that make $40,001 to $70,000 make more than the government limit to receive any additional private professional services. Those that fall in the category of $40,000 or less may qualify for governmental assistant programs to obtain professional services. Whereas, participants who make $70,001 or above may be able to afford additional private professional services. The area in which the respondent lives is not statistically significant. There is minimal variation between the adjusted means.
Table 4: General Stress by respondents’ work for pay outside the home, respondents’ educational level, annual household income, mentally-challenged individuals’ age, and residence.

<table>
<thead>
<tr>
<th>General Stress</th>
<th>N=90</th>
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<tbody>
<tr>
<td>Grand Mean=18.83</td>
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</tr>
<tr>
<td><strong>Variable</strong></td>
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</tr>
<tr>
<td>Respondents’ work for pay</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34</td>
</tr>
<tr>
<td>No</td>
<td>56</td>
</tr>
<tr>
<td>Respondents’ education level</td>
<td></td>
</tr>
<tr>
<td>High school or Below</td>
<td>22</td>
</tr>
<tr>
<td>Some college</td>
<td>29</td>
</tr>
<tr>
<td>Two-year college degree of beyond</td>
<td>39</td>
</tr>
<tr>
<td>Household Income</td>
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</tr>
<tr>
<td>$40,000 or less</td>
<td>28</td>
</tr>
<tr>
<td>$40,001 - $70,000</td>
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<td>33</td>
</tr>
<tr>
<td>Mentally-challenged individuals’ age</td>
<td></td>
</tr>
<tr>
<td>17 years and below</td>
<td>31</td>
</tr>
<tr>
<td>18-25 years old</td>
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<tr>
<td>26 years and older</td>
<td>32</td>
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<tr>
<td>Residence</td>
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</tr>
<tr>
<td>Rural</td>
<td>22</td>
</tr>
<tr>
<td>Suburban</td>
<td>49</td>
</tr>
<tr>
<td>Urban</td>
<td>19</td>
</tr>
</tbody>
</table>

Controlling for mental retardation level and mentally-challenged individual attends public school.

* .05, + .10

In Table 5, the relationship between socioeconomic status and financial stress are examined. The relationship between the mentally-challenged individuals’ age and financial stress is statistically significant. The older the mentally-challenged individuals’ age the higher the financial stress. Although the findings for respondents’ work for pay outside the home are not statistically significant, the pattern is consistent with marital and general stress.
Table 5: Financial Stress by respondents’ work for pay outside the home, respondents’ educational level, annual household income, mentally-challenged individuals’ age, and residence.

<table>
<thead>
<tr>
<th>Financial Stress</th>
<th>N=90</th>
<th>Adjusted Mean</th>
<th>Correlation Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Grand Mean</td>
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<td></td>
<td></td>
</tr>
<tr>
<td><strong>Variable</strong></td>
<td></td>
<td></td>
<td><strong>Beta</strong></td>
</tr>
<tr>
<td>Respondents’ work for pay</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>34</td>
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</tr>
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<td>No</td>
<td>56</td>
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<td>Respondents’ education level</td>
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<td>High school or Below</td>
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<td>Two-year college degree or beyond</td>
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<td>.51 **</td>
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<td>18-25 years old</td>
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<td>Urban</td>
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<td>30.32</td>
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</tr>
</tbody>
</table>

Controlling for mental retardation level and mentally-challenged individual attends public school.

** .01

Table 6 examines the relationship between socioeconomic status and overall stress. The respondents who work for pay outside the home experience more overall stress than those who do not work for pay outside the home. Even though the mentally-challenged individuals’ age is not statistically significant, the patterns of overall stress are consistent to the marital and general stress with the older the mentally-challenged individual the lower the reported overall stress. Furthermore, the lower the annual
household incomes the lower the reported overall stress levels. The caregiver’s hours of work per week can be explained for the higher stress levels. This data (Tables 3-7), does not seem to offer empirical support for the supposition that caregivers with higher socioeconomic status would report lower stress levels.

Table 6: Overall Stress by respondents’ work for pay outside the home, respondents’ educational level, annual household income, mentally-challenged individuals’ age, and residence.

<table>
<thead>
<tr>
<th>Overall Stress</th>
<th>N=90</th>
<th>Variable</th>
<th>N</th>
<th>Adjusted Mean</th>
<th>Correlation Ratio</th>
<th>Beta</th>
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</thead>
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<tr>
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</tr>
<tr>
<td>Some college</td>
<td>29</td>
<td>59.90</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Two-year college degree of beyond</td>
<td>39</td>
<td>62.46</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Household Income</td>
<td></td>
<td></td>
<td>28</td>
<td>57.57</td>
<td>.11</td>
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<tr>
<td>$40,000 or less</td>
<td>28</td>
<td>57.57</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>$40,001 - $70,000</td>
<td>29</td>
<td>61.93</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>$70,001 or higher</td>
<td>33</td>
<td>61.58</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mentally-challenged individuals’ age</td>
<td></td>
<td></td>
<td>31</td>
<td>60.52</td>
<td>.13</td>
<td></td>
</tr>
<tr>
<td>17 years and below</td>
<td>31</td>
<td>60.52</td>
<td></td>
<td></td>
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<td></td>
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<tr>
<td>18-25 years old</td>
<td>27</td>
<td>62.81</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>26 years and older</td>
<td>32</td>
<td>58.38</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residence</td>
<td></td>
<td></td>
<td>22</td>
<td>58.95</td>
<td>.21</td>
<td></td>
</tr>
<tr>
<td>Rural</td>
<td>22</td>
<td>58.95</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Suburban</td>
<td>49</td>
<td>61.94</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>19</td>
<td>58.32</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Controlling for mental retardation level and mentally-challenged individual attends public school.

* .05
While the above discussion helps us understand the relationship between the caregivers’ socioeconomic status and reported stress level, it does not help support the first hypothesis of the higher the socioeconomic status of the caregiver. The lower the reported stress level of the caregiver was not in the predictable direction of this research.

4.3 Informal Supports and Formal Supports Variables related to Marital, General, Financial, and Overall Stress

Table 7 observes the relationship between marital stress, formal supports, and informal supports. The data from this table are not statistically significant. There is no difference between formal and informal supports and marital stress according to the adjusted means. The participants who receive formal and informal supports have a slightly lower adjusted mean than those who do not receive any supports.

<table>
<thead>
<tr>
<th>Table 7: Marital Stress by Formal and Informal Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Stress</td>
</tr>
<tr>
<td>Grand Mean=11.80</td>
</tr>
<tr>
<td>Variable</td>
</tr>
<tr>
<td>Combination of School supports and Formal supports</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Informal Supports</td>
</tr>
<tr>
<td>No</td>
</tr>
<tr>
<td>Yes</td>
</tr>
</tbody>
</table>

Controlling for mental retardation level and whether mentally-challenged individual attends public school.
Table 8 examines the relationship between formal and informal supports and general stress. The data show no statistical significance between those who receive supports and those who do not receive supports. There is a minimal difference in the general stress levels and formal supports. The participants who receive formal supports have an adjusted mean of 18.75, whereas the participants who do not receive formal supports have an adjusted mean of 19.02. There is no difference in the adjusted means for those receiving or not receiving informal supports and general stress of the caregiver.

Table 8: General Stress by Formal and Informal Supports

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Adjusted Mean</th>
<th>Correlation Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combination of School supports and Formal supports</td>
<td></td>
<td></td>
<td>Beta</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>19.02</td>
<td>.02</td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
<td>18.75</td>
<td></td>
</tr>
<tr>
<td>Informal Supports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>18.83</td>
<td>.00</td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
<td>18.83</td>
<td></td>
</tr>
</tbody>
</table>

Controlling for mental retardation level and whether mentally-challenged individual attends public school.
Table 9 further explores the relationship between formal and informal supports and financial stress. Again, the associations are not statistically significant with an infinitesimal difference in the adjusted means. There is a very weak correlation between formal and informal supports and financial stress.

Table 9: Financial Stress by Formal and Informal Supports

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Adjusted Mean</th>
<th>Correlation Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combination of School supports and Formal supports</td>
<td></td>
<td></td>
<td>Beta</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>29.10</td>
<td>.01</td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
<td>30.73</td>
<td></td>
</tr>
<tr>
<td>Informal Supports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>30.13</td>
<td>.01</td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
<td>30.27</td>
<td></td>
</tr>
</tbody>
</table>

Controlling for mental retardation level and whether mentally-challenged individual attends public school.
Table 10 reports the relationship between formal and informal supports and overall stress. The data again are not statistically significant. While many caregivers do not receive any formal or informal supports, there is little to no difference in the adjusted means of those who receive supports and those who do not.

### Table 10: Overall Stress by Formal and Informal Supports

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>Adjusted Mean</th>
<th>Correlation Ratio</th>
</tr>
</thead>
<tbody>
<tr>
<td>Combination of School supports and Formal supports</td>
<td></td>
<td></td>
<td>Beta</td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>59.73</td>
<td>.05</td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
<td>60.77</td>
<td></td>
</tr>
<tr>
<td>Informal Supports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>28</td>
<td>60.96</td>
<td>.04</td>
</tr>
<tr>
<td>Yes</td>
<td>62</td>
<td>60.21</td>
<td></td>
</tr>
</tbody>
</table>

Controlling for mental retardation level and whether mentally-challenged individual attends public school.

From the data gathered in tables 7 through 10, it appears there is no empirical support for the conclusion that the greater the utilization of formal caregiver supports, the lower the stress level of the caregiver. Furthermore, there is no empirical support for the conclusion that the greater the utilization of informal caregiver supports, the lower the stress level of the caregiver. There are several participants who receive no supports. This could be connected to the lack of developed networks and social services (Moroney 1979). The results of formal and informal supports are not significant in this study. However, Heller and Factor (1991, 1993) did find that caregivers who used greater numbers of informal supports were likely to also use more formal supports. In this study, the number of respondents who utilize informal supports
is the same as the number of those who utilize formal supports. However, the results show a slight increase in utilization of informal supports if the respondent is using formal supports. The findings of Tracey (2003), which suggested that the utilization of formal supports depends strongly on the caregivers’ ability adds further support to the case for formal and informal supports.
CHAPTER 5
CONCLUSION

This research began with three main objectives. The first objective was to determine caregivers with higher socioeconomic status, would report lower stress level. However, the results actually revealed that the higher the respondent’s socioeconomic status, the higher the reported stress level of the caregiver. The second objective was to examine if an increase in the caregiver’s utilization of formal supports decrease the caregiver’s reported stress level. The results found no association. The third objective was to determine if an increase in the caregiver’s utilization of informal supports would decrease the caregiver’s reported stress level. The results found no association. Further discussion of main objectives categorizes them by section, including: socioeconomic status, formal supports, and informal supports.

The socioeconomic status objective examined respondents’ education and found as the education levels increased so did the stress. Since a caregiver’s increased education is more likely to result in a more demanding career, this theory is plausible. The caregivers who work outside the home for pay experience more stress than caregivers who stay at home. A possible explanation is the caregivers who work outside the home may worry about their mentally-challenged individual at home. What are they doing? How are they doing? Many parents believe no one can care for their
child better than they can. According to Grant and Whittell (1999) caregivers acknowledge that their mentally-challenged loved one usually needs specialized care that the caregiver is reluctant to relinquish or delegate to others.

Unlike Hodapp and Krasher (1994), current data from this study reports an average household income of approximately $50,000 per year. However, the caregivers who fall between $40,001 and $70,000 reported higher levels of stress. One credible explanation is that middle income families typically do not meet eligibility requirements for governmental assistance and these families might be dual income households. Medicaid and Medicare are financial supports available to families with greater financial need. However, higher income (>70,000) usually have more discretionary income that allows them to participate in events such as Special Olympics and take vacations. Higher income families are able to appropriate time to relax, and they are typically solvent enough to pay for needed supports and services.

In this research, the mentally-challenged individuals’ age, indicates that the older the individual, the lower the stress of the caregiver. Several implications arise from this topic. One is that the younger the mentally-challenged individual, the higher the stress level. Kerr and McIntosh (1999) found that the most difficult time for the parents is generally weeks and months following the birth of a mentally-challenged individual. As the child gets older the parents obtain more information, education and training about the actual disability and care required (Britner et al. 2003). Over time, the caregiver learns to cope and adapt to a caregiving routine (Seltzer and Krauss 1993, Kerr and McIntosh 1999).
However, once the mentally-challenged individual reaches adulthood, the caregivers’ financial stress levels tend to increase. This sample contains a large portion of mildly mentally-challenged individuals, who are more aware of their surroundings and want to be normal. These individuals want to date, shop, and participate in other activities that cost money, but yet very few mentally-challenged individuals have jobs. There is little, if any, additional money to help support these activities.

There are several possible explanations for why the utilization of formal supports and informal supports has no effect on caregivers’ stress levels. The caregivers who had formal supports were equal in number to the caregivers who had informal supports. The first explanation is that the average age of the caregivers in this research is 52. Older caregivers tend to be more at ease with their caregiving tasks (Hayden and Heller 1997). This study further reveals that older caregivers have lower expectations of the service system. Seltzer and Krauss (1993) indicates that older caregivers believe there is no need for assistance. In most cases, these caregivers have adapted to provide the needs of the mentally-challenged individual.

Primary caregivers with more demanding careers have much less time to coordinate formal services. The vast majority of these services are available Monday through Friday 8am to 5pm. Such complicated logistics help support the finding that these from higher socioeconomic groups report greater stress levels. Caregivers who work outside the home may struggle to obtain career advancement, which also contributes to higher stress levels (Slater and Wikler 1986).
Many caregivers do not utilize formal supports because they do not know what services actually exist or the correct terminology usually needed to request access to these services (Lehman and Roberto 1993). The most common type of formal support is case management. Mistrust on the part of caregivers, and gross inexperience and high turnover on the part of the case manager both contribute to a decrease use of this particular support (Tracey 2003). Only 21 percent of the caregivers surveyed reported using case management services. More experienced and better trained case management helps caregivers in obtaining knowledge and services of other formal supports (Tracey 2003). More experienced caseworkers with lighter case loads tend to increase the utilization of more formal supports.

Informal supports consist of unpaid individuals who are friends, family, acquaintances, etc., who help the primary caregiver when needed. In this study the utilization of informal supports have no effect on the caregivers’ stress levels. There is, however, some interesting media research called the “Mega Church” which reports people are not as connected as they were in the past. Cummings (2001) discussed caregiving in the mid-1800s, where families took care of mentally-challenged individuals as well as extended family members in the natural home setting. Society is now much more mobile and versatile. Many family members now live further away, which significantly reduces their availability. The result is that fewer families use the informal supports of family and community.

To ascertain why the utilization of formal and informal supports do not affect caregivers’ stress levels, research must also consider current societal trends. Caregivers
have access to more information than they had in the past. They have access to technology, online support “blogs”, discussion boards, books, articles, and documents written and designed to help them better understand their mentally-challenged individuals’ disability. Availability of these resources can increase the number of possible coping strategies. There are multiple “self-help” books for various issues that everyday people to find solutions to their stress. People are also more likely now than in the past to seek counseling to help deal with their caregiving stress. Caregivers also have the option of consulting with a physician to determine if anxiety reducing medication may be prescribed for them.

The data collected was further categorized using the two extremes of caregivers’ stress levels: the most stressed and the least stressed. Four caregivers with the highest reported stress levels. All four were married, had an annual household income greater than $60,000, worked for pay at least 40 hours a week outside the home, and had spouses who worked outside the home for pay as well. Three out of the four of the mentally-challenged individuals involved function at the moderate mental retardation level and attend public school. All four caregivers spend between 5-8 hours a day with the mentally-challenged individual after working a 40 hour week. Three out of four caregivers utilize zero or one formal and/or informal supports.

Conversely, caregivers with the lowest reported stress levels have different characteristics than those with the highest reported stress levels. Three out of five caregivers in this group have annual household income of $10,000-$20,000 and are married. Two out of three married respondents reporting lower stress levels did not
work outside the home for pay; neither did their spouses. Four of the mentally-challenged individuals involved function at the mild mental retardation level. The majority of these caregivers spend 14-16 hours a day with the mentally-challenged individual. Only one mentally-challenged individual attends public school. These reported lower stress levels can possibly be attributed to the absence of career stressors combined with the large amount of caregiving time. The caregiver does not need to worry about how the mentally-challenged individual is doing.

The results of this study provide information on the often overlooked issues surrounding caregivers of mentally-challenged individuals. It is vital that future research in this area continue. The stress level of respective caregivers directly affects the care and well-being of the caregiver, his/her family, the mentally-challenged individuals, and society as a whole. Recommendations for future expanded research include surveying a larger, more diverse sampling, a wider time frame, and possible grant funding. Additional questions would address more specific items such as particular supports available for the caregiver, and not only the mentally-challenged individual. Other changes would include questions about the place of technological advancement (i.e., how many respondents have internet access, cell phones, etc.). Such adjustments would likely produce better results and more significant accurate and reliable findings. A larger sample could also address the limited ethnic group responses in this study. Upon completion of present research, the benefit of these suggestions would greatly improve future research.
APPENDIX A

INFORMED CONSENT FORM
SUBJECT CONSENT FORM

I have been asked to participate as a subject in the research project entitled Deinstitutionalization: The consequences of the Caregiver under the direction of Jennifer Pettit.

I understand the purpose of this study is to help expand the knowledge of caregiving to those in need, to increase the awareness of advocacy needed for this specialized group, and an overall knowledge of common issues with regards to caregiving of mentally-challenged individuals.

Data for this study will consist of approximately 200 surveys completed by adult caregivers, from the State of Texas, who are caring for a mentally-challenged individual in their natural home setting. The 63 question survey will include a combination of open and closed-ended questions and should take approximately 30 minutes to complete. The survey will be self-administered and unmonitored to help with the feeling of privacy. Data collection will be conducted within a timely fashion over a 4 month period.

I understand that the potential risks from participation in the study as minimal. The participants will be provided a resource contact list to help caregivers, if needed. I understand that I will not benefit from my participation in the research project. The alternative procedure for this survey is not to participate in the study. I understand that I will not be paid for participation in this study.

I understand that informed consent is required of all persons in this project. The principal and alternate procedures, including the experimental procedures in this project, have been identified and explained to me in language that I can understand. The risk and discomforts from the procedures have been explained to me. The expected benefits from the procedures have been explained to me. An offer has been made to answer any questions that I may have about these procedures. If there are any questions before, during or after the study, I may contact: Ms. Jennifer Pettit at (817) 919-1041 or Dr. Beth Anne Shelton at (817) 272-3131.

I have been told that I may refuse to participate or stop my participation in this project at any time. All new findings during the course of this research which will influence my desire to continue or not to continue to participate in this study will be provided to me as such information becomes available. If I am injured or have an adverse reaction because of this research, I should immediately contact one of the personnel listed above. No additional compensation will be provided. Agreeing to this does not mean I am giving up any legal rights that I may have. If I have any questions regarding my rights as a subject participating in this study or research-related injury, I may contact the
Office of Research Compliance at (817) 272-0834. I have a right to privacy, and all information that is obtained in connection with this study and that can be identified with me will remain confidential as far as possible within state and federal law. However, information gained from this study that can be identified with me may be released to no one other than the investigators and my physician. The results of this study may be published in scientific journals without identifying me by name.

I voluntarily agree to participate as a subject in the above named project. I understand that I will be given a copy of the consent form I have signed.

___________________________   ____________________________
Date       Signature of Subject

Using language that is understandable and appropriate, I have discussed this project and the items listed above with the subject.

___________________________   ____________________________
Date       Signature of Principal Investigator
APPENDIX B

SURVEY QUESTIONNAIRE
SURVEY # _______________
Please check or fill in the blanks for each of the following questions:

1. What is your relationship with the mentally-challenged individual? (mark one)
   Father
   Mother
   Step-father
   Step-mother
   Sister
   Brother
   Grandmother
   Grandfather
   Aunt
   Uncle
   Guardian
   Other (specify)

2. Are you the primary caregiver?
   Yes
   No

3. If not, who is? Relationship to the mentally-challenged individual.
   ______________________________
   ______________________________

4. What is your birthday? (month/day/year)
   ______________________________
   ______________________________

5. How many mentally-challenged individuals live in your residence?
   Number: _______________

6. What is the sex of the mentally-challenged individual who resides with you?
   Male
   Female

7. Not counting when you are sleeping at night, how many hours in an average day do you spend with the mentally-challenged individual?
   Number of hours: __________

8. What is the mentally-challenged individual’s age?
   ______________________________

9. What is your sex?
   Male
   Female

10. What is the highest level of education you have completed? (mark one)
    Less than High school diploma
    High school (diploma or GED)
    Some College
    Two year-college degree
    Four-year college degree
    Graduate school
    Beyond Graduate degree
    Other __________________

11. Do you currently work for pay outside of the home? (mark one)
    YES
    NO

(If you answered no to question #11, please skip to question #15).
12. If so, how many hours do you work for pay in an average week? 
   Hours: ________________

13. What is your occupation? 
   ______________________

14. Does your job include supervising other workers? 
   Yes
   No

15. What is your marital status? 
   (mark one) 
   Never married
   Married
   Divorced
   Separated
   Widowed
   Cohabiting

   (If you are neither married nor cohabiting, please skip to question # 18)

16. Does your spouse or partner work for pay?  (mark one) 
   YES
   NO

17. What is your spouse’s or partner’s occupation? 
   ______________________

18. What was your total household income last year, after taxes?  
   (mark one) 
   $9,999 or less
   $10,000-$20,000
   $20,001-$30,000
   $30,001-$40,000
   $40,001-$50,000
   $50,001-$60,000
   $60,001-$70,000
   $70,001-$80,000
   More than $80,000

19. Did you receive any additional monetary support last year?  
   (mark all that apply) 
   Child Support: 
   $____________________
   Social Security: 
   $____________________
   Disability: 
   $____________________
   Other: 
   $____________________
   None

20. What is the mental retardation level of the mentally-challenged individual for whom you care? 
   Mild (IQ=60-69)
   Moderate (IQ=50-59)
   Severe/Profound (IQ=49 and below)
21. How many children under the age of 18 do you have living in your household? This would include the mentally-challenged individual. (mark one)

   0  4
   1  5
   2  6
   3  7 or more

22. How many people total (adults and children) do you have living in your household? (mark one)

   1  5
   2  6
   3  7
   4  8 or more

23. How many people within your household help on a daily basis with the caregiving of the mentally-challenged individual? (mark one)

   1  5
   2  6
   3  7
   4  8 or more

24. What is your religion, if any?

   (If no answer on #24, please skip to #27)

25. How often, on average, would you say you attend religious services? (mark one)

   Never
   Once a year or less
   Every few months
   About once a month
   Several times a month
   About once a week
   More than once a week

26. If you are a member of a religious community, do you receive any financial support from your religious community? (mark one)

   YES
   NO

27. What is your ethnic background? (mark one)

   African American
   American Indian
   Asian
   Caucasian (not of Hispanic background)
   Hispanic (please specify)

   Other: (please specify)
28. From which of the following, if any, do you receive help like babysitting, transportation, etc? (please check all that apply and how often you receive help)

Church
(how often) ____________________

Immediate Family
(how often) ____________________

Extended Family
(how often) ____________________

Friends
(how often) ____________________

Co-workers
(how often) ____________________

Neighbors
(how often) ____________________

Other (please specify)
____________________________________
(how often) ____________________

29. Which of the following formal, paid, supports do you receive regularly for the mentally-challenged individual? (please check all that apply and tell how often you receive these supports)

Physician
(how often) ____________________

Psychologist
(how often) ____________________

Behavioral Support
(how often) ____________________

Case Management
(how often) ____________________

Respite
(how often) ____________________

In-home training
(how often) ____________________

Speech Therapy
(how often) ____________________

Physical Therapy
(how often) ____________________

Occupational Therapy
(how often) ____________________

Counseling
(how often) ____________________

School Support
(how often) ____________________

Childcare
(how often) ____________________

Other (please specify)
____________________________________
(how often) ____________________
30. Does your mentally-challenged individual(s) currently attend school? (mark one)  
   YES  
   NO  

   (If you answered no to question #30, please skip to question #32)

31. Please mark the formal supports that are available and provided by the school for your mentally-challenged individual: (please mark all that apply)  
   Behavioral Support  
   (how often) ____________________  
   Counseling  
   (how often) ____________________  
   Speech Therapy  
   (how often) ____________________  
   Occupational Therapy  
   (how often) ____________________  
   Physical Therapy  
   (how often) ____________________  
   Other (please specify)  
   _______________________________  
   None provided

32. What is the highest grade level he/she has completed?  
   _______________________________

33. Is your mentally-challenged individual employed?  
   YES  
   NO

34. If yes, how many hours per week do they work?  
   _______________ hours

35. Do you currently live in the State of Texas? (mark one)  
   YES  
   NO

36. What type of area would you say you live in? (mark one)  
   RURAL (under 25,000 population)  
   SUBURBAN (25,000-99,999 population)  
   URBAN (over 100,000 population)

37. How long have you lived at your current residence? (mark one)  
   Less than a year  
   1-3 years  
   4-7 years  
   8 or more years

38. How far do you have to travel, one-way, to get to the mentally-challenged individual’s primary care doctor? (mark one)  
   ___________ Miles
Each statement is followed by four responses. Please circle the response (only one for each statement) that best represents your daily experience with caregiving of the mentally-challenged family member.

<table>
<thead>
<tr>
<th>Statement</th>
<th>Have Not Experienced</th>
<th>Experienced but not Difficult</th>
<th>Experienced and Somewhat difficult</th>
<th>Experienced and very difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td>39. Not being able to manage and coordinate your daily routine at home</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>40. Receiving contradictory advice from other people</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>41. Less time with adults (other than partner)</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>42. Less time to do the things you enjoy</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>43. Less freedom to do what you want to when you want</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>44. Lack of intellectual stimulation</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>45. Changes to your work commitments</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>46. Loss of independence</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

*(If you are neither married nor cohabiting, please skip to question #53)*

<table>
<thead>
<tr>
<th>Statement</th>
<th>Have Not Experienced</th>
<th>Experienced but not Difficult</th>
<th>Experienced and Somewhat difficult</th>
<th>Experienced and very difficult</th>
</tr>
</thead>
<tbody>
<tr>
<td>47. Change to your marital relationship</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>48. Feeling more distant from your partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>49. Less time with your partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>50. Changes in you and your partner’s sexual relationship</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>51. Problems sharing child care tasks with your partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>52. Problems sharing household tasks with your partner</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>
Each statement is followed by three responses. Please circle the response (only one for each statement) that best represents your caregiving situation.

**Independent:** The mentally-challenged individual does not need the help of another person to do a task.

**Assistance:** The mentally-challenged individual needs the help of another person to do part of a task.

**Dependent:** The mentally-challenged individual needs the help of another person to do all of a task.

<table>
<thead>
<tr>
<th>Question</th>
<th>Independent</th>
<th>Assistance</th>
<th>Dependent</th>
</tr>
</thead>
<tbody>
<tr>
<td>53. What kind of assistance does the mentally-challenged individual need with eating?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>54. What kind of assistance does the mentally-challenged individual need with dressing?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>55. What kind of assistance does the mentally-challenged individual need with personal hygiene?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>56. What kind of assistance does the mentally-challenged individual need with toileting?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>57. What kind of assistance does the mentally-challenged individual need with mobility?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>58. What kind of assistance does the mentally-challenged individual need with behavior management?</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Each statement is followed by five responses. Please circle the response (only one for each statement) that best represents your caregiving situation.

<table>
<thead>
<tr>
<th></th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Undecided</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>59. I feel that my family argues more about money now than we did before I was responsible for caregiving.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>60. I worry about my finances because I have had to pay for food for the person I care for.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>61. I feel that caregiving is a financial burden for me.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>62. I feel that I am unable to buy clothing for myself because of caregiving expenses.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>63. Overall, I feel that caregiving strains my family and social life.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>64. I feel guilty sometimes because I worry about caregiving costs.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>65. Overall, I feel that caregiving has been a financial drain on me and/or my family.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>66. I worry about my finances because they are being used to pay for major living expenses for the person I take care of.</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
</tbody>
</table>
APPENDIX C

RESOURCE CONTACT INFORMATION
Resource Contact Information

**The Arc of Greater Tarrant County**  
259 Bailey, Suite B  
Fort Worth, Texas 76107  
Phone: 817-877-1474  
Website: www.thearc.flash.net

**Texas Rehabilitation Commission**  
218 Billings St #310  
Arlington, Texas 76010  
Phone: 1-800-634-2616  
Website: www.rehab.state.tx.us

**Early Childhood Intervention**  
3840 Hulen  
Fort Worth, Texas 76107  
Phone: 817-466-8000

**Advocacy, Inc.**  
1420 West Mockingbird Ln.  
Ste. #450  
Dallas, Texas 75247  
Phone: 214-630-0916  
Website: www.advocacyinc.org

**Special Olympics Texas**  
500 W. 7th Street Ste.#302  
Fort Worth, Texas 76102  
Phone: 817-332-3433  
Website: www.sotx.org

**Texas Education Agency**  
Website: www.tea.state.tx.us

**Texas Mental Health Mental Retardation Services**  
Website: www.mhmr.state.tx.us
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BIOGRAPHICAL INFORMATION

Jennifer R. Pettit was born in Fort Worth, Texas. She received an Associate in Arts from Tarrant County Junior College in 1994. She also earned a Bachelor of Arts in Psychology from the University of Texas at Arlington. Jennifer began her graduate work at the University of Texas at Arlington in the fall of 2000. She has worked full-time as a high school teacher and part-time as an aquatics coordinator and swim team coach all while pursuing her masters degree. Her plan after graduation is to get married and pursue a college teaching career.