

THE ROLE OF ESTATE RECOVERY IN MEDICAID LONG-TERM CARE:
PERSPECTIVES OF OLDER ADULT HOMEOWNERS

BY

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ABSTRACT

The Role of Estate Recovery in Medicaid Long-term Care: Perspectives of Older Adult Homeowners

This qualitative study of older homeowners explored their perspectives on the estate recovery provisions that Medicaid recipients are required to accept if they depend on the program for their long-term care. Fifty-one homeowners age 55 and older who resided in a Midwestern metropolitan area participated in focus group discussions. Six groups were held at a large university medical center and attracted White participants (n=37) almost exclusively. Two groups were conducted at an urban senior center with African-Americans (n=14) participants. Findings that emerged from analysis of focus group data suggest that (1) participants viewed homeownership as conferring many social, psychological, economic and health benefits (2) participants had little information about Medicaid estate recovery (3) Medicaid was viewed as a necessary “safety net” to be used as a “last resort” and (4) support and non-support of estate recovery policy and the importance of inheritance varied greatly by research venue and, therefore, by racial composition of the focus groups. Implications for social work practice, policy and research are discussed with special attention to the complex dynamics of age, race, and asset building.

KEY WORDS: homeownership; long-term care, older adults; Medicaid estate recovery; inheritance; race; asset building.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS	iii
ABSTRACT	iv
TABLE OF CONTENTS	v
LIST OF TABLES	viii
CHAPTER ONE: INTRODUCTION AND OVERVIEW	1
Purpose of the Study	3
Motivations for Research	3
Relevance to Social Work	5
Needs Statement	7
<i>The Aging of America</i>	7
<i>Long-term Care Needs and Service Provision</i>	8
<i>The Medical Assistance Program</i>	10
<i>The Estate Recovery Provision of the Medicaid Program</i>	12
<i>Criticisms and Contentions Surrounding Estate Recovery</i>	16
<i>Estate Recovery and “The American Dream”</i>	20
Theoretical Frameworks	21
<i>Social Constructionism</i>	22
<i>Asset Theory</i>	23
Summary	25
CHAPTER TWO: LITERATURE REVIEW	26
The Meaning of Home, Legacy and Generativity	26
<i>The Meaning of Home</i>	27
<i>Legacy and Generativity</i>	31
Benefits of Homeownership	33
<i>Economic Benefits</i>	34
<i>Social Benefits</i>	35
<i>Health Benefits</i>	37
<i>Benefits for Older Adults</i>	37
Homeownership and Inheritance	38
Summary	40
CHAPTER THREE: METHODOLOGY	42
Research Design and Rationale	42
Research Questions	46
Key Concepts	46
Phases of the Study	47

Protection of Human Subjects -----	48
Data Collection -----	49
<i>Data Collection Strategy</i> -----	51
<i>Sampling and Recruitment</i> -----	52
<i>Data Collection Sites</i> -----	53
<i>Engagement with the Research Sites</i> -----	55
Description of Research Sites -----	57
<i>Research Site A</i> -----	57
<i>Research Site B</i> -----	58
Data Collection Instrumentation -----	58
Data Analysis -----	62
Methodological Rigor -----	67
<i>Trustworthiness</i> -----	68
<i>Credibility</i> -----	68
<i>Transferability</i> -----	71
<i>Dependability</i> -----	71
<i>Confirmability</i> -----	72
Summary -----	72
CHAPTER FOUR: FINDINGS -----	74
Focus Group Composition and Socio-demographic Characteristics -----	75
Substantive Topics and Major Themes -----	80
<i>Homeownership: The Meaning of Home, and Advantages versus</i>	
<i>Disadvantages</i> -----	80
<i>The Meaning of Home</i> -----	81
<i>Advantages of Homeownership</i> -----	83
<i>Advantages: Psychological Benefits</i> -----	84
<i>Social Benefits: Families, Pets, and Neighbors</i> -----	86
<i>Advantages: Social Benefits</i> -----	88
<i>Advantages: Economic Benefits</i> -----	90
<i>Advantages: Health-related Benefits</i> -----	91
<i>Disadvantages of Homeownership</i> -----	92
<i>Disadvantages: Taxes</i> -----	96
<i>Disadvantages: Finding Help</i> -----	97
<i>Medicaid Estate Recovery</i> -----	98
<i>Knowledge of Estate Recovery</i> -----	99
<i>Estate Recovery: Education and Information Needed</i> -----	100
<i>Estate Recovery Policy: Support versus Non-Support</i> -----	103
<i>Medicaid and Long-term Care</i> -----	109
<i>Medicaid: A Safety Net and a Last Resort</i> -----	110
Summary -----	118
CHAPTER FIVE: DISCUSSION, IMPLICATIONS AND CONCLUSION -----	120
Discussion -----	120

<i>Findings and Discussion: Homeownership</i> -----	120
<i>Findings and Discussion: Estate Recovery</i> -----	122
<i>Findings and Discussion: Knowledge and Information Needed</i> ----	131
Implications -----	134
<i>Implications for Social Work Practice</i> -----	134
<i>Implications for Social Policy</i> -----	136
<i>Implications for Research</i> -----	138
Limitations -----	138
Conclusion -----	140
REFERENCES -----	142
APPENDICES	
APPENDIX A HUMAN SUBJECTS APPROVAL -----	156
APPENDIX B CONSENT FORM -----	159
APPENDIX C GUIDED QUESTIONS -----	163
APPENDIX D NOTE TAKING FORM -----	166
APPENDIX E SOCIO-DEMOGRAPHIC INFORMATION FORM -----	168
APPENDIX F DEBRIEFING FORM -----	170
APPENDIX G CODING FACE SHEET -----	172
APPENDIX H THEMATIC TEMPLATE -----	174
APPENDIX I ACROSS GROUP THEMATIC COMPARISONS -----	176

LIST OF TABLES

Table 1 *Focus Group Composition* -----77

Table 2 *Characteristics of Participants* -----78

CHAPTER ONE

INTRODUCTION AND OVERVIEW

The desire to leave accumulated wealth to the next generation is a deeply embedded value in American society and one that holds important implications for well-being. Most people in the United States who accumulate wealth during the course of their lifetimes do so, at least in part, through homeownership. Home equity comprises the largest share of personally held assets in the United States, and enables intergenerational wealth transfer. Without home equity, many people would have no accumulated assets to transfer wealth to their children and grandchildren (Shapiro, 2004). With the anticipated surge in the older adult population over the next several years, the issue of intergenerational wealth transfer will undoubtedly hold a prominent role in the private lives of older adults and their families and in the public discourse as well.

Unfortunately, the opportunity to pass on wealth attained through homeownership may be compromised by federal policy, especially for lower-income and minority homeowners. The estate recovery provision in Medicaid requires that older adults who are in need of public assistance for long-term care services agree to “pay back”, at least in part, the cost of those services by agreeing to give the state proceeds from the sale of their estates after death (U.S. Dept. of Health and Human Services, 2006). While there are some exceptions to estate recovery mandates, the policy generally requires older adults to agree to estate recovery in order to apply for Medicaid long-term care services, whether these are provided in one’s home or in a

nursing home setting. Importantly, accumulated assets that comprise the “estates” of lower-income and minority elders are mostly held in the form of home equity (Karp, Sabatino & Wood, 2005; Shapiro, 2004).

Owning one’s home is considered the fulfillment of the “American Dream”, and the concept of “home” is imbued with multiple meanings. Home is often how people define themselves, a way to maintain control, and a way to maintain a sense of power and exert influence in the face of many changes and challenges in late life (Rakoff, 1977; Rutman & Freedman, 1987; Mallet, 2004; Saleebey, 2004). Home is safety. Home is security. Homeownership has been associated with positive effects on health, including fewer chronic health conditions (Baker & Taylor, 1997; Robert & House, 1996; Stronks, van de Mheen, van den Bos, & Mackenbach, 1997). Homeownership is positively associated with successful transitions from nursing homes to community settings, and negatively associated with nursing home admissions (Greene & Ondrich, 1990; Opoku, et al., 2006).

Given the subjective and objective importance of “home” to personal and social well-being, it is not surprising that the prospect of losing one’s home may constitute a barrier to using Medicaid for long-term care services (Karp, Sabatino & Wood, 2005). Of further concern is the fact that African Americans have not had, nor do they presently have, the same opportunities for homeownership, inheritance, and intergenerational wealth transfer as their White peers (Shapiro & Wolff, 2001; Shapiro, 2004; Brown, Kuttner & Shapiro, 2004). These concerns set the stage for

further examination of homeownership, long-term care, and the Estate Recovery Program.

Purpose of the Study

The purpose of this study is to examine the perspectives of a diverse group of homeowners, age 55 and older, on the estate recovery provisions in Medicaid for long-term care. While various aspects of inheritance, homeownership, inter-generational wealth transfer, Medicaid long-term care and estate recovery have been previously explored (Curry, 2001; Curry, Gruman, & Robison, 2001; Goggins, 1997; Kane, 1996; Kapp, 2006; Moody, 1994; Oliver & Shapiro, 2006; Scanlon & Page-Adams, 2000; Shapiro, 2004; Stum, 1998, 2001; Takacs & McGuffey, 2002; Walker, Gruman & Robison, 1998, 1999; Weiner, 1996), there have been virtually no prior studies which have examined how estate recovery may shape, or differentially shape, the perspectives of a diverse group of older adult homeowners on the use of Medicaid for long-term care given estate recovery provisions. Findings from this study have the potential to increase the social work practice, policy and research knowledge base by obtaining first-hand perspectives on an issue that not only affects present-day older people and their families, but one which has lasting effects on well-being for future generations.

Motivations for Research

My motivations for undertaking this research are derived from my professional experience with older adults and their families in community and hospital-based social work. As a professional social worker, I assisted individuals and

their families in negotiating the maze of service options, and guided them in long-term care decision making. The use of Medicaid invariably surfaced in conversations about services, and I felt it my professional obligation to inform individuals about the estate recovery provision of Medicaid law. Approaching this subject was difficult as many older adults were skeptical of social workers to begin with, seeing them as there to “put them in a nursing home,” or as the person who “asked nosy questions about their money.” The rapport and trust I had established with clients was often diminished by the knowledge they gained of estate recovery. I will never forget the response of many older adults and their families when they learned about the program. Many felt a sense of betrayal or dismay. Some expressed that they had worked all of their lives, paid their taxes like good citizens, and noted that when they needed help, they couldn’t get it without giving up their “life’s blood.” I became increasingly concerned that estate recovery may be a barrier to accepting Medicaid services. Although this concern has been raised in the empirical literature, little research had been done on the topic (Karp, Sabatino & Wood, 2005). I was also concerned, as noted in the literature, that individuals would forego needed services, which may result in premature or unnecessary institutionalization or suffer further deterioration (Karp, Sabatino & Wood, 2005). Therefore, I vowed that I would work in my professional career to further investigate this issue. This study constitutes one step towards enhancing our understanding of this complex and often contentious issue.

Relevance to Social Work

Studying the role of estate recovery on the use of Medicaid for long-term care is relevant to social work for several reasons. First, a primary professional obligation in social work is to advocate for social justice with and on behalf of vulnerable individuals and groups (National Association of Social Workers, 1996). This study reflects this priority by contributing to the social work knowledge base on a social and economic justice issue of critical importance to older adults, with special attention to minority elders. I believe that findings from this study will be useful to social workers engaged in direct practice with older adults and their families, as well as those in policy practice.

Secondly, the projected growth of the aging population and minority elders demands the preparation of competent gerontological social workers (Sisco, Volland, & Gorin, 2005). Social workers who work with older adults must have knowledge of delivery systems, eligibility requirements for programs and services, and be able to impart this information to older adults and their families (Berkman, Gardner, Zodikoff, & Harooytan, 2005). It is imperative that social workers understand how estate recovery may impact their clients' decisions about using Medicaid funding for long-term care services. Moreover, understanding the perspectives of older adults who may be faced with the prospect of estate recovery can help to create strengths-based social policies that reflect the clients' views and needs (Chapin, 2008). Finally, consistent with responsibilities outlined in the National Association of Social Workers' (NASW) Code of Ethics (1996), social workers have a professional

obligation to help shape social policy to meet the needs of an increasingly diverse older population.

This study will also contribute to the scholarly research on estate recovery and Medicaid. Little recent scholarly work has been done by the profession related to Medicaid estate recovery. When the Estate Recovery provision of Medicaid was signed into law in 1993, there appeared an abundance of scholarly work and advocacy efforts on the issue, including a resounding response from the social work profession (Burwell & Crown, 1996; Curry, 2000; Dobrof, 1996; Goggins, 1997; Kane, 1996). In recent years, however, the issue appears to have fallen below the profession's radar. The fact that estate recovery is not very likely to go away, especially with fiscally-constrained state and federal budgets and Medicaid shortfalls (Takacs & McGuffey, 2002; Karp, Sabatino & Wood, 2005) may account, in part, for this general lack of attention. Notably, a recent query to the NASW headquarters revealed that the association does not have a position statement on estate recovery (Hermans, 2007). This is concerning, and surprising, given that social justice is a primary ethical principle espoused within the Code of Ethics (NASW, 1996). Perhaps the social work profession is not fully aware of the potential impact of Estate Recovery on present and future generations of older people, and importantly, the potential negative effects of this social policy on minority individuals. Clearly, this presents a call for serious inquiry by the profession.

Needs Statement

The Aging of America

The U.S. population of people 65 years and older numbered 35.6 million in 2002, or 12.3 percent of the population (U.S. Dept. of Health & Human Services, 2003). By 2030, it is expected to more than double to 74 million individuals. Perhaps most noteworthy is the growth in the 85 and older population, the group most likely to need long-term care services such as assistance with activities of daily living and other personal, social and medical services, for chronic health conditions. This group is expected to increase from 4.6 million in 2002, to 9.6 million in 2030. The proportion of racial and ethnic minority adults 65 and older is also expected to increase. Estimates indicate that by the year 2050, 36 percent of the older population will be non-White with African Americans representing 12 percent of adults 65 and older, up from eight percent in 2002 (U.S. Dept. of Health & Human Services, 2003). Hispanic populations are expected to increase from six percent in 2004 to nearly 17 percent in 2050. Asian and Pacific Islanders, who in 2002 represented about 2.9 percent of the population age 65 and older, will grow to seven percent by the year 2050 (U.S. Census Bureau, 2004). Due to the increased likelihood of disability and chronic illness with aging, this growing and diverse population of older adults will undoubtedly place heavy demands on the long-term care system for services and funding assistance.

Long-term Care Needs and Service Provision

“Long-term care” refers to the provision of services to individuals who need assistance with activities of daily living (ADLs) such as bathing, dressing, eating, cooking, shopping, household chores, medications, legal and financial matters, or mental health concerns due to limitations imposed by chronic health conditions (Harrington, LeBlanc & Tonner, 2001). Many older adults have at least one or more chronic illnesses which affect their ability to perform ADLs (Federal Agency Forum, 2004). Estimates suggest that about 30% of older people who need long-term care require assistance with three or more activities of daily living (Family Caregiver Alliance, 2005). Despite these limitations, older adults as a whole show great emotional stability and resilience, and the majority are neither sick nor frail (Carstensen, 1996; Hooyman & Kijak, 2002), with only 4.4 percent of older adults 65 and older residing in nursing homes (Kaiser Family Foundation, 2006).

Historically, long-term care in the U.S. was provided almost exclusively by families. Changes brought about during the Industrial Revolution profoundly impacted the family’s ability to care for their older members, and consequently, the cultural norms of the family as the primary source of caregiving assistance were compromised (Applebaum, 1978; Pope, 2002). Due to the changing structure of the family, as well as increasing life expectancy, the number of older people needing assistance continued to grow (Applebaum, 1978). Whereas in the mid-1800s, only 5% of the population was over age 65, by 1920 this group had increased by fifty-nine percent (Achenbaum, 1983). Today, adults 65 and older make up approximately 63%

of all people with long-term care needs (Kaiser Family Foundation, 2006). The majority of this care is provided by family and friends with the remainder provided in some combination of paid and unpaid help (Family Caregiver Alliance, 2005). The extent to which family and friends provide assistance varies across racial and ethnic groups, reflecting cultural and socio-economic differences (Family Caregiver Alliance, 2005). Studies of long-term care use among minority older adults provide somewhat conflicting evidence. However, it is evident that ethnic minority elders, when compared to their White counterparts, are more likely to under-utilize long-term care services, especially institutional care such as nursing homes (Mui, Choi & Monk, 1998). Some studies have suggested that African American elders are less likely than similar non-minority older adults to use nursing homes, and more likely to use informal care, paid home care, rely on their families for care, or not use any long-term care services at all (Bradley, et al., 2002; 2004; Luong, 2000; Wallace, Levy-Storms, Kington, & Andersen, 1998). Wallace and colleagues (1998) contend that this could be due to discrimination which may limit individuals' access to services. Cultural beliefs and values are also thought to influence differences in long-term care use among African Americans as it is commonly believed that they have stronger family ties and strong notions of filial piety (Connell & Gibson, 1997). Others have shown that when race alone is considered, the odds of residing in a nursing home increased (Opoku, et al., 2006). However, when income and disability factors were considered, Opoku and colleagues found an insignificant effect of race on nursing home use as compared with community living.

The Medical Assistance Program

The Medical Assistance Program (Medicaid), enacted in Title XIX of the Social Security Amendments of 1965 (Public Law 89-97) is the primary source of funding for long-term care for low-income elderly and disabled persons (Stone, 2004; Takacs & McGuffey, 2002). Although its primary purpose is to provide a safety net for those who do not have access to health insurance, it has become the primary long-term care funding mechanism for middle-class individuals as well as the poor (Kaiser Family Foundation, 2006; Takacs & McGuffey, 2002). The program is a federal-state matching, means-tested entitlement program administered by the U.S. Centers for Medicare and Medicaid Services (U.S. Dept. of Health & Human Services, 2006). It provides funding for an array of institutional and community-based services. With varying restrictions, states must cover low-income families with children, individuals receiving Supplemental Social Security Income (SSI), pregnant women and children, children receiving foster care and adoption assistance, dual eligible Medicare beneficiaries, and special protected groups (Kaiser Family Foundation, 2006). Some of the mandated services under federal law include inpatient and outpatient hospital care, physicians' services, and skilled nursing home care.

The Medicaid Program is funded largely through the private sector via a purchase of service system (Takacs & McGuffey, 2002). Eligibility is dependent on an individual's assets, income, family size, and age, among other criteria, and is left to the states to decide under broad federal guidelines. Physical and medical criteria related to health status and ability to perform activities of daily living must also be

met for eligibility (Stone, 2004). Generally speaking, individuals must impoverish themselves in order to obtain Medicaid benefits. Sometimes this is done through the Medicaid spend-down provision, and sometimes it takes place through the asset transfer provision of Medicaid law. Medicaid coverage is excluded for individuals with home equity greater than \$500,000, or up \$750,000 at the option of the states (Kaiser Family Foundation, 2006).

Federal Medicaid law attempts to dissuade people from transferring assets to become eligible for Medicaid by imposing a period of exclusion from benefits via a “look-back” period of 60 months from the time of Medicaid application. If an individual has transferred assets for less than fair market value, a penalty provision is enforced by the use of a formula which divides the value of the transferred asset by the average monthly private pay cost of nursing home care. The resultant amount signifies the time period from which the individual will be excluded from receiving Medicaid services (U.S. Dept. of Health & Human Services, 2004).

According to the American Bar Association, more than 55 million Americans count on the federal-state Medicaid program for health care and long-term care services (Wood & Klem, 2007). The Medicaid Program served nearly 4 million elderly individuals in 2002, and 6.6 million individuals with disabilities (Kaiser Family Foundation, 2006). Although less than ten percent of all Medicaid beneficiaries use long-term care services, they account for about one-third of total Medicaid spending (Kaiser Family Foundation, 2006). In 2002, fifty percent of all nursing home care was funded by Medicaid, with 60 percent of all nursing home

residents using Medicaid as their primary source of payment (Kaiser Family Foundation, 2006).

Long-term care spending by Medicaid accounted for 42 percent of the \$160 billion spent on long-term care in the United States in 2004. This is expected to increase to \$237 billion by 2011 (Kaiser Family Foundation, 2006). Financing Medicaid long-term care has created enormous fiscal burdens for the states, with many wrestling with how to pay for it. In 1999, 14.6 percent of all general state funds were spent on Medicaid long-term care, creating what many contend is a huge public burden which threatens the states' abilities to provide for other needs (Karp, Sabatino & Wood, 2005; Wegner & Yuan, 2002).

The Estate Recovery Provision of the Medicaid Program

To offset Medicaid long-term care costs, the federal government enacted the Estate Recovery Program in 1993 as part of the Omnibus Reconciliation Act (U.S. Government Accountability Office, 2000). The program requires states to recover the amounts correctly paid for Medicaid services from the estates of deceased Medicaid beneficiaries. By the federal definition, "estates" include "all real and personal property and other assets included within the individual's estate as defined for purposes of individual state probate laws" (Oppenheim & Moschella, 2005, p. 11). States have the option of expanding their definition of "estate" to include property that passes outside of probate which commonly includes: life insurance payable to a named beneficiary; property that is held in joint tenancy with right of survivorship, property held in a trust, and annuities (Karp, Sabatino & Wood, 2005; Oppenheim &

Moschella, 2005). As of 2004, thirty-three states used expanded definitions of “estate” for estate recovery purposes (Karp, Sabatino & Wood, 2005). States also set minimum and maximum recovery thresholds for their estate recovery programs (Karp, Sabatino & Wood, 2005). As an example, the state of Wisconsin sets the minimum value of an estate from which it will recover Medicaid costs at \$50, and the amount below which recovery will not be attempted also at \$50, whereas the state of Alaska sets a minimum estate value threshold of \$75,000 (Karp, Sabatino & Wood, 2005).

The Estate Recovery Program mandates that states seek recovery for payments made by Medicaid for nursing home or other long-term institutional services, home and community-based services, and related hospital and prescription drug costs (U.S. Dept. of Health and Human Services, 2006). States also have the option of recovering for non-mandatory services they provide under Medicaid, and most states do so (Karp, Sabatino & Wood, 2005). Recoveries may only be made from the estates of deceased individuals who were age 55 or older when they received Medicaid services, or who, regardless of age, were permanently institutionalized (U.S. Dept. of Health & Human Services, 2006). In addition to recovery at the death of the recipient, states have the option of placing pre-death liens on homes of living individuals who are considered unlikely to return home due to permanent institutionalization. In 2004, nineteen states reported using pre-death liens for permanently institutionalized individuals (Karp, Sabatino, & Wood, 2005). States must provide notice about estate recovery to individuals at the time of Medicaid

application and at the time of specific recovery action (Karp, Sabatino & Wood, 2005).

Exemptions to estate recovery can be granted when there is a surviving spouse, when certain individuals reside in the home, and when undue hardships exists (U.S. Dept. of Health & Human Services, 2006). With certain limitations, special populations, including Native American Indians and Alaska natives, are exempt from estate recovery, although not all states include these provisions in their estate recovery programs. Recovery can also be waived when it is not cost-effective, as determined by individual states. States are required to waive estate recovery when undue hardship would result, but have considerable discretion in defining “hardship.” The federal government offers guidelines for the kind of property to be considered for hardship exceptions. These include income producing property such as family farms or businesses, or the consideration of a homestead of “modest value”. Only ten states report using a decision about “modest value” of a homestead in determinations of hardship waivers, and 33 states reported they do not use this as a factor (Karp, Sabatino & Wood, 2005). The extent to which hardship waivers are granted varies widely across the states, and most states grant waivers on a “case by case” basis. Importantly, individuals who have less resources may not have the financial capability or access to necessary legal services to challenge denial of hardship waivers which often require court action (Karp, Sabatino & Wood, 2005).

In addition to extending the look back period for asset transfers from three to five years, changes to Medicaid law resulting from the Deficit Reduction Act (DRA)

of 2005 have allowed for certain individuals with long-term care insurance to bypass estate recovery provisions up to a certain amount. The DRA also requires beneficiaries with annuities to name the state as the remainder beneficiary (Kaiser Family Foundation, 2006).

The amounts collected through estate recovery programs are low as a percentage of total state Medicaid expenditures, and costs of recovery are high. Some question whether the costs of operating estate recovery program, including the potential long-term costs of deferring individuals from seeking early care, justify the financial benefits incurred (Karp, Sabatino & Wood, 2005). In 2005, recoveries among the states amounted to \$411 million, up from \$81 million in 2003 (Klem & Wood, 2007). The average amount recovered was just over one-half of one percent (0.61%) of total state Medicaid long-term care expenditures with the high end of recovery at 2.09 percent (Klem & Wood, 2007). Average amounts collected per cases vary widely across the states from \$93 in Kentucky to \$25,139 in Hawaii as of FY 2003 (Karp, Sabatino & Wood, 2005). While the amounts collected in 2005 increased in more than half of the states, 15 states recouped less in 2005 than they did in 2003 (Klem & Wood, 2007).

States must return a portion of recovered funds to the federal government with the remainder going to state general funds or state Medicaid programs. The state of West Virginia (2006) reported that in their best financial year the federal government received 70% of their total collections, their estate recovery collection agency

received 10%, and the state received the remaining 20 percent. States which fail to implement estate recovery can be cut off from Medicaid funds.

Much like the operation of the Medicaid program, states are given considerable discretion to implement estate recovery, and have initiated state-specific legislative and regulatory efforts to recover funds. Essentially, there are 50 variations of estate recovery programs in operation, adding to the complexity of the issue. Data collected by the states in estate recovery programs is highly inconsistent, making it difficult to assess recovery practices and identify problems (Karp, Sabatino & Wood, 2005).

Criticisms and Contentions Surrounding Estate Recovery

Estate recovery is a controversial topic which is tied to issues of Medicaid eligibility, transfer of asset rules, and public versus private responsibility for care (Karp, Sabatino, & Wood, 2005). One highly contentious aspect of estate recovery relates to the asset transfer provision of Medicaid, commonly carried out through estate planning. Estate planning allows individuals to legally divert and protect their assets from recovery while ensuring Medicaid eligibility (Curry, Gruman & Robison, 2001). While the extent of this practice has not been well-documented, a recent study using data from the Health and Retirement Survey (HRS) found little evidence of asset transfer for purposes of Medicaid eligibility. Rather, findings suggest individuals sought out legal advice and estate planning in order to protect a spouse from impoverishment, for providing an inheritance, to repay one's children for their assistance, or for gathering information about long-term care decision-making related

to costs such as nursing home care (Kaiser Family Foundation, 2006). As noted earlier, recent changes reflected in the Deficit Reduction Act (DRA) of 2005 have made it more difficult for individuals to transfer assets. States can now "look back" to find transfers of assets for 60 months prior to the date the individual is institutionalized or, if later, the date he or she applies for Medicaid (Kaiser Family Foundation, 2006). If a transfer of assets for less than fair market value is found, the state must withhold payment Medicaid services (Kaiser Family Foundation, 2006). Protections for spouses of Medicaid recipients were created in 1998 when Congress enacted the Medicare Catastrophic Coverage Act which allowed a community spouse to avoid impoverishment and depletion of accumulated assets (Georgetown University, 2007).

While the extent of asset transfer for Medicaid eligibility is under-studied and largely unknown, it is clear that those who have access to information, resources, and attorneys have the option to shelter their assets via asset transfers, precluding these from consideration for Medicaid eligibility (Karp, Sabatino & Wood, 2005). Many lower income people do not have the means and resources to engage in estate planning efforts, putting them at a clear disadvantage. The recovery of estates, therefore, may fall most heavily on the poor, raising an issue of social justice (Karp, Sabatino, & Wood, 2005).

Other contentions regarding estate recovery highlight potential psychological effects of the program. Some contend that those facing the prospect of estate recovery may become depressed at the thought of losing their homes, may feel ashamed about

their inability to care for themselves, and may feel embarrassed about “ending up” on public assistance (U.S. Congressional Record, 2001). A critical concern is that individuals will forego needed care in order to avoid losing their homes (U.S. Congressional Record, 2001; State of Pennsylvania, 2002). A study completed by the state of Pennsylvania found that 54 percent of 73 interviewees declined Medicaid services because of estate recovery (State of Pennsylvania, 2002). Pre-death liens placed on homes while the Medicaid recipient is institutionalized have also been criticized as they may deprive a surviving spouse from receiving credit or loans (Citizens for Better Care, 2004). Still others contend that the program creates a loan that must be repaid, unlike Medicare beneficiaries who are not subject to recovery for benefits they received (State of West Virginia, 2002). Others have raised a similar concern, contending that estate recovery programs should provide consumer protections, since it is essentially a “loan” program (Karp, Sabatino & Wood, 2005). Some further suggest that estate recovery creates “increased distrust in government, and citizens (sic) wonder why it is spending money to take their homes instead of funding a decent long term care system” (Citizens for Better Care, 2004, p. 1).

Some regard the Medicaid Estate Recovery Program as ageist and discriminatory based on recovery from individuals aged 55 and older. Furthermore, since the state cannot pursue recovery when there is a surviving spouse, estate recovery may end up affecting older women more severely since they generally outlive their male partners (Takacs & McGuffey, 2002; State of West Virginia, 2006). Finally, the State of West Virginia (2006) asserts that estate recovery is

discriminatory against homeowners, and notes that the program may also reduce incentives to pay property taxes or maintain homes, thereby reducing property values.

Attempts have been made to eliminate estate recovery, referred to by U.S. Senator Russell Feingold as a “death tax on the elderly,” but have failed, albeit by a narrow margin (U.S. Congressional Record, 2001). In 2001, the Attorney General in the state of West Virginia sued the Department of Health and Human Services, challenging the constitutionality of estate recovery. The suit alleged violation of the states’ 10th amendment rights to undue coercion by the federal government (U.S. Court of Appeals, 2001). Describing estate recovery as “bad public policy”, the state expressed that the program constituted a “betrayal of the New Deal” in that “the federal government promised it would take care of its citizens, yet never suggested that the elderly and destitute would later be required to forfeit their homes for which they had worked so diligently” (U.S. Court of Appeals, 2001, p. 11). West Virginia argued that if they withdrew from estate recovery, their state health care system would collapse because they could not replace the lost funding. Therefore, they felt they had no choice but to comply. They therefore argued that they were unduly coerced into implementation. The Court in this case held: “As a general rule, Congress could use its broad powers under the Spending Clause to induce states to behave in a certain way by offering federal funds to states that agree to certain congressionally imposed conditions, and the states can ultimately decide whether or not they will comply” (U.S. Court of Appeals, 2001, p. 6). In the end, the Court issued a judgment in favor of the Department of Health and Human Services, and the

State of West Virginia subsequently was forced to implement an estate recovery program or risk losing Medicaid funding. Interestingly, the State Attorney General's Office now posts tips on its website on how residents can avoid estate recovery and urges citizens to contact their members of Congress which they have listed on their website. In 2007, the state of Michigan also lost its attempt to forego implementation of estate recovery, and became the last state to initiate an estate recovery program. Interestingly, the state failed in its attempt to convince legislators that a \$5 yearly charge against mortgage holders would be a successful way to eliminate estate recovery. Fearing cut-off from federal Medicaid funds, they were forced to comply (Klem & Wood, 2007).

Estate Recovery and "The American Dream"

Considering that a primary means of holding wealth in the United States is through homeownership (Shapiro, 2004), and that home equity is the primary recoverable asset under estate recovery (Karp, Sabatino & Wood, 2005), one might readily ascertain a cause for concern. How do families affected by estate recovery pass wealth on to the next generation? Does estate recovery fall more heavily on low income people and deny them opportunities for intergenerational wealth transfer? Are African Americans more severely affected by estate recovery policy given historical disadvantages and present disparities in wealth accumulation, especially home equity (Oliver & Shapiro, 2006; Shapiro, 2004)? Does estate recovery serve as a barrier to receiving needed long-term care services? Is estate recovery an equitable social policy? What do individuals contemplating the need for assistance in paying for long-

term care think and feel about estate recovery provisions? These questions set the stage in this study for thinking about the issue of estate recovery policy as a social justice issue, and provide a rich context in which to support the primary research questions posed in this study. It should be noted that throughout this discussion, social justice is defined in accordance with Barker's (1999) definition in *The Social Work Dictionary* as: "an ideal condition in which all members of a society have the same basic rights, protection, opportunities, obligations, and social benefits" (p. 451). This definition is well-suited to the primary purpose of this study and the research questions it seeks to address.

Theoretical Frameworks

This study draws upon two primary theoretical frameworks which provide the substantive and intellectual underpinnings for this study. These are: social constructionism and asset theory. While social constructionist theory provides an overarching perspective in the post-positivist realm that helps us understand meanings people hold about the topics discussed, asset theory provides a "mid-level" framework that holds explicit propositions regarding the effects of tangible assets on social and economic well-being.

I used a social constructionist orientation primarily in the development and implementation of the research methodology. Asset theory, on the other hand, provided guidance to inform the development of the focus group questions and topics. Both of these views are important but do not stand alone. A social constructionist view, important in an exploratory study like this, compliments and is supported by

asset theory and can help us to understand why the issue of estate recovery might be unjust, and in need of further explanation. Asset theory, on the other hand, provides substantive content which poses that intergenerational wealth transfer makes a difference in well being. It would be remiss to ignore asset theory, which speaks directly to issues of social and economic justice.

Social Constructionism

Social constructionist insights provide an overarching, conceptual framework in which to understand the perspectives of older adult homeowners regarding estate recovery and long-term care. Proposed by Berger and Luckman (1967) in their seminal work, *The Social Construction of Reality: A Treatise in the Sociology of Knowledge*, the theory asserts that one's "reality" is shaped through the interaction of self and society. The theory holds that the meanings people ascribe to their experiences are situated in the context of, and are shaped by, socio-cultural, political and historical processes, with language serving as the primary vehicle through which understanding takes place (Berger & Luckman, 1967; Gergen, 1999).

In opposition to the scientific paradigm which contends that "reality" can be objectively known through unbiased observations of the world, and that there is an ultimate "truth" that can be observed and known, social constructionist theory proposes that there are multiple constructions of reality which are bound by time and context, and that these develop through interactions with one's community, culture, and society (Burr, 1995; Gergen, 1999). In other words, in constructionist thought, reality does not exist outside of the interplay of a myriad of complexities in people's

lives, and one's conception of reality is shaped by one's experiences within a particular time and setting. Rather than seeking universal truths, social constructionist theory emphasizes individual differences and experiences. Attention to the details of individual meaning can help reduce misunderstandings and reduce stereotypes (Blundo & Greene, 1999).

The theory also posits that social constructions are institutionalized through societal institutions and policies which may hold severe consequences for individuals such as poverty, oppression or discrimination (Maines, 2000). Social constructionism is similar to the ecological perspective commonly used in social work practice which recognizes the reciprocal nature of relationships and transactions between the individual and the social environment (Germain & Gitterman, 1996).

We can best understand the range of meanings held by the participants in this study by examining their experiences in the context of their lives, and by interpreting the meanings they give to those experiences. This study seeks to understand the meaning that older adult homeowners' ascribe to various aspects of homeownership, long-term care and the estate recovery program. Enhanced understanding can shed important light on the development of client-centered programs and policies that meet clients' needs and build upon their strengths (Chapin, 2008).

Asset Theory

Asset theory, proposed by Sherraden (1991), is central to the discussion of homeownership and estate recovery. Asset theory proposes that savings, accumulation of assets, and investments are a way to address poverty, as opposed to

the more traditional means of addressing poverty through income, spending, and consumption. Sherraden (1991) contends that in order for those who are poor to escape poverty, opportunities for wealth accumulation must be present, noting that the poor have been historically left out of the mainstream public policy structures within which asset accumulation is possible. This has been particularly true for African American individuals throughout American history.

Asset theory, according to Sherraden (1991), goes beyond traditional theories of poverty and social class which essentially point to individual-level or structural causes for poverty. Whereas individual-level theories suggest that poverty is related to an individual's undesirable behaviors such as an inability to delay gratification, structural theories point to individual behaviors as adaptations to poverty, and maintain that the social structure treats poor people in an unfair manner.

Sherraden (1991) argues that household income and consumption are not adequate definitions of welfare because they fail to consider the long-term and dynamic nature of household wealth as opposed to measuring goods and services consumed. Rather than supplying short term income transfers to the poor, which will be consumed or spent, government policy should address structures that promote lifetime asset accumulation (Sherraden, 1991).

Asset accumulation is likely to result in social, psychological and economic effects (Sherraden, 1991). Sherraden discusses the benefits and effects of asset accumulation:

Simply put, people think and behave differently when they are accumulating assets, and the world responds to them differently as

well. More specifically, assets improve economic stability; connect people with a viable, hopeful future; stimulate the development of human and other capital; enable people to focus and specialize; provide a foundation for risk taking; yield personal, social and political dividends; and enhance the welfare of offspring. (p. 148)

Asset theory provides an important fit with the research questions posed in this study which seeks to elicit older adult homeowners' perspectives on estate recovery. As noted earlier, multiple empirical studies provide evidence of the benefits of homeownership which include enhanced social, economic, psychological and personal well-being. Findings from the scholarly literature regarding the benefits of homeownership support the effects of asset accumulation proposed by Sherraden (1991). To the extent that estate recovery may compromise these benefits raises cause for concern, especially for African American individuals, who historically have been denied access to opportunities for homeownership. Shapiro and Wolff (2001) suggest that, "The acquisition, growth and maintenance of wealth occurs within contexts structured by history, state policy, the confluence of public and private institutional contexts, and family financial conditions", p. 14.

Summary

This chapter has explored the importance of wealth attained through homeownership, and how opportunities for intergenerational wealth transfer may be compromised for older adults, and especially African American elders, due to the Medicaid Estate Recovery Program. Future trends in long-term care service use by various older adult population groups have been presented, and various aspects of the Medicaid Program, estate recovery, and homeownership have been explored. The

importance of this issue for future research, social policy, and social work practice has been discussed. Social constructionist theory and asset theory have been presented as overarching conceptual and intellectual frameworks in which to better understand this topic.

CHAPTER TWO

LITERATURE REVIEW

The Meaning of Home, Legacy and Generativity

Several key constructs in the scholarly literature provide the underpinnings for analysis of the Estate Recovery Program and how it may affect people's lives. The meaning of home, leaving one's legacy, and the notion of generativity can be thought of as inter-related and overlapping constructs that together represent security and well-being. Each of these concepts is discussed in the literature from multi-disciplinary perspectives, and, taken as a whole, are commonly viewed as important constituents of older adult well-being. Estate recovery may serve to threaten these dimensions of security both in a subjective and objective sense. Therefore, the "meaning of home", the concept of legacy, and the human need for generativity constitute critical concepts for further examination.

The Meaning of Home

Much has been written in the scholarly literature on the meaning of home. The fields of psychology, gerontology, education, medicine, and social work have explored the concept of home, and it is clear that "home" has emerged as a multi-dimensional construct (Mallet, 2004). Numerous studies have examined older adults' perceptions of home. In a qualitative study of elderly women, Swenson (1998) found that "home" had multiple meanings. It variously meant physical buildings, memories of people and events, ownership and responsibility, and personal identity. Home is commonly presented as an expression of identity and sense of self (Mallet, 2004), as a

“symbol of the self, a symbol of aspirations, and a symbol of status” (Swenson, 1998, p. 391). A study by Borglin, Edberg and Hallberg (2005) which examined quality of life among older people, found that home was portrayed as place where a person can feel safe and secure. Home has been referred to as “a space, a place, a feeling, a practice, or an active state of being in the world” (Mallet, 2004, p. 62). The following excerpt captures multiple meanings of home (Relph, 1976):

Home is the foundation of our identity as individuals and as members of a community, the dwelling-place of being. Home is not just the house you happen to live in, it is not something that can be anywhere, that can be exchanged, but an irreplaceable center of significance. (p. 39)

Clearly, the concept of “home” has multiple meanings and represents many aspects of well-being.

In a study which identified subjective values related to the meaning of home for older adult homeowners, factor analysis of survey data revealed that home was viewed as a part of a “family tradition” (O’Bryant, 1983, p. 38), wherein the home would remain in the family after death. Homeownership was also viewed in O’Bryant’s (1983) study as providing “status value” which was represented by freedom from landlord-tenant relationships, having more responsibility as property tax payers, and psychological effects of increased self-esteem. Rutman and Freedman (1987) found the concept of home defined in terms of influence over one’s environment: “Home is the place or space in which personal control can be exerted

most fully” (p. 29). In interviews with older people, they found the concept of home to mean, “comfort, familiarity, security and independence” (p. 24). Participants in their study also described “home” as a place of attachment and ownership, a place of accomplishment, and a place that made them feel good about themselves. In a study concerned with people’s feelings about their homes, Rakoff (1977) found that having “control over one’s own private space gave people a feeling of freedom from the control and intrusion of others . . . to achieve a kind of self-fulfillment” (p. 102).

While the majority of the literature on the meaning of home speaks of “home” in a positive and beneficial light, some scholars note it is not positive for everyone. Mallet’s (2004) review of the literature on the meaning of home found that it may be associated with feelings of oppression and disempowerment. Her review presents criticisms of idealized notions of home, noting that “home”, for many, may represent insecurity, fear and isolation (Mallet, 2004). Wardaugh (1999) notes that for a significant number of women, children, and young people home is not a safe and secure place due to violence and sexual abuse in the home. He also suggests that “those who are abused and violated within the family are likely to feel “homeless at home” (p. 96).

Despite negative associations with the concept of home as noted by Mallet (2004) themes of identity, independence, personal control, and security are predominant in the literature. These themes also speak to the multiple ways people develop forms of attachment to their homes. Rubinstein and Parmalee (1992) propose that attachment to a place, such as home, is connected to older adult developmental

tasks including the maintenance of identity and continuity in the face of uncertainty in old age, and the protection of self against deleterious adjustments of later life.

Milligan (1998) suggests that place attachment occurs within environments where meaningful interaction takes place, and that it is an “emotional link formed by an individual to a physical site that has been given meaning through interaction” (p. 2). She offers an interactionist theory of place attachment composed of two inter-related components, the interactional past, or one’s memories, and the interactional potential, or one’s anticipated or imagined future experiences of a site, such as a person’s home.

Rowles (1983), who extensively studied place attachment with older people, describes three dimensions of place attachment in old age: “physical insideness”, referring to familiarity due to lifetime residence in one’s home which helps to compensate for physical limitations in old age; “social insideness”, referring to establishing one’s place in a community over an extended period of time, and “psychological or autobiographical insideness”, referring to a “temporal depth of meaning” (Rowles, 1983, p. 303). Support of these dimensions is furthered by James Hillman (1992) who suggests that, “the identity of individuals is bound in the places and spaces where they live, and the self is an interiorization of the community (in Saleebey, 2004, p. 5). “For some,” Saleebey says, “this place is home” (2004, p. 5). Saleebey proposes that thinking about the “small environments where people play out most of their lives” (p. 32) might help to develop alternative approaches to human problems (2004). Saleebey (2004) largely contends that inasmuch as places, spaces,

and objects serve as repositories of memories and identity determinants, they should not be ignored.

Legacy and Generativity

The concepts of legacy and generativity are closely intertwined and the terms are often used interchangeably in the literature. Legacy has been described in terms of the transmission of cultural norms, family traditions, experiences and recollections, wisdom, or values (Frolík, 1996; Kane, 1996). It has been interpreted as a way of dealing with one's mortality, and a way to be remembered (Kane, 1996). Legacies are often viewed as being an extension of the self and are closely aligned with identity (Frolík, 1996; Kane, 1996).

According to Kivnick (1996), the theoretical framework of Erik Erikson is central to what she calls "psychosocial legacy" (p. 1). Generativity versus self-absorption, the seventh of Erikson's eight life cycle tasks, is generally associated with the adult's concern for the next generation (McAdams, Hart & Maruna, 1998). In contrast to Erikson's individually-focused model of generativity, McAdams and colleagues (1998) propose that generativity should focus on the various contexts through which it connects the individual to the social world. They contend that individual motivations for generativity lie in people's inner desires to seek symbolic immortality, and in a desire to be needed. They also suggest that cultural demands, as reflected in social norms, require that adults take responsibility for the next generation. The construct of generativity, according to McAdams and de St. Aubin, involves "creating, maintaining, and offering" (1998, p. 25).

Kotre and Kotre (1998) contend that generativity acts as an “intergenerational buffer” against passing on harmful, or destructive legacies. In accordance with this contention, when an individual has been the recipient of a harmful legacy from the previous generation, such as alcoholism, or domestic violence, the individual makes every attempt to assure that they do not pass that legacy onto the next generation. According to Kotre and Kotre (1998), buffering protects future generations.

What might further explain individuals’ needs to leave a legacy? Social exchange theory may help to account for some individual motivations. Whether legacy takes the form of leaving assets for one’s spouse, gifts to charity, or making exchanges for care by one’s children (Frolik, 1996), social exchange theory offers a useful frame of reference. Social exchange theory is built on the notion of reciprocity and negotiated exchange using comparisons of alternatives and cost-benefit analysis (Blau, 1964; Gouldner, 1960). For example, a child may exchange care giving of an aging parent, knowing that inheritance from the parent will compensate them in the future. Ultimately, the child and parent are trading resources, a basic tenet of exchange theory. This exchange would benefit the aging individual who wishes to avoid costly nursing home, and ultimately benefit the child financially. According to this theory, mutual agreement and equity of exchange are the desirable goals (Blau, 1965; Gouldner, 1960). However, in the example provided, this may not always be the case as children or aging parents may feel coerced or obligated to participate. Aging individuals who can’t reciprocate for the care provided by their children (due

to not having assets to bequeath, for example) may be at risk of neglect (Gouldner, 1960).

From a legal perspective, legacy refers to property that is passed on through a will. It is often used interchangeably with the word “bequest”. By law, individuals in all fifty states who are of majority age have a right to make a legal testament, or to will, how their property will be distributed upon their death (Frolik, 1996). In other words, in a legal sense, legacy is a way for one generation to pass possessions and assets on to the next generation. According to Moody (1994) leaving one’s legacy through inheritance satisfies human needs for personal power, self-protection, maintaining a moral order, and the need to live beyond one’s death. Leaving one’s legacy in the form of inheritance such as one’s home, property, or other wealth, is often associated with a sense of personal empowerment, the ability to exert influence, and maintaining control in older age (Kane, 1996; Moody, 1994). Kane (1996) says that for the recipients of a legacy, it can be thought of as, “literally, the last word” (p.1).

Benefits of Homeownership

Numerous studies since the 1980s have used family wealth and asset accumulation as indicators of well-being, broadening the predominant focus in the scholarly literature on income as a measure of economic well-being (Shapiro, 2001; Sherraden, 2005). Sherraden’s (2005) work on asset building and social policy has been highly influential in developing new ideas about poverty, economic well-being, and assets such as homeownership. Social work scholars from the University of

Kansas have been instrumental in several research efforts which have examined various aspects of asset accumulation, wealth and well-being. These include asset-based poverty initiatives through the national SEED (Savings for Education, Entrepreneurship and Downpayment) program, and research on the effects of homeownership on youth well-being (Scanlon & Page-Adams, 2000). Page-Adams and Scanlon (2001) review several studies on the relationship between homeownership and various aspects of well-being, noting some evidence of association with: economic security, family health, children's well-being, marital stability, social and civic participation, property value effects, property maintenance, and residential mobility.

Given the attention to intergenerational transfer of wealth via homeownership, studies that focus on family and older adults are important. In this section, findings from studies on the economic benefits of homeownership as one form of wealth for families and older adults are presented. Also presented are some studies that focus on the social and health benefits of homeownership for families, and studies which specifically examine benefits of homeownership for older people.

Economic Benefits

The economic benefits of homeownership are well-documented. One major economic benefit of homeownership is home equity, the primary source of household wealth for most families (Shapiro, 2004). Oliver and Shapiro's (2006) longitudinal study on household wealth conducted from 1984 to 1995 with 11,257 households, found that home equity accounted for 62.5% of African American household wealth,

and 43.3% of White household wealth. In a study conducted by Rossi and Weber (1996) using data from the General Social Survey and the National Survey of Families and Households, it was found that while homeowners had more credit card and personal loan debt than renters, they also had about \$11,000 more in financial assets. A study by Page-Adams and Vosler (1996) of 193 laid off auto workers found that, after controlling for education and income, homeownership was associated with less perceived economic strain. In a secondary analysis of data from a study conducted by the U.S. General Accountability Office of 17,656 bankruptcy cases, Domowitz and Sartain (1999) found, after controlling for various other social and economic factors, individuals who did not own homes were seven times more likely to file for bankruptcy than homeowners. Further findings from their analysis showed that non-homeowners were twice as likely to file for bankruptcy as the general population (Domowitz & Sartain, 1999).

Social Benefits

Homeownership has also been found to confer social benefits. In a study which examined the effects of homeownership on the length of employment, Goss and Phillips (1997) found that owning one's home reduced the duration of unemployment, after controlling for education, race, occupation, gender, home equity, and other social and economic variables. Homeownership was found to be associated with increased high school graduation and college entry rates for African American youths in a study which examined the role of family background, college costs, and local economic conditions on college entry (Kane, 1994). Boehm and

Schlottmann (1999) found that children of homeowners were more likely to achieve higher levels of education, and that parental housing tenure significantly influenced whether or not children would become homeowners. In a study conducted by Green and White (1997), children of homeowners were less likely than renters to have children before the age of 18, or to drop out of school. Page-Adams (1995), who examined domestic violence data from 2,827 married women and their husbands, found that homeownership showed a significant negative effect on marital conflict and domestic violence when controlling for income and women's independent economic resources. In a study that compared low-income home buyers with low-income renters, homeownership was associated with a positive and significant impact on life satisfaction (Rohe & Basolo, 1997).

Several studies have found homeownership to be associated with residential mobility and tenure. Butler and Kaiser (1971) studied residential preferences of 1,476 households and found that homeownership reduced residential mobility. Rohe and Stewart (1996) who reviewed studies of residential mobility also found that homeowners were less likely to move than renters. Significant differences have also been found in neighborhood, civic, and voluntary organization participation by homeowners. Steinberger (1981) and Blum and Kingston (1984) found that homeowners were more likely to participate in voluntary organizations. Homeowners also have also been found to have larger personal and social networks than individuals who live in apartments (Blum & Kingston, 1984; Fischer, 1982).

Health Benefits

The scholarly literature presents many studies on the health benefits of homeownership. In an analysis of health behaviors, homeownership was significantly associated with not smoking (Kendig, Browning, & Teshuva, 1998). Using several measures of socioeconomic status, Baker and Taylor (1997) found using several measures of socioeconomic status, that homeownership was most consistently related to health among mothers of infants in England. In a longitudinal study of 13,391 men and women in the Netherlands which examined the relationship between various socioeconomic measures and health, homeownership was found to be positively related to fewer chronic health conditions and better perceived health, when compared with educational and occupational measures (Stronks, van de Mheen, van den Bos, & Mackenbach, 1997).

Benefits for Older Adults

Turning to studies on older adults, many positive effects of homeownership on economic, social and health factors are evident. A recent study of 6,183 older adults age 65 and older by Opoku and colleagues (2006) using data from the longitudinal National Long Term Care Survey, found that those who did not own their own homes were 18.25 times as likely to be institutionalized as those who were homeowners. Robert and House (1996) found that, after controlling for income, education and liquid assets, homeownership, had a positive effect on functional health, particularly for those ages 75 to 84. A study by Mirowsky and Ross (1999) found that older adult homeowners were less likely to report economic hardship than older renters after

controlling for marriage, medical insurance, education, household size, retirement, lifestyle and health. Studies of residential mobility showed that older adult homeownership was tied to increased residential tenure (Butler & Kaiser, 1997). A study of intergenerational family decision making in Singapore and Taiwan found that older adults who were homeowners participated more in family decision making than those who were not homeowners (Williams, Mehta, & Lin, 1998). In a study of frail elderly individuals, Greene and Ondrich (1990) found that, after controlling for income and education, homeownership was negatively associated with nursing home admission and positively associated with successful transition from nursing homes back to community settings.

Homeownership and Inheritance

In 2002, rates of homeownership in the United States reached an historic high of 69 percent (Shapiro, 2004). Recent U.S. Census Bureau (2005) figures show homeownership rates of 80 percent for people age 65 and over. Shapiro (2004) notes:

Homeownership constitutes the single most important way the typical American family accumulates assets. It also provides access to the nicest communities, the best public services, and quality education.
(p.3)

Incentives for homeownership in America are strong. Since the 1930s, the federal government has actively worked to promote homeownership through the Federal Housing Administration (FHA), the Federal Home Loan Bank system, the Federal National Mortgage Association (FNMA), and other programs (Brown, Kuttner & Shapiro, 2005). The federal home mortgage tax deduction encourages homeownership through the tax system and remains the largest incentive, with tax

subsidies more than twice the amount spent on other housing programs (Brown, Kuttner, & Shapiro, 2005). However, many scholars point to the inadequacies of policies in helping poor and minority individuals achieve wealth through homeownership (Leondar-Wright, Lui, Mota, Muhammad, & Voukydis, 2005; Oliver & Shapiro, 2006; Shapiro, 2004; Shapiro & Wolff, 2001). Moreover, the recent crisis in the mortgage lending industry has highlighted the deleterious effects of subprime mortgages targeted to minority individuals (Swarns, 2008).

Despite gains in homeownership rates, remarkable disparities exist between African Americans and Whites in rates of homeownership and home equity. In 2002, 75% of Whites were homeowners, whereas only 50% of African Americans attained homeownership. Home equity accounts for nearly 60% of total wealth for the middle class, and constitutes the majority of net worth for most families. However, median home equity amounts in 2002 were approximately \$58,000 for Whites and \$40,000 for African Americans (Shapiro, 2004). Using data from the Panel Study of Income Dynamics, Boehm & Schlottmann (2004) found that minority and lower income homeowners gained access to homeownership more slowly than their White counterparts, that they were less likely to maintain their status as homeowners, and less likely to upgrade their homes over time.

Until recently, the appreciation of home values across the U.S. has resulted in significant increases in home equity values, yet homes in African American neighborhoods have appreciated significantly less than those in predominantly White neighborhoods (Shapiro & Wolff, 2001). Shapiro (2004) contends that “the

homeownership process is fraught with discrimination and major consequences for wealth accumulation” (p. 108). He notes that African Americans have differential access to credit, pay higher credit rates for mortgages, and experience what he calls “a segregation tax” (2004, p. 121) due to residential segregation by race. In 2001, according to a Brookings Institute study, home values for African Americans were 18 percent less than home values for White homeowners (Shapiro, 2004). The study also found that the higher the rate of residential segregation, the greater the gap in home values. Shapiro (2004) contends that home equity is “color coded” (p. 121), and that residential segregation substantially benefits Whites through greater home equity accumulation.

When considering the value of the home for future generations, it is important to recognize the role of family inheritance. According to Shapiro (2004), “Family inheritances, especially financial resources, are the primary means of passing class and race advantages and disadvantages from one generation to the other” (p. 61). In his examination of inheritance patterns over a 15 year period, he notes that only 7.7% of African American families received inheritances compared to 28% of White families, nearly a four-fold difference (Shapiro, 2004). As well, median inheritance figures were \$10,000 for White families, and only \$798 for African American families. “For those fortunate enough to receive bequests”, Shapiro (2004) says, “Blacks received eight cents of inheritance for every dollar inherited by Whites” (p. 69).

Despite the solid support in the empirical literature for the benefits of homeownership, on the inequity in opportunities for wealth accumulation between African Americans and Whites, and on criticisms of the Medicaid Estate Recovery program, research is lacking on how African American and White older adult homeowners view the use of Medicaid for long-term care when estate recovery is a factor. This study attempts to shed light on this issue through a qualitative study of older homeowners' perceptions of these issues.

Summary

This chapter has provided a review of the empirical and scholarly literature on various aspects of the Estate Recovery Program, the meaning of home, the importance of legacy and generativity for older adults, and a discussion of the social, economic, and health-related benefits of homeownership to individuals and families as well as older adults. This chapter concluded with a discussion of the literature on homeownership and inheritance with a special emphasis on the racial wealth gap and minority elders.

CHAPTER THREE

METHODOLOGY

Chapters 1 and 2 introduced the nature of the problem under study, reviewed the relevant empirical and theoretical literature, and identified the study's primary research questions. This chapter will present the research design and rationale, phases of the inquiry, data collection and analysis procedures, and components of methodological rigor.

Research Design and Rationale

This study is an exploratory, qualitative study that uses focus group methods to explore the perspectives of a diverse group of older adult homeowners on the estate recovery provisions of Medicaid. While quantitative studies in the social sciences seek to test hypotheses, predict outcomes or explain relationships between variables in ways that allow findings to be generalized beyond study participants (Patton, 2002), the goal of qualitative research is to gain a deep and rich understanding of the views of participants about a social phenomenon of interest (Padgett, 1998).

Qualitative research is well-suited to exploratory research (Morgan, 1997; Patton, 2002) of this kind, and for a number of reasons qualitative methods provide the best “fit” among the various qualitative methods with the questions that guide this inquiry.

First, questions regarding “how” people think and feel about long-term care through Medicaid, given the estate recovery policy, require qualitative methods to capture the depth and complexity of perspectives on this complicated issue. Merriam (1998) contends that qualitative research should “seek to discover and understand a

phenomenon, a process, or the perspectives and world views of the people involved” (p. 11), and the use of qualitative methods for answering “how” questions, for exploring a topic, and for obtaining a detailed view of the research topic has been supported by a number of scholars in the social sciences (Creswell, 1998; Padgett, 1998; Patton, 2002). Qualitative methods provided a good match with the questions that guided this study because they acknowledge multiple, socially-constructed realities that are best understood from the viewpoint of participants (Denzin & Lincoln, 2000; Lincoln & Guba, 1985). The literature also supports focus groups as a valuable qualitative method for studying issues that affect socially marginalized groups (Kitzinger, 1994; Madriz, 1998).

Among the qualitative methods, focus group research is especially well-suited to this study which is designed to explore how people discuss long-term care services through Medicaid when they have an opportunity to learn and talk about estate recovery with a group of peers. Focus groups tend to expand rather than limit the range and scope of topics that emerge in discussions with participants (Patton, 2002). To capture the dynamic give-and-take in the evolution of perspectives that occurs when people talk with others who are like themselves and, potentially facing similar life events in the future, requires a methodology such as focus group research that allows us to record the full discussion, noting how people’s perspectives are shaped by both new information and a peer group discussion of that new information. For many participants, this study offered a first opportunity for exploration of long-term

care, Medicaid and estate recovery, and how participants' impressions were developed and shaped by group members and knowledge gained along the way.

A third reason for choosing qualitative methods for this inquiry is that it is the first study of its kind. Yegidis and Weinbach (2006) note that “exploratory research designs tend to be the first kind of research conducted on a problem or question” (p. 114). To my knowledge, no studies have specifically examined the role of Medicaid estate recovery on the perspectives of a diverse group of older adult homeowners who are reaching the age at which decisions may need to be considered about the use of Medicaid to cover long-term care services. This study seeks to add to the existing knowledge base, and to build a foundation for future studies.

Focus group research as a qualitative method also “fits” this inquiry because it explicitly recognizes the role of the researcher as the primary instrument for data collection (Lincoln & Guba, 1985; Creswell, 1998). The skill level of the facilitator/moderator in engaging participants, especially important in focus group interviews (Morgan, 1997), fits the premise that participants and researchers mutually interact and affect each other in the inquiry process (Lincoln & Guba, 1985). This qualitative study also assumes that knowledge “evolves, emerges, and is inextricably tied to the context in which it is studied” (Creswell, 1998, p. 19; Lincoln & Guba, 1985). Lincoln and Guba (1985) contend that context is critical to the meaning that is generated, and to the understanding of the phenomenon under study. Dahlgren (1998) reinforces this view noting that, “all talk through which people generate meaning is contextual, and that the contexts will inevitably colour the meaning” (p. 292).

Qualitative research also recognizes that inquiry is not value-free, and that the researcher must be aware of how his or her values influence the entire research process including the identification and framing of the problem, selecting a theory, and throughout the data collection and analysis (Rodwell, 1987). My personal and professional values about social justice have clearly influenced my decision to research the topic of Medicaid estate recovery. Therefore, throughout the study I have been cognizant of the potential for my values to unduly influence participants and have made every attempt to prevent my beliefs and values from getting in the way of participants telling their stories and expressing their views.

Finally, the sensitive nature of topic of interest under study demands qualitative methods to help people feel more comfortable discussing their perspectives as they develop rapport with a group of peers. The Medicaid Estate Recovery Program is a controversial topic (Karp, Sabatino & Wood, 2005; Takacs & McGuffey, 2002). A qualitative approach is often used to explore topics that are of a sensitive nature and involve human emotions (Cobb and Forbes, 2002). Individual sentiments tied to the “meaning of home” and leaving one’s legacy combined with the potential fear of losing one’s home or assets, provide further examples of the sensitive aspects of this topic, pointing to a qualitative approach as a good fit for this study.

Research Questions

The primary research questions explored in this study are:

- 1) When given an opportunity to learn about and discuss estate recovery, how do older adult homeowners describe their perspectives on using Medicaid for long-term care?
- 2) How do the perspectives of older adult homeowners on the use of long-term care through Medicaid evolve when they have a chance to learn about and discuss estate recovery with one another?
- 3) How do themes that emerge from group discussions among older adults regarding Medicaid estate recovery provisions differ by race, if at all?

Key Concepts

Key concepts in this study include: “the meaning of home”, the concepts of legacy and inheritance, long-term care, older adult, and race.

The “meaning of home” is subjective and varied. One size does not fit all, and there are multiple meanings ascribed to “home”. Themes emerging from the research literature primarily associate the “meaning of home” with subjective dimensions of well-being, usually of a positive nature, such as safety, security, comfort, and independence. For purposes of this study, the concept will be defined broadly as a “subjective dimension of well-being which represents aspects of psychological health” (Diener, 2000).

The concept of legacy also has multiple meanings, both of a subjective and objective nature. In legal terms it refers to the actual transmitting of one’s property or possessions in the form of a will. It is also referred to as the transmission of values, traditions, wisdom, and beliefs, and, as a way to live beyond oneself (Frolik, 1996; Kotre, 1984). In this study, legacy is defined as a “subjective or an objective concept

which denotes something of monetary or non-monetary value that is transmitted to the next generation.”

“Inheritance” is usually thought of as a bequest received due to a death, most commonly that of a parent (Shapiro, 2004). Since the Estate Recovery Program collects from the estates of individuals upon their deaths, the term “inheritance” will be defined in this study as “wealth received through a bequest upon the death of the Medicaid recipient.”

“Older adult” is defined in this study as individuals age 55 and older. This age is selected because it is a time when many people may be thinking about retirement, may be caring for aging parents, or may be thinking about their future needs as they grow older (Ekerdt, 2000). It is also consistent with the age at which Medicaid estate recovery is implemented for community-dwelling older adults who use Medicaid long-term care services (U.S. Dept. of Health & Human Services, 2006).

“Race” is defined by participant self-identification and includes the categories of White and African American for the purposes of this study.

Phases of the Study

This study was conducted over a period of one year and seven months. Phase One (Research Design) consisted of a review of the research design elements including sampling and recruitment strategies, contacting sites for recruitment and hosting of the study, hiring and training the study’s research assistant/co-facilitator, submitting human subjects protocols, and completing the necessary paper work to ensure payment of participants and the research assistant. The study’s methodologist

played a key role in guiding the development of this phase of the inquiry which took place over a three month period of time (March to May, 2007).

Phase Two (Data Collection) of the study took place over a four month period (June through September, 2007). Eight focus groups consisting of 51 individuals were conducted at two research sites. Transcription of the recorded sessions was also completed in Phase Two and preliminary analysis was begun.

The final phase of the study, Phase Three (Data Analysis) was conducted over an eight month time period (October, 2007 through May, 2008) and included reading the transcripts of the focus group data; importing documents into ATLAS.ti software; developing coding categories and themes; identifying preliminary themes and patterns, and review and cross-coding of the transcripts by an outside consultant. Phase Three also included composing a summary of the study's preliminary findings which were discussed with participants at a follow-up member check meeting held at each of the two research sites. Regular consultation was held with the study's methodologist throughout all phases of the study.

Protection of Human Subjects

The study protocol was approved by the University of Kansas Medical Center Human Subjects Committee (see Appendix A) and written consent to participate was obtained by all participants. Every effort was made to ensure the protection of human subjects throughout all phases of the research process. Prior to the implementation of the focus groups, participants were informed about the purposes of the study, the potential risks and benefits, voluntary participation, and the right to withdraw from

the study without penalty at any time. Participants were also provided with the contact names and phone numbers of the University of Kansas Medical Center Human Subjects Committee and the principal investigator of the study which were included in the participant consent form (see Appendix B).

Study participants were also made aware that their involvement in the study would in no way affect their relationship with, and services received by, the hosting sites. Participants were also informed that study reports and documents would not contain information that would identify them in any way. Participants at both research sites were informed that in addition to the focus group meeting, that they would be asked to attend a follow-up meeting at a later date to discuss the findings and verify their accuracy.

Due to the nature of focus group settings, confidentiality cannot be absolutely safeguarded (Morgan, 1997). Participants were briefed prior to their participation that information obtained within the groups should be kept confidential with respect to group participants. Finally, participants were informed that all written correspondence such as field notes, logs, transcribed interviews and digital recordings resulting from the study would be stored in a locked file cabinet accessible only to the primary researcher for a period of six years, consistent with Human Subjects Committee guidelines. Participants were provided a copy of the signed consent document for their records. The approved consent form is enclosed in Appendix B. Participants were provided at \$20 token of appreciation for their participation in the study and a cash donation was made to each of the study sites for the use of their facility.

Data Collection

The primary source of data collected in this study was derived from focus group conversations with 51 individuals who participated in eight focus groups conducted at two research sites located within a large Midwestern metropolitan area. For confidentiality reasons, the research sites will be referred to as “Site A” and “Site B”. Six focus groups (n=37) were held at Site A, and two groups (n=14) were held at Site B. The size of the groups ranged from 5 to 12 participants. According to Morgan (1997), groups of this size are considered adequate in number. Morgan also notes that a total of three to five groups on a given topic are usually adequate to reach “saturation” (p. 45), noting that more groups do not generally provide new insights. He also recognizes that variability of participants within groups may affect the number of groups needed. Because of the complex nature of the Medicaid Estate Recovery Program and the likelihood that participants may have had some or no knowledge about the program in advance, it was determined that a larger number of groups would more adequately address the research questions in this study.

Focus group participants were drawn from several municipalities within the designated bi-state Kansas City, Kansas and Kansas City, Missouri area. The specific research sites were selected because they were thought to best meet the study’s inclusion criteria of homeownership, and age of 55 and older, as well as having the potential to attract a diverse group of research participants.

Data Collection Strategy

The primary data collection strategy for this study is the use of focus groups. As noted earlier, focus groups have been frequently used with marginalized groups, to “give voice” (Morgan, 1997, p. 20; Madriz, 1998) to those who might not otherwise be heard. In addition, focus groups provide the potential for empowerment of group participants through raising awareness about specific issues such as political/social concerns (Wilkinson, 1999). Focus groups have also been distinguished by their emphasis on “the explicit use of group interaction” (Morgan, 1988, p. 12). A major argument in favor of using focus groups is that they allow for experiences and perspectives to be revealed that may otherwise not be easily reached without group interaction (Morgan, 1997). Morgan and Krueger (1993) note: “The comparisons that participants make among each other’s experiences and opinions are a valuable source of insights into complex behaviors and motivations” (p. 15). Kitzinger (1994) suggests that focus groups enhance opportunities to gain information about group norms, and provide insight into how social processes within groups affect what the groups may tend to denounce or silence.

Limitations of focus groups include a decreased number of questions that can be asked due to time constraints, and a limited availability of response time by participants due to the need to ensure that all participants have an opportunity to be heard (Patton, 2002). As is generally the case in focus group research, these limitations were balanced by the range and depth of topics that emerged during the focus group discussions (Patton, 2002). A final limitation noted by Morgan (1988),

relates to relying on group interaction. He contends that one can never really know whether or not group behavior would reflect individual behavior outside of a group setting.

Issues of reliability and validity of the data are also an issue in the use of focus groups. However, the purpose of focus groups is not to quantify data to test hypotheses or make inferences to a broader population. Rather, focus groups seek to deepen one's understanding about a phenomenon and solicit people's opinions and perspectives (Franklin & Lowry, 2008). Brown (1999) notes, "While individual interviews serve to solicit the perspectives of a single individual, focus groups, in contrast, seek to capture the interactive exchange among participants and to generate multiple and diverse stories and experiences" (p. 113).

Sampling and Recruitment

A purposive, convenience sampling method was used in this study in order to select participants who were thought to best represent "information-rich" cases that would facilitate in-depth understanding of the research topic (Patton, 2002, p. 230). This study had two selection criteria: homeownership and an age of 55 or older. The criteria of owning one's home is an obvious fit with the aims of the study which are to examine perspectives on the estate recovery provisions of Medicaid under which the primary recoverable asset is derived from home equity (Karp, Sabatino & Wood, 2005). The age of 55 and older was selected based on the Medicaid policy designation of this age for estate recovery for community-dwelling Medicaid recipients (U.S. Dept. of Health & Human Services, 2006) and also because many

people in this age cohort were likely to be thinking about their future needs as aging individuals (Ekerdt, Koslosla, & DeViney, 2000).

Data Collection Sites

Both research sites in this study lie within the metropolitan Kansas City area and provide programs and services to the older adults who reside there. This area is part of a larger, metropolitan statistical area (MSA) which is a bi-state, 11 county area with a total population of approximately 1.7 million individuals (Gotham, 2002). In this study, participants were drawn primarily from a contiguous five-county area within this MSA. These counties traditionally define the metropolitan Kansas City area (Gotham, 2002) and include: Wyandotte, Jackson, Johnson, Platte and Clay counties. Wyandotte County has consistently ranked as one of the poorest counties in Kansas and the metropolitan area, whereas Johnson County ranks as one of the wealthiest counties in the United States (Gotham, 2002). Wyandotte and Jackson counties are noted to have a disproportionate share of poor persons and racial minorities. In Kansas City, Kansas, African Americans make up about 31% of the population, non-Hispanic Whites make up 55.8%, and Hispanic/Latino individuals make up 16.8% of the population (Gotham, 2002). U.S. Census data shows homeownership rates in 2002 in the metropolitan Kansas City area for all populations were 67.9%. For Whites in the Kansas City MSA, homeownership rates in 2000 were 72.3%; for African Americans homeownership rates were 47.7%. This area also has a high degree of residential housing segregation (Gotham, 2002). Furthermore, according to the U.S. Census (2000), median family income and poverty rates show

also show wide variation across the counties within the metropolitan area. In terms of age, in Kansas City, Kansas, 11.6% of the population in 2000 was 65 years or older (U.S. Census, 2003). For purposes of this study, it was determined that selecting participants from this metropolitan area would provide an economically and ethnic/racially diverse group of older adults homeowners appropriate to meet the aims of the study.

At the inception of this study it was anticipated, based on discussions held between the primary researcher and staff from Site A, that the racial and ethnic makeup of respondents would be likely to provide a representation of about 30% African-American and 70% White participants, with a small percentage of Hispanic/Latino individuals. However, this turned out not to be the case with individuals who participated in this study. Out of 37 individuals who participated in the six Site A focus groups, only five individuals self-reported on the study's demographic form as other than White. These included: one Asian individual, two African American individuals; one Latino/Hispanic individual, and one Native American individual. Therefore, an additional research site was added in order to more adequately capture the views of African American older adults. After Human Subjects approval was received to include an additional research site, a local senior center was added, which will be referred to as Site B in this discussion. This senior center was located in a predominantly African-American neighborhood within metropolitan Kansas City, Kansas. The primary researcher visited the research site,

explained the purposes of the study, and received approval from agency's executive and governing personnel to initiate the study.

Adding the additional research site to increase the number of African American participants in this study is in line with basic tenets of qualitative research. Patton (2002) suggests considerations of sample size should be lead by the purpose of the study, the interests of key stakeholders, and the anticipated "reasonable coverage of the phenomenon under question" (p. 246). He further advises that sample sizes can be modified, as needed, in qualitative research as a study proceeds, noting that flexibility is a desired feature of qualitative research (Patton, 2002). This is also consistent with the qualitative notion of emergent design highlighted by Lincoln and Guba (1985) who point out that, "succeeding methodological steps are based upon the results of steps already taken (p. 102). Sandelowski and colleagues (1989) make an interesting observation about qualitative research suggesting that it involves "negotiating the paradox of planning what should not be planned in advance" (p. 100).

Engagement with the Research Sites

Prior to the formal recruitment and screening of participants, I participated in an annual spring event at the Site A in May of 2007. This event brought together older adults, health care providers, social service organizations, and Site A staff. It was focused on the provision of information, services, food and entertainment for older adults and their families from the Kansas City metropolitan area. Here, I provided information to older adults who were interested in learning more about this

study. Those who expressed an interest in participating in the study provided me with contact information, and they were later contacted by me via telephone to assess their interest in participating in the study. Participants were then informed about details of the study and screening for the study's inclusion criteria. Recruitment posters announcing the upcoming study were also placed at Site A and announcements were made about the study at various Site A events by the their staff. Consequently, several individuals contacted me by phone to inquire further about the study.

I also made several visits to the Site B research location to provide information about the study. Flyers had been previously mailed to this site and were distributed there by the organizational staff. Participants from the Site B research site were pre-screened by an administrative staff member who also organized and scheduled the focus groups at the site. The involvement of the staff in recruiting and scheduling participants was extremely beneficial because the staff was able to readily engage prospective participants. In her focus group study of low-income African American women, Jarrett (1993) notes that “people generally participate in qualitative field studies because of the relationship with the researcher” (p. 188), as opposed to impersonal means which she contends are ineffectual. At both research sites, the relationships that staff members had with participants was critical to successful recruitment.

Description of Research Sites

Research Site A

This research site operates under the auspices of a large university-based medical center located in a major metropolitan city in the Midwest. The mission of the organization is focused on the quality of life and well-being of older adults. It is a state-funded interdisciplinary center that provides educational, clinical and research programs related to aging. Staff members from the organization's community outreach program helped to promote this study and provide access to the study participants. One of the most popular programs they sponsor is a weekly informational lunch series where a range of topics on areas of interest to older adults are presented by the medical staff, community service providers, and other professionals. Some of these topics include end-of-decision making, long-term care planning, care giver education, and mental health and wellness, to name a few. The majority of participants in this study were recruited via these sessions where I had an opportunity to provide a short verbal presentation about the study at each of the sessions throughout the summer of 2007. This opportunity helped me to become familiar with the research setting and engage with potential participants and staff members. The focus groups for this study were held immediately following each informational lunch session, making it convenient for older adults who were already at the research site to participate.

Research Site B

Research Site B in this study consisted of a senior center that serves older adults in the Wyandotte County area of Kansas City, Kansas. This senior center was established in 1975 as an outreach program to meet the needs of primarily poor, economically disadvantaged seniors in the northeast area of Kansas City, Kansas (Greater Kansas City Community Foundation, 2005). Under contract with the local Area Agency on Aging, the senior center receives funding to provide services to older adults, age 50 and older under the auspice of the federal Older American's Act. Some of these services include the provision of congregate meals, senior center activities such as exercise programs, arts and crafts, benefits-related counseling, and transportation. Staff members from Site B readily engaged with me and my research assistant, and were generous in their support of the study by providing access to their senior center members as well as use of their facility to conduct the focus groups and member check meeting.

Data Collection Instrumentation

The guiding questions for this study were developed primarily from social constructionist theory as an overarching theory, and asset theory (Sherraden, 1991) as a substantive framework. Social constructionist theory helps us to explore and understand the varying perspectives people hold about their homes and estate recovery within the context of their lives and circumstances. Asset theory, which varies from income-based approaches to building wealth via the development of

programs and policies that support asset acquisition, was useful in the formation of the questions posed to focus group participants.

With these theoretical frameworks in mind, a semi-structured topic guide using four open-ended questions (see Appendix C) was used to address key issues and stimulate discussion (Creswell, 1998). Introductory comments were used to introduce the topic, prepare the group for participation, and to encourage participant involvement and interaction (Rodwell, 1998). These comments included thanking the participants for their contribution, providing a brief review of the details of the focus groups including the length of the session, confidentiality, “ground rules”, audio recording and note taking. Participants were also informed that it was not necessary for them to know anything about the Estate Recovery Program or Medicaid to participate in the group discussions.

Guided questions, with probes, were aimed at soliciting participants’ thoughts and feelings about homeownership; their level of awareness about the Medicaid Estate Recovery Program; and what they thought they might do if they needed long-term care. As recommended by Rodwell (1998), transition questions were incorporated into the discussion guide to move the participants to the specific questions. A summary of the discussion was presented, when necessary, to clarify participant views and inquire if participants wished to make further comments.

Ground rules were established related to issues such as allowing equal time for all participants to speak, and respect for divergent opinions. Participants were informed prior to the initiation of the discussions that they there were no “right or

wrong” answers, and they were encouraged to speak freely about their perspectives. Participants were also reminded of the need to allow time for everyone to speak and to show respect for others’ opinions.

Two facilitators, myself and a co-facilitator/note taker (research assistant), participated in all group sessions except for one in which the co-facilitator was unable to attend due to an emergency situation. Group facilitation was performed largely by me. However, the research assistant, who held an MSW degree and worked as a professional social worker, assisted with facilitation as needed. She was, however, primarily responsible for note taking and debriefing activities, and preferred that as her primary role. A note-taking form was devised and used throughout the group sessions (see Appendix D). To best facilitate group participation, the research assistant willingly assumed more responsibility for group facilitation at Site B because of her shared heritage with the group participants as an African American individual. The scholarly literature supports the notion of homogeneity in focus group research as a desired characteristic, especially when there may be perceived power differentials or where there are topics of a more sensitive nature (Madriz, 1998).

Group sessions were audio taped, and I typed all of the subsequent transcripts. Prior to the initiation of the focus groups, participants were asked to complete a brief survey to obtain socio-economic data including age, education, gender, race/ethnicity, marital status, annual household income, and years as a homeowner (see Appendix E). Demographic surveys were coded by a number that coincided with a number assigned to individual participants so that these characteristics could be matched to

the respective participants and groups. Demographic information was used, as appropriate and fitting, in the identification of notable themes which emerged from the focus group discussions.

Participants were also asked to complete a short payment participation form so they could receive a stipend for their participation. Despite assurances of confidentiality, many group members were reluctant to complete this form due to the requirement by the research-sponsoring institution that Social Security numbers be provided in order for participants to receive compensation. Despite assurances of confidentiality by the sponsoring institution and the primary researcher, however, one participant declined to submit a Social Security number, and therefore, was not paid for participation.

The focus group sessions lasted approximately 1½ to 2 hours. Participants engaged in lively discussions and were respectful of the opinions of others, despite differing opinions on the topics at hand. Particulars of this will be discussed in the findings section.

Beverages and snacks were served following the focus group discussions to facilitate rapport building among the group members and the research team. Written information about the Medicaid, the Estate Recovery Program, and long-term care specific to the states where participants resided were provided as handouts at each site following the focus group discussions.

A debriefing session was held with me and the research assistant immediately following the focus groups, when possible, to identify what went well and what areas

could be further developed or modified (Kidd & Parshall, 2000). When it was not possible to debrief immediately following the groups, the research assistant and I later reviewed our thoughts and feelings about the groups using the debriefing form (see Appendix F).

In addition to the taped and transcribed focus group discussions, other recording methods were used throughout the study. These included an ongoing methodological log, and a reflexive journal that I maintained throughout the study. These methods constituted the research audit trail which provided a record of all the study correspondence, documents and records. Finally, a comprehensive member check was conducted at each of the two research sites several weeks after the initial groups were held. The member check provided an opportunity for participants to discuss the findings, and correct any misunderstandings or misgivings they had about the data (Lincoln & Guba, 1985). At research Site A, 14 of 37 total participants attended the member check meeting. Seven of 14 total participants from Site B attended the member check meeting. Feedback received from participants at the member check meetings supported the preliminary findings, and minimal discrepancy was noted between my interpretation of the findings and that of the participants. Site B participants indicated a desire to place additional emphases on certain discussion topics which will be discussed in the findings section.

Data Analysis

As noted earlier, in contrast to making assumptions about causal relationships as is done in quantitative research, qualitative research attempts to portray a holistic

picture of participants' perspectives relative to the social context of the problem under study (Patton, 2002). Patton summarizes the complexities of this process:

The ongoing challenge, paradox, and dilemma of qualitative analysis engage us in constantly moving back and forth between the phenomenon of interest and our abstractions of that phenomenon, between the descriptions of what has occurred, and our interpretations of descriptions, between the complexity of reality and our simplification of those complexities, between the circularities and interdependencies of human activity and our need for linear, ordered statements of cause-effect. (p. 481)

The goal of analysis in this study is to gain an in-depth understanding of participant views and to bring together integrate the information received from the focus groups into meaningful themes which reflect the multiple realities, experiences, and perspectives of group participants.

Data analysis and interpretation was ongoing throughout the study. This is an important feature of qualitative research (Patton, 2002). Notes were taken during each focus group to describe the interaction among participants, including verbal and non-verbal communication. Notes also included the order of speakers who were identified by a number, e.g., P-1 (participant number one), to make it possible to track participants' contributions (Kidd & Parshall, 2000). Observations, insights and decisions reflected in the methodological and reflexive logs were used to tie my understandings of the data back to the raw data (Lincoln & Guba, 1985). This is important because it can help to minimize misunderstandings derived from interaction with participants, and bias on the part of the researcher (Lincoln & Guba, 1985).

Analysis of the data began with a review of the methodological log, focus group notes, and transcripts in order to "get a sense of the whole" (Patton, 2002,

p. 441). In addition to my performing the transcription from the audio files, I read and re-read the transcripts several times. My typing of the transcripts was beneficial because it provided me with an opportunity to be “close” to the data, and to engage with the data earlier than I might have if I were waiting for the return of transcription documents from another source. It also provided me with an opportunity early on to identify emerging insights. I also read each completed transcript while listening to the audio recordings. This allowed me to re-capture such things as intonation, pitch, speed, volume and emphases placed on a particular topic. Once the preliminary review of the transcripts was completed, I re-read the transcripts, making notes in the margins to identify potential codes, categories, themes and patterns. A preliminary coding sheet was developed (see Appendix G) which served as a semi-detailed “face sheet” for each of the transcripts. This coding sheet identified the number of the group, the date it was held, the number of participants, initial codes and categories, notable quotes, and general thoughts and comments I had about the group discussion. Once the preliminary reading and “pre-coding” of the transcripts was completed, they were uploaded into ATLAS.ti software for further analysis.

ATLAS.ti qualitative analysis software was used primarily to help organize and manage the data. The use of computer software for analysis of qualitative data has been the subject of debate (Kidd & Parshall, 2000). Computer software for qualitative data analysis has been frequently used by researchers to organize and analyze focus group data (Bradley et al., 2002; Curry, Bradley, & Robison, 2004; Pletsch, Doerr, & Irwin, 2001). Common criticisms of computerized analysis include

potential distortions of context and meaning, and the potential for detaching the researcher from engagement with the data (Kidd & Parshall, 2000). Despite these critiques, the benefits of ATLAS.ti appeared to outweigh the concerns.

According to Patton (2002), computerized analysis software allows for analysis of large amounts of information, offers the opportunity for multiple individuals to work collaboratively through network computer systems, and allows for easy inter-connections of information across multiple data sources. In this study, ATLAS.ti allowed me to organize and manage a large amount of data, and to delete, modify, group, and readily search and retrieve phrases, codes and categories. It was especially helpful for its ability to readily retrieve coded chunks of text within and across the focus group transcripts.

A constant comparative method of data analysis developed by Glaser and Strauss (1967) and later followed by Lincoln and Guba (1985) was used to identify the initial codes and categories, and from these, themes and patterns were identified. Initially, an inductive method was used where no attempts were made to link the transcripts to the research questions or reveal themes or categories (Creswell, 1998). In other words, the inductive approach “worked from the ground up” to identify the smallest data units, or descriptors (Lincoln & Guba, 1985) that could be derived from the text. Using ATLAS.ti software, these data codes were compared across groups, refined, and subsequently multiple iterations of codes and categories were produced. As the codes and categories were continuously refined, saturation eventually developed among the codes and categories, and no new categories emerged.

From these final categories, themes and patterns emerged. These were then compared and contrasted compared within and across groups to identify similarities and differences. To facilitate this process, I developed a template used to record “within group” and “across group” themes, and their presence or absence in the focus groups (see Appendix H).

In the discussion of the study’s findings, Krueger and Casey’s (2000) guidelines of *extensiveness* and *frequency* for coding focus group data were used. These guidelines helped me to better organize the topic areas and themes and better ascertain their presence or absence within and among the focus groups. Because the unit of analysis in this study is the “group” as opposed to the “individual”, *extensiveness* in this study refers to the number of groups that discussed a particular topic, as opposed to the number of individuals who commented on the issue. For purposes of this study, a topic and thematic area was defined as “extensive” when discussed in four or more of the focus groups. Krueger and Casey (2000) also note that the *frequency* of comments made on a particular topic can help in understand what topics are important to participants, and therefore, the frequency of comments on a particular topic was also considered in this analysis.

Attention was also given by me and the co-facilitator throughout the group discussions to aspects of group process, including group member agreement, disagreement, group tensions and dynamics. In keeping with Morgan’s (1997) discussion on factors that influence the emphasis that is given to a particular topic,

attention to participant enthusiasm and energy, as well as the depth of feeling demonstrated on a given issue are also noted in this study (Krueger & Casey, 2000).

According to Krueger and Casey (2000), precautions should be taken against using extensiveness and frequency as the only criteria for analysis. Krueger (1994) notes that while participants may consider a topic important, the frequency of comments they provide on an issue may be limited, but that does not necessarily mean it is unimportant. Given the changeable nature of discussions in focus groups, he recommends that the researcher also consider factors such as tone of voice, intensity of the comments made, rapidity of speech, gestures, and non-verbal behavior. In this analysis, notes on the transcripts, notes taken during the focus group discussions, debriefing notes and audio files were reviewed by me to assess these factors. In addition, when I initially coded the transcripts in ATLAS.ti, I simultaneously listened to the corresponding audio tape.

Methodological Rigor

Trustworthiness

According to Padgett (1998), “A trustworthy study is one that is carried out fairly and ethically and whose findings represent as closely as possible the experiences of the respondents” (p. 92). A trustworthy study should answer the question, “How do we know this is a good study?” (Cobbs & Forbes, 2002). From a positivist perspective, quantitative research is considered trustworthy based on the criteria of internal validity, external validity, reliability, and objectivity (Lincoln & Guba, 1995). A widely used set of standards that parallel those of the positivist

paradigm was developed by Lincoln and Guba (1985) for evaluating qualitative research, and was applied in this study. These criteria are: credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985). Reflexivity, a noted constructivist criterion to support credibility, is also included as a component of trustworthiness. Reflexivity relates to the researcher's ability to reflect on the nature of their involvement in the study, and the positioning of themselves in the data. Reflexivity also reflects self-awareness, one's political and cultural consciousness, and ownership of one's perspective. According to Patton (2002), "being reflexive involves self-questioning and self-understanding" (p. 64). He asserts that to be reflexive is to undertake an ongoing examination of "what I know, and how I know it" (p. 64).

Credibility

Credibility, (internal validity) refers to the notion that the data presented by the researcher is an adequate representation of participants' views. Strategies used to enhance credibility in this study included: *prolonged engagement*, *triangulation*, *member checking*, and *peer debriefing* (Lincoln & Guba, 1985). Prolonged engagement includes activities undertaken by the researcher to learn the culture of the participants, to test one's understanding of that culture, and to build trust (Lincoln & Guba, 1985). In this study, I attended several events hosted at the Site A which allowed me to learn more about the culture of the organization and how participants fit into that culture. For instance, the majority of participants in this study were recruited from the informational lunch series sponsored by Site A as previously

noted. At these sessions, I was able to get a sense of the participants' place and "fit" in the culture of the site by observing their interactions with staff and others, as well as through conversations I had with participants. Many participants had been actively involved in the organization's activities for a number of years. Many were also involved in clinical research trials conducted at research Site A. My engagement with participants prior to the focus groups gave me an enhanced understanding of the organization, and helped me to gain insight into participants' "worlds." In addition, I brought to this experience many years of social work practice with individuals and organizational settings like those employed in this study, where I interacted with older adults and their families who were gathering information, and considering long-term care options. I spent less time prior to the focus groups with Site B participants, although I visited the research site twice prior to the focus groups, holding lengthy discussions with key administrative personnel. I also had an opportunity to meet some of older adults who attended activities at Site B, and also some of the staff members. I was also given a tour of the facility by a leading administrative staff member who provided an in-depth historical discussion about the organization.

Another technique used in this study to enhance credibility was *triangulation*. This commonly involves the use of multiple sources of information as well as the cross checking of this information to identify potential consistencies and inconsistencies (Lincoln & Guba, 1995). In this study, triangulation was achieved through the use of multiple focus groups with diverse groups of participants, (this produced multiple and diverse experiences and stories), the use of varying group

settings, and multiple methods to confirm the study's findings. My typing and review of the transcripts of the focus group discussions, debriefing notes, and focus group notes also provided other sources from which to check the credibility of the data.

Member checking was used to confirm the study's findings with participants at both research sites. Member checks allowed participants to confirm or deny the accuracy of my interpretation of the research findings. Throughout the study, the study's methodologist conducted periodic checks of the audit trail, including the accuracy of the coding, the development of the emerging themes, and a review of the preliminary report of the study's findings that was used in the member check meetings. The tentative conclusions that I derived from the data were supported by participant agreement in the member check meetings, which also served to enhance the credibility of the study.

Peer debriefing also regularly took place over the course of this study with the study's methodologist as a means of reviewing the emerging findings. In addition, debriefing sessions were held with the research assistant. Finally, consultation was held with a professional academic colleague who was well-versed in qualitative data analysis. The primary purpose of this endeavor was "to explore aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind" (Lincoln & Guba, 1985, p. 308). The consultant, who had no vested interest in this study, reviewed two randomly selected transcripts, one from each research site. The consultant was provided with a list of preliminary codes that I had developed, and then, she independently coded the transcripts. We met on a number of occasions and

compared our individually coded transcripts for convergence of codes and categories. While few disparities existed in the interpretation and application of codes and categories, consensus was reached after a thorough discussion. The major recommendations made by the consultant were for the addition of six new codes, some of which were incorporated into the coding scheme.

Transferability

Transferability (external validity) refers to the likelihood that information and lessons learned in one context can be useful in another (Rodwell, 1998). Lincoln and Guba (1985) contend the researcher must ensure that the data is sufficiently “thick” to make potential judgments about transferability possible. Transferability is supported in this study through the use of “thick and rich” descriptions of participant perceptions. These are illustrated in this study via direct quotes from the focus group discussions, from content derived from the focus group notes, and from descriptions of the research sites and context. The use of a purposive study sample, which is designed to ensure that a broad range of perspectives are gathered, also enhances transferability in this study (Lincoln & Guba, 1985).

Dependability

Dependability (reliability) relates to consistency in the study’s processes for the collection of data. Dependability is commonly addressed via an audit trail. The purpose of an audit trail is to provide a detailed account of the study’s protocols and methods. The peer debriefing and consultant review processes noted in the credibility section of this chapter also served to foster dependability. The use of a

methodological log that contains decisions made throughout the inquiry and the justifications for those decisions, also enhances dependability of this study. The reflexive journal, transcripts, audio tapes, and products from the data analysis (e.g., transcriptions with notes, data category files and code definitions, information on the coding process, and multiple variations of data output from ATLAS.ti data analysis) also enhance the dependability of this study.

Confirmability

Confirmability (objectivity) relates to the provision of evidence to support the findings of the study. The triangulation of data sources and member checking serve to support the confirmability of the study. Direct quotes are used in the study's narrative descriptions that best illustrate the themes and patterns that emerged from the data, providing further evidence of confirmability. Paying attention throughout the study to the potential biases that could exist in the study and implementing a plan to minimize them also helps to establish confirmability.

Summary

This chapter has presented the methodological components of this exploratory, qualitative study which used focus group methods to examine the perspectives of a diverse group of adult homeowners, age 55 and older, who live in a large, Midwestern metropolitan city on Medicaid long-term care and estate recovery. Key concepts derived from the literature and the study's research questions have been presented. Human subject protocols have been reviewed, sampling and recruitment

have been addressed, and methods for data collection and analysis, and ensuring methodological rigor have also been discussed.

CHAPTER FOUR

FINDINGS

This study focused on older adult homeowners' perspectives on the use of Medicaid for long-term care in light of Medicaid's estate recovery provisions. A diverse group of fifty-one homeowners age 55 and older who resided in a large, Midwestern metropolitan area participated in eight focus group discussions at two facilities which served older adults. The findings from this study illuminated participants' perceptions about the advantages and disadvantages of homeownership, their awareness of, and perspectives on, the estate recovery program, as well as inheritance, and long-term care.

Major themes that emerged from the focus group analysis illustrate broader, systemic forces and other factors which influence and intersect with the many topics discussed in the focus groups. These are:

- Collectivism versus Individualism;
- Fairness and Equity;
- Views of Government, Politics and Economics;
- The Importance of Family;
- Getting Older;
- A Changing Society;
- A Need for Education and Information

The primary research questions addressed in this study are:

1. When given an opportunity to learn about and discuss estate recovery, how do older adult homeowners describe their perspectives on using Medicaid for long-term care?
2. How do the perspectives of older adult homeowners on the use of long-term care through Medicaid evolve when they have a chance to learn about and discuss estate recovery with one another?
3. How do themes that emerge from group discussions among older adults who are homeowners regarding Medicaid estate recovery differ by race, if at all?

This section is organized in the following manner. First, information about each of the eight focus groups is provided related to group composition and location as well as socio-demographic information gathered from brief self-administered participant surveys (see Appendix E). Next, topics that evolved from the guided questions are discussed and major themes that emerged from the analysis of the focus group data are presented.

Focus Group Composition and Socio-demographic Characteristics

A total of eight focus groups were conducted consisting of 5-9 participants per group for a total of 51 participants. Table 1 shows the composition of groups by date, location, the number of participants, age, gender, and race/ethnicity. Six groups were conducted at Site A (n=37) and two groups were conducted at Site B (n=14). Table 2 presents characteristics of all group participants based on information gathered from demographic surveys.

Participant ages ranged from 56 to 93 years old with a mean age of 73.81 years. Site A participants were made of up 86.5% individuals who self-identified as White, while the Site B participants all self-identified as African American, although

they stated their preference to be referred to as “Black” in the focus group discussions. The majority of group participants were female, making up 78.4% of the total sample. Differences in marital status by research site were noted. As compared to only 19.4% of Site A participants who reported being widowed, the majority (71.4%) of Site B participants reported this status.

Regarding household income, the distribution of income in low (less than \$19,000), medium (\$19,001 to \$39,999) and high (\$40,000 or more) categories was fairly evenly dispersed. Thirty-seven percent of the sample reported a yearly household income below \$19,999; 31% reported between \$20,000 and \$39,999; and 32% reported incomes of \$40,000 or more. However, when comparing income by research site, more than two-thirds of the Site B participants reported having lower incomes (less than \$19,999). In contrast, more than one-third of the Site A participants reported having incomes of \$40,000 or more. Furthermore, almost 75% of Site A participants reported having an income classified as mid (35.2%) or high (37.6%). When compared to the majority of Site A participants who reported having some college or a higher level of education, the majority of Site B participants reported having some college or less.

In summary, when comparing the two Sites, the typical participant at Site A was female, was married, and had some level of higher education. The typical Site A participant was also White, has been a homeowner for more than 21 years, and had an annual income of \$40,000 or more. A typical Site B participant was an African American female who was widowed, had either some high school education or was a

high school graduate, had owned their home for greater than 16 years, but earned less than \$19,999 per year.

Table 1

Focus Group Composition (N = 51)

Group	Date	Center	# Participants	Age Range	Gender	Race/Ethnicity
1	6-6-07	Site A	5	59-67	F=2 M=3	White = 5
2	6-13-07	Site A	7	58-70	F=6 M=1	Asian = 1 Hispanic = 1 White = 5
3	6-27-07	Site A	9	64-93	F=6 M=3	White = 9
4	7-11-07	Site A	6	60-84	F=5 M=1	AA = 1 Native American – 1 White = 4
5	7-18-07	Site A	5	72-83	F=4 M=1	AA = 1 White = 4
6	7-25-07	Site A	5	68-86	F=4 M=1	White = 5
7	9-7-07	Site B	9	65-89	F =8 M=1	AA = 9
8	9-28-07	Site B	5	56-87	F=5	AA = 5

Table 2

Characteristics of Participants (N = 51)

Variables	Site A (N = 37)	Site B (N = 14)	Total (N = 51)
Age	M =71.73 Range 58-93 SD = 8.99	M=78.71 Range 56-89 SD = 9.36	M = 73.81 Range 56-93 SD = 9.56
Gender			
<i>Males</i>	27.0%	7.1%	21.6%
<i>Females</i>	73.0%	92.9%	78.4%
Marital Status			
<i>Single/Never Married</i>	22.0%	0.0%	16.0%
<i>Married</i>	38.9%	28.4%	36.0%
<i>Divorced or Separated</i>	19.4%	0.0%	14.0%
<i>Widowed</i>	19.4%	71.4%	34.0%
Level of Education			
<i>Some H.S.</i>	0.0%	21.4%	5.9%
<i>H.S. Graduate</i>	21.6%	35.7%	25.5%
<i>Some College</i>	29.7%	35.7%	31.4%
<i>College Graduate</i>	21.6%	0.0%	15.7%
<i>Graduate School</i>	27.0%	7.1%	21.6%
Race/Ethnicity			
<i>African American</i>	5.4%	100.0%	31.4%
<i>White</i>	86.5%	0.0%	62.7%
<i>Latino/Hispanic</i>	2.7%	0.0%	2.0%
<i>Asian</i>	2.7%	0.0%	2.0%
<i>Native American</i>	2.7%	0.0%	2.0%
Years as Homeowner			
<i>2-5 years</i>	6.1%	7.1%	6.4%
<i>6-10 years</i>	0.0%	7.1%	2.1%
<i>16-20 years</i>	0.0%	14.3%	4.3%
<i>21 or more years</i>	93.9%	71.4%	87.2%
Household Income			
<i>Less than \$10,999</i>	5.9%	33.3%	13.0%
<i>\$11,000 to \$19,999</i>	20.6%	33.3%	23.9%
<i>\$20,000 to \$29,999</i>	17.6%	8.3%	15.2%
<i>\$30,000 to \$39,999</i>	17.6%	8.3%	15.2%
<i>\$40,000 to \$49,999</i>	17.6%	8.3%	15.2%
<i>\$50,000 or more</i>	20.0%	8.3%	17.4%

Substantive Topics and Major Themes

In this section, topics from the focus group discussions and major themes that emerged from the analysis of the focus group data are presented. Substantive topics include the meaning of home, advantages and disadvantages of homeownership; knowledge of, and perspectives on estate recovery and inheritance; and views of Medicaid and long-term care.

Major themes that cut across the topics discussed by participant include: Individualism versus collectivism; fairness and equity; getting older; a changing society; the importance of family, views of government, politics and economics; and, the need for education and information. These themes will be presented as they emerge from the topics discussed both within and across the focus groups.

Homeownership: The Meaning of Home, and Advantages versus Disadvantages

As noted in Chapter 1, the primary means by which the Medicaid Estate Recovery Program recoups the cost of Medicaid long-term care services is from home equity (Karp, Sabatino & Wood, 2005). Therefore, it is important to understand participants' perspectives about homeownership. As a way to build rapport among the group participants, and to set the stage for subsequent questions about estate recovery and long-term care, participants were asked to discuss their thoughts and feelings about homeownership. The following guided question was used to stimulate discussion: "One of the things that everyone here today has in common is homeownership. We'll start by asking you to talk together about owning your own

homes. Can someone get our discussion started by sharing what it means to you to be a homeowner?”

Overall, responses indicated that homeownership was viewed as more advantageous than disadvantageous. The frequency of comments on the advantages of homeownership clearly outweighed those that represented disadvantages. Topics of particular interest to participants on this point included social, economic, psychological/emotional, and health-related benefits. Disadvantages were noted in the areas of maintenance and upkeep of the home, property taxes, insurance and other costs, and finding affordable and trustworthy help to maintain one's home.

The Meaning of Home

The meaning of home as an aspect of homeownership emerged in seven of the eight group discussions and many similarities were found on this topic across the groups. In analysis of the data on the meaning of home, no dramatic differences by research site emerged. Most participant comments reflected positive sentiments. “Home” was variously referred to as an aspect of identity, a safe and comforting place, and a place for family as noted by many group members' comments.

One group member referred to home in a collective sense noting that, “Our homes become extensions of us” (P5: FG5, Site A). Despite urgings from her adult children to consider alternative living arrangements, and despite discussions with her husband, who was also a group participant, about assisted living, she noted, “They (our homes) reflect our lifestyle. We're reluctant to give that up.” After living in her home for thirty years where she enjoyed having “lots of room” and ample places to

store things, another participant articulated what home is to her: “It’s primarily a - what can I say – a solitary place for me to be away from the hazards and the discomforts of life” (P3: FG3, Site A).

A participant who viewed home as an “accomplishment” after having reporting that she had lived in “shack after shack” reflects on the security, and freedom from worry that her home offers her: “It’s nice to have somewhere to, you know, when you go in at night, you can lay down and you can relax and you ain’t got to worry about the rent man knockin’ on your door. Where’s my money? ” (P23: FG4, Site A). Another participant relays that despite living in a county that has high real estate taxes, “I consider it a real blessing to own my home” (P26: FG4, Site A) .

Participants also talked about home as providing a benefit for their families, and a place that offered comfort and familiarity. One participant shares: “It’s very comforting. It’s easy to raise a family” (P17: FG3, Site A). Another participant, when discussing long-term care services, shares that if she needed help, she would prefer to remain living at home. She describes her home in terms of the familiarity and comfort it brings her: “When you’re in your own home you’re around the things that are familiar to you and it’s more comfortable - the things that have your smell and your DNA that you’ve left there and not other people’s” (P1: FG4, Site A).

While home meant comfort and security, many participants also described it as, “A big responsibility. Everything that goes wrong, it’s your problem.” (P41: FG7, Site A). Another participant shares a similar notion: “It’s a great responsibility, but it’s a good feeling to have your own home. ” (P4: FG4, Site A)

Homeownership tenure was perceived by the many participants in this study as a symbol of achievement and pride. Nearly 90 percent of participants reported having owned their homes for 21 years or more, and many of the comments they made were preceded with references to their tenure as homeowners. When discussing what homeownership meant to her, one woman, whose spouse was also a group participant, noted:

We've owned our home for - all except for one year after we were first married, and it's a responsibility and an advantage. I like it. Like she said, it's your own, and you can do what you want with it. (P27: FG4, Site A)

The most senior member among the focus group participants describes her experience:

I've lived in (city) for - since 1950, and so we still maintain our home. I'm 93 years old. We still can mow our lawn and take care of our home. It's a treasure for me. I enjoy my neighbors and I really I think everybody should own a home if they could. (P21: FG3, Site A)

Advantages of Homeownership

Similar to discussions on the meaning of home, participants in all focus groups talked at length about the advantages of owning their homes and clearly, the advantages of homeownership outweighed the disadvantages as evidenced by the many positive comments shared across the groups. Participants were proud of their status as homeowners, and happy to talk about what it was like.

The advantages of homeownership presented by participants were consistent with the scholarly literature on the benefits of homeownership, and spanned all of the focus group discussions. Participants discussed psychological, social, economic, and

health-related benefits of homeownership. There were no major differences, however, across the groups on perspectives regarding the advantages of homeownership.

Advantages: Psychological Benefits

That homeownership conferred psychological or emotional benefits was evident in seven of eight of the focus groups. Feelings of safety and security representing subjective feelings of well-being were commonly expressed to describe this. As noted by one participant, “As long as I have a home and it’s paid for, I have a place to live and I can probably survive anything” (P1: FG1, Site A). Comments from three participants in three separate focus groups reiterated the notion of security and the importance of “place” in rendering security. One participant notes, “I think the positive is that you have a permanent place and you’re not always having to move if you’re in an apartment. It’s your place, and it’s more permanent, I think, than apartments” (P51: FG8, Site A). Another participant, who spoke proudly of her achievement as a homeowner, talks about advantages that she sees:

To me, the advantage is, you know, you have a place to lay your head every night. You don’t have to depend on anyone else as to where you’re going to sleep the night. You know, stuff like that. And, also, you know that *it’s yours*. (P23: FG4, Site A)

One group member who became first-time homeowner at age 55 shared her story. After raising her children in an apartment where she had lived for thirty years, she purchased the residence when it was converted to a condominium. The experience had a definite impact: “It changes your feelings when you’re owning and not just renting. I mean somehow things seem a little more important, they seem a little bit different, attitudes somehow. ” (P35: FG6, Site A)

Her enthusiasm about being a first time homeowner was palpable. When asked by the group facilitator if she'd like to say more about that, she replied:

It kind of changes the way you feel when you actually own your own property. Even if I own it with my kids, still, we do own it. And I haven't owned anything since I was divorced and lost everything. So, that was a long time ago - so it's been a change back again now. A little bit more security thinking, you know, that you own your home and you do have an investment. (P35: FG5, Site A)

One participant provides a snapshot of her experience as a long-time homeowner:

Well, I've lived in my home - the same home - for 51 years. We bought it when we were married and we moved in. And I had been raised in an apartment, so the house seemed quite large when we moved in as two people. And over the years it shrunk because we had three children. (Laughs). And, now it's - they're gone - but it's just about the right size for me again. And, it's my haven. At this point in my life I can't see myself being any place else. (P29: FG5, Site A).

Other discussions on the advantages of homeownership clearly spoke to themes of independence and self-reliance as reflected by comments from individuals across several of the focus groups. "Well, for me, I like the independence, and I like being in charge of what I do" (P32: FG5, Site A). Another participant mirrors this sentiment: "Nobody can come in and tell you, you do this, and you do that. This is my home. I do as I please" (P39: FG7, Site B). "You're pretty well your own boss" (P36: FG6, Site A). "And, I know, to me it's a blessing to have a home that I don't have to go answer to nobody, you know, to pay for anything." (P23: FG4, Site A).

The ability to alter one's living space, remodel, and redecorate was another aspect of freedom participants felt as homeowners: "You can add on if you want to your home. I mean, if it's too small you can add onto another room or something, and

you can have as many people as you would like to live in your home” (P44: FG7, Site B). Another participant shares, “You can paint your living room purple if you want ’cause it’s yours, but there’s no one to call when the door needs repairing except yourself” (P24: FG5, Site A).

One gentleman who also participated in the focus group with his spouse, talks about the importance of his home for creating and maintaining independence, as well as for providing a place where he can use his creative skills and talents:

The other thing about being a homeowner, though, I think it makes you more independent because you have to do things yourself, for yourself. And, that’s one of the things I really enjoy about it. . . . I think the other thing is that it allows me to have all my tools in the basement that I can haul out my saws when I want to build a piece of furniture or something. (P15: FG3, Site A)

Clearly, homeownership conveyed special meaning to participants in this study who, consistent with the literature on the meaning of home, found a sense of safety and security, and freedom and independence in their homes.

Social Benefits: Families, Pets, and Neighbors

Five of eight focus groups discussed positive sentiments about the value of homeownership for their families, for the value of neighbors, and for being part of a larger community. Participants in several of the groups saw homeownership as beneficial to their immediate and extended family members. Comments from three separate groups on the benefits of home and family speak of these benefits:

When I first became a homeowner it was because I didn’t want to pay rent. I wanted something for my money. But not only that, I felt like I needed the space to raise my family. A yard for them to play in - and I had it fenced in and they could be safe there. And now I’m reaping the benefits of not only has it paid off, but I also enjoy my flower gardens. (P10: FG2, Site A)

She goes on to describe her yard where the children play:

I have all kinds of swings and slides and teeter totters. It looks like a little play area. It's large enough where I can put a play area and it's completely fenced, and they love it out there. It's nothin' like watchin' little kids out there playing and screamin' and squealing, and running. Even my neighbor says, I sometimes – I want to come over and play, too, and she's a grown up! (P10: FG2, Site A)

The importance of homeownership to participants' families runs across all of the focus group discussions. One individual who attended the focus group with her husband, reports:

I think it's a blessing to have a place with your family, with your kids that - we have four children, and the one son has been overseas a lot and he comes back and he's got a place to stay. He can stay - we have a place in our basement where he can stay with his family. And that's a blessing. (P27: FG4, Site A)

Having grandchildren was also discussed frequently in the focus group discussions, and like homeownership, grandchildren were a source of pride for group participants.

The following exchange illuminates this point:

Facilitator: So, you have some - it sounds like you have some very positive memories of your grand kids and your home being a place where they can come, and a happy time.

P32: Yes. And they love to come over to my house. They love my undivided attention. You know, somebody calls, honey, I got my great grandkids over here. I can't talk to you.

P22: And that gives stability to children's lives, you know. I think it does.

P32: It makes 'me feel good.

P22: I know with my grandson, his folks were talking about the fact that some people own two houses, that they might have a vacation house. And he said, well, we have two houses. Our house and gram's! (P22: FG4, Site A).

The freedom to have pets as a homeowner was reflected in some group conversations. Interestingly, nearly fifty percent of pet owners in the United States consider their pets to be members of their family (American Veterinary Medical Association, 2007). Participants discussing homeownership did not exclude their pets as important:

P1: And you've got your dog.

P2: And you've got your cat.

P3: For good, better or worse (Laughter). I've just adopted my third cat as of today, which I couldn't do if I lived in an apartment. And, I would be lost without my animals. Since I don't have family, they are my family. (FG1, Site A)

Another participant promotes pets and homeownership: "I like it because you're not limited by if you love animals that you can't have in apartments. You can maybe have one, maybe. Maybe none" (P51: FG8, Site B).

Advantages: Social Benefits

A broad range of benefits in relation to neighbors and communities were discussed in the focus group discussions. Being part of a neighborhood and a community played a prominent role in participants' lives. This was mirrored in discussions across all of the focus groups. Neighbors enhanced social networks, with important benefits:

My neighbors are wonderful. We don't have any family. Neither my husband nor myself have any families here, so my neighbors are my family. And I have wonderful neighbors on (name of) Street. (P21: FG3, Site A)

She continues to reflect on her neighbors and her social network: “We have good neighbors. Last Saturday night we had a block party. They put - closed off the street and we all brought food, had tables and we had a good time” (P21: FG3, Site A).

Having neighbors also brought a sense of security to group members. “When we’re going out of town we check in and say, I’m gonna’ be gone, just keep an eye on the house. And, if – I know if anything happened there would be somebody there” (P15: FG3, Site A). “I have wonderful neighbors”, notes one group member, “and we’re a close knit community and we kind of look out for each other” (P37: FG6, Site A).

Another participant reflects on herself as getting older and how her neighborhood has changed:

I was thirty when we moved there. And, the neighbors were all 70 and older when we moved there, and now that’s where we are. And everybody has changed houses from 2-5 times in our neighborhood. So, right now we have two small children across the street that love to come into my house. And we play with them. We’ve got a closet there for them with all their toys and stuff, so we feel like we’re living in a mansion. (P3: FG5, Site A)

Changing neighborhoods were reflected in another group member’s comments which stood in contrast to the majority of group sentiments about neighbors:

Well, she sounds like she’s got wonderful neighbors. Now, when we first moved in - we live in the suburbs - into our home, everybody knew everyone cause the kids were little and your kids played together and you knew - you knew everybody in your neighborhood. But, it’s changed in the last 10 years. I honestly say I don’t know my neighbors other than across the street and next door. I don’t their names. I wouldn’t know them if I saw them on the street because we lost contact. The children are now grown. (P17: FG3, Site A)

The contribution homeownership made to being part of a community citizenship was clearly evident in one participants’ comment:

I think one of the things I was taught as I was getting older was that it was important to own a home. And, that as a Black person, owning real estate was establishing roots, and also establishing a level of respectability in the community. (P48: FG8, Site B)

Advantages: Economic Benefits

Themes of independence and individual achievement were evident in discussions about the economic benefits of homeownership. The impact of the broader marketplace on home equity and homeownership as an asset was also mentioned in several group discussions. Seven of the eight focus group discussions mentioned various economic benefits of homeownership.

Consistent with individualist ideology on “ownership”, comments commonly reflected the notion that people felt like they “had something” when they were homeowners, had “something to show for it”. Participants in more than half of the groups commonly referred to home owning as, “It’s yours.” This specific language describing being a homeowner was used in over half of the groups. One individual expresses personal motivations related to purchasing her home:

For me, it was a financial decision because I look at, you know - when you rent you pay money all the time, and nothing to show for. It will never become yours. But, when you own your own house . . . this is going towards finally, when you finish, this becomes *yours*. (P2: FG1, Site A)

A similar perspective relates to financial benefits of homeownership in the following exchange among two group participants:

P8: I think most people bought a home as a way to save money and to invest in something long-term. It’s an asset. It’s one of the biggest assets people will have (FG2, Site A).

P9: And you get equity. I bought mine years ago and now it has increased in value three-fold. And if you have a home, it’s something that you - even if the

equity market is going down, at least you have more than you have if the financial institutions go under, more than you have if the dollar flips over and becomes virtually worthless. (FG2, Site A)

One individual discusses the importance of home ownership as a woman:

Some of the research I've done regarding estate planning was that the best gift a woman can give herself is her home paid for by 55. So, that was what I shot for and that's what I accomplished. (P24: FG4, Site A)

A number of participants talked about the merits of owning versus renting:

I wouldn't consider renting because it's a good investment financially to actually own the house, although I've got a mortgage and I'm paying for it. I think it just makes financial sense to own instead of renting. (P33: FG6, Site A)

I can do all the things, you know, that you can't do if you live in an apartment. You can paint it any color that you want to paint it. (Laughs). Landscape it. But you can't do those things in an apartment. (P24: FG4, Site A)

One participant shared that she was taught when she was very young about the importance of buying versus renting. Throughout the years that she and her husband bought homes and built equity, she emphasized that paying a house payment was also a way to promote saving and help one's children:

It's kind of mandatory saving because when you make a house payment it's like putting that much money in the bank. So, we've always been homeowners thinking that that was a good investment. And we've even, with one of our kids, we've let them borrow some money against the house to start their business. So, it was a blessing to them and to us, too. (P25: FG4, Site A)

Advantages: Health-related Benefits

Four of the eight focus groups discussed health-related benefits as an advantage of home owning. One participant spoke emphatically about the benefits of having a yard and garden:

I have a beautiful garden, and since I retired, I spend so much time in the garden. I plant my own vegetables. It's all organic, no fertilizers, you know. It's all, you know, very good for my health. And yes, it keeps you young, too. It's my form of exercise – my doing – you know, your own yard, your own landscaping. It keeps me healthy. (P9: FG2, Site A)

One participant balances positive and the negative aspects of yard work: “Yard work is healthy, yet it is a chore in every way” (P14: FG3, Site A).

Considerations of spousal health and well-being are also reflected by one participant in another focus group:

Having a house is so much worth it because if we didn't have our own home, I think that my husband would sit there and watch television instead of now he has to do the lawn sprinkling and move it around every hour, and he's adding onto the shed and that. It's a lot of exercise and I think that we all need that. (P29: FG5, Site A)

Disadvantages of Homeownership

The most frequent issue commented on across the focus groups regarding disadvantage of owning one's home was related to maintenance and upkeep. All groups presented this as a major disadvantage. They frequently talked about the need for constant attention to maintenance, continuous costs, and the problem of finding reliable and affordable help. Exceptions to this were few, though one participant readily shared her positive perspective on what was otherwise viewed as negative:

Well, some of the things that I think might be negative about the upkeep of a home - the physical part of it - is also a plus because as someone says one time, don't ever get caught up because once you're caught up then you don't have anything that motivates you to keep going. (P22: FG5, Site A)

Another participant viewed tasks like yard work as positive because they provided a form of exercise. Largely, though, participants viewed maintenance as a negative

aspect of homeownership. Everything from trimming tree limbs, to fences that need repair, to painting and bursting pipes were discussed across the focus groups. One participant sums it up: “Everything that goes wrong, it’s your problem” (P41: FG7, Site B). Reminders of home maintenance were ever present:

It’s just that there’s always something, especially if you’ve owned your home for many years like we have. Then there’s a hot water heater, and then there’s the last storm we just had – we had 18 trees – and there’s just branches and twigs. There’s just work! (P41:FG7, Site B)

Maintenance costs were also reflected in comments across the groups: “Yes, lots of work to maintain it. Leaking roof. Leaking faucet. I have to climb the roof to fix something myself because you want to save on the payment, expenses.” (P6: FG2, Site A)

A major theme emerged that highlighted participants’ recognition of getting older and how abilities to care for one’s home changed with age. But, as I get older - the wash machine is down in the basement . . . And, it’s gettin’ so I can’t get down to it. But - so, as you get older there are problems of that nature. (P26: FG4, Site A). Another participant reflects on getting older:

There are a lot of benefits to having - there are pros and cons always, but I do find that the older I get the more difficult it is to maintain the house in the way that I’d like to keep it. (P10: FG2, Site A)

The following participant exchange reflects concerns about aging and homeownership:

P4: Well, there’s just the constant upkeep. You’ve got the lawn to mow. You’ve got to fertilize it. You got to shovel the steps and walk. You’ve got the insurance.

P1: Or else you have to hire somebody to do it.

P4: Yeah, you're right.

P3: And you increasingly get to the point where you can't do it yourself.

P1: Right. (FG1, Site A).

One participant also recognizes getting older and the importance of family supports in this process:

There's tasks like painting your house, cutting grass, I think as you get older becomes more difficult. So it becomes a burden in a lot of ways that is hard, I think, as far as taking it on. It makes a difference if you have a supportive family around and being able to make a difference, but a lot of people don't have that. (P4: FG1, Site A)

One participant talked about what she sees as older people being over-charged because of their age:

I'd like to follow up on something (another participant) said. On the - working with contractors or people who do things - the cost of it. I think when people come and they see the gray hair they seem to think we're still living on the turnip truck they thought we were born on. The prices just go through the roof. . . It seems that prices are definitely escalating because of our age. (P15: FG3, Site A)

While maintenance and upkeep were viewed mostly as negative, one individual linked these to pride of ownership:

Upkeep is very necessary because you want to – you want it to look, you want to keep your home, the grass cut and everything to make it look nice and clean. And, you want to be proud of your home, so therefore you want to keep it up. Keep it looking – inside and out. It's your home. And it gives you – it's a great responsibility, but it's a good feeling to have your own home. (P45: FG7, Site B)

One participant carries the conversation on pride of ownership further as he discusses the struggle of keeping up with costs of home maintenance:

Well, you know, the sense of pride perhaps exists more in the younger generations than it does with anybody else because after a certain point, you're just trying to hold onto what you have. Like last night when they were talking about hailstones the size of golf balls – well, one of the biggest worries most old people are going to have if they own a house is that, oh, Lord, I hope that thing doesn't tear up my roof, which often happens in a storm. And it starts from just a little bitty leak and because you don't have sufficient money, you can't get that roof fixed. (P42: FG7, Site B)

Another participant discussed concerns about keeping her home updated to meet the needs of potential buyers, which she saw as a costly undertaking. Another follows: “Yeah, it changes, and then you have to change, which has an impact if you're on a fixed income 'cause then you won't be able to do a lot of changes.” (P48: FG8, Site B). Participants who owned condominiums provided exceptions to the problem of maintenance. One participant noted, “You have all the good stuff and you don't have to do the work!” (P27: FG6, Site A)

The costs of maintenance were clearly a problem for group participants. Some groups mentioned this more emphatically than others. The following exchange illustrates one group member's frustration:

If you have money to maintain a home, uh, it's nice all the way around - everything - you can have visitors - going out in the yard and sitting quietly. But you can own a home and if it's in the wrong place, it's really no advantage because you're constantly at war with your neighbors. But, it really boils down to dollars and cents. If you have enough money and use it wisely, fine. But if you don't have the money, you're just kind of up the creek. (P42: FG7, Site B)

Another participant expresses how changes in society coupled with getting older, impacts people's lives as homeowners:

We are vulnerable. Somebody – (participant's wife's name) is out in the yard. Somebody could come up behind her - whack her, steal her car (P31: FG5, Site A).

Disadvantages: Taxes

In six of the eight focus groups, property taxes were discussed as a downside of homeownership. The following exchange between two participants reflects on the possibility of losing one's home if taxes are not paid:

P1: I suppose you could lose it lose it somehow.

P4: And that's the thing that I don't understand.

P1: And the taxes can go up.

P4: Thousands of dollars in investment. And, if you don't have any income – like as far as paying the government then . . .

P1: Just failure to pay taxes it could be taken away. (FG1, Site A)

In another participant exchange, taxes and other costs are expressed:

P8: And even if you've owned your house for a long time, and may not even have house payments anymore, you've got taxes. You have to carry homeowners insurance - all that is much more costly as you get into retirement, as I think most of are living on pensions.

P9: My house has increased in value three fold, but I got to pay taxes three fold too. They raise it - increased it three fold, also. (FG 2, Site A)

One group member expressed concern about the valuation of her home and increasing property taxes, reflecting a sentiment of distrust of the tax evaluation process:

They just come, put a value on it. I questioned it this year. And I said how's the value of my home changing when this is the year I didn't do anything unusual to it? I didn't have any enhancements to the outside. They couldn't see on the inside. But, I think I put down new runners on the steps. That's it. But they increased the value of my home, and I'm looking at the neighborhood, and I'm in a nice little neighborhood. But, I don't see an unusual number of people moving in and out, so I'm not understanding how they can assess those taxes. So, that's a little disadvantage. (P48: FG7, Site B)

Some, however, saw tax advantages in homeownership:

There's a tax advantage of that if you - if you can itemize deductions, you get the mortgage deducted, and recently - with so many deductions was gone away, for mortgage, it is still one of the best - one of the only things that exist. (P2: FG1, Site A)

Disadvantages: Finding Help

Five of eight focus groups discussed the issue of finding help to adequately maintain one's home. Many times, this discussion was placed in the context of getting older and concerns about paying for help:

And, wouldn't it be nice if somewhere. . . you could call and get someone that is responsible recommended that didn't take all your savings to repair your roof? (P18: FG3, Site A)

In addition, trust was also a concern:

Lot of subcontractors are not honorable people. They're not honest. They'll steal. They'll over charge you. They'll hide if you're paying them by the hour and stuff. I've had a lot of bad experiences with subcontractors. (P19: FG3, Site A)

Focus group participants shared many of their thoughts and feelings about what it was like to be a homeowner, with the majority of participants expressing that homeownership, despite its advantages, as being more advantageous than disadvantageous. While there were many participants who had a number of concerns

about their ability to keep up with financial aspects of homeownership such as taxes, insurance, maintenance and upkeep, these concerns were outweighed by the pride of ownership, having a place for family, the benefits of being part of a neighborhood and larger community, and a place you could call “yours.” The next section focuses on participants’ thoughts and feelings about Medicaid estate recovery and long-term care.

Medicaid Estate Recovery

Following the discussions on homeownership and the meaning of home, participants were provided a brief description of the Medicaid program and long-term care, and an overview of the estate recovery program. They were then asked: “What, if anything, had you heard about estate recovery for long-term care services through Medicaid before coming to this meeting today?”

The main findings from these discussions are: 1) participants had little, if any, awareness of estate recovery prior to coming to the focus groups; 2) perspectives on support versus non-support of estate recovery policy varied both within and across groups; 3) estate recovery was viewed less favorably by Site B participants who strongly opposed estate recovery; 4) there was more ideological variance on views of estate recovery than I anticipated coming in to the study.

Major themes that emerged during the discussions on estate recovery included the need for education and information, concerns about fairness and equity in long-term care, social versus individual responsibility, criticisms of government and politics, and the importance of inheritance.

Knowledge of Estate Recovery

Participants across the groups had varying levels of information about estate recovery policy. Some knew very little, some had anecdotal information and others had outright misinformation. Many participants were surprised to learn about the policy, and angry that they had received no information about the program up until this point.

Within-group, and across-group differences were present on estate recovery. In one group, a Site A group consisting of nine participants, (Group 3), the overwhelming majority of comments supported that participants had some knowledge of estate recovery prior to coming to the group, albeit anecdotal. In the remaining seven focus groups, comments reflecting “knowledge” and “no knowledge” of estate recovery were fairly evenly divided within the groups. More often than not, however, participant comments on estate recovery, whether they were expressing knowing or not knowing about the program, were followed by a question seeking more information or clarification.

When asked, what, if anything, they had heard about estate recovery, participants in Focus Group 1 responded in a fashion that was similar to the other groups:

P2: I don't know anything about it.

P1: It's news to me, too.

P3: I thought you had to sell your home before you became eligible for Medicaid . . . That you could not be a property owner and have assets at a certain level and still be eligible for Medicaid. (FG1, Site A)

Others in a different group acknowledged their concerns about what would happen to their homes:

P35: I knew there was a recovery, but not as far as your home was concerned, you know, if you sell and then - or they take possession, or sell it, or whatever you paid into it. I didn't know.

P36: Well, I didn't know that. I didn't know that they took that.

P33: I wasn't aware of that. But I'm painfully ignorant of anything about Medicaid except you don't want to ever have to do it. I mean that's basically my perception before this. (FG4, Site A).

Estate Recovery: Education and Information Needed

The theme of education and information was evident across all group discussions on estate recovery. Participants seemed surprised, and even irritated that they didn't know about the program, or had little information, and that public information on estate recovery was not made available to them. Some participants made comparisons to the Medicare program and information they received about Medicare just prior to their eligibility. One participant acknowledged the lack of public information on Medicaid and estate recovery:

There seems to be a real disparity about the amount of information put out by Medicare and what's put out by Medicaid. Like, I basically didn't even know there were local Medicaid offices. I don't - I mean, I get all this information from Medicare, especially before I turned 62 or whatever. But, I don't remember ever receiving any educational information from Medicaid. Did any of you ever get anything? They just don't advertise. (P33: FG6, Site A)

A Site B participant also commented on the lack of information available to the public. She adamantly expressed her views in a small group of five older African American women who joined her in the discussion, criticizing the state of affairs on Medicaid information:

I think they should do a much better job of making Medicare and Medicaid understandable so that when people need to make choices that they understand it well enough to make an intelligent selection, and not have to guess or get tricked into somethin' because they just don't know. (P48: FG7, Site B)

She continues:

Like you know, I have been to two classes for Medicaid and Medicare, Part D, and I'm a fairly intelligent woman. But when I walked away, it's like, there is no way the average senior is gonna' understand this.

Others agreed with her, spawning further discussion:

P51: That's true.

P48: It's just not clear. And then they say, oh, just go seek help.

P52: Where?

P48: It's not there. It's just not there. And when I say it's not available - there are people who know pieces of it well enough to get you through *that* piece. But when you ask about the relationships of 1, 2 or 3 items, they don't know it!

P51: And then they put something in really little print where we can't hardly anything. And then if something come up, then they say, you signed, see this? You know - it's right there. But they shouldn't do that. (FG8: Site B)

When asked by the group facilitator what might make things better, a Site B participant offered the following advice:

Just don't make it complicated. If you're safe - even down to the recovery, if you're telling me - let's just take the Medicare the Part D. Don't go through all of that rigamorow. Here's what you pay for this range of money, here's what you'll pay for this range of money, and here's what you'll pay for this range of money. The pattern they have right now is so convoluted that people who apply don't understand it (P48: FG8, Site B).

She continued, emphatically expressing disparaging views about the lack of information available on the topic:

And even with the Medicaid and the recovery plan, we should *not* be in this forum discussin' it. We should have known about it before we walked in. When I say we, anybody that hits 40 years old who is seriously thinking about retirement in the next 20 years ought to understand what they are up against to know or what kind of effort they should be putting forth either savings, or even making plans to take care of themselves.

Cautioning other group members about the importance of having good information to plan for the future, she suggested that without information, people may simply find another way to deal with the problem:

Right now, people are talking about retirement - fifty and fifty-five years old, whereas back in the day it was 65 and 70. People are gonna' have a lot more free time. They're gonna' have a lot more discretionary income, but they may spend it differently if they'd understand what they're gonna' be up against as far as long-term care and those other things.

She goes on:

And, right now, people go along their happy way because they don't - they don't understand any of it. So, they don't know what's comin' along. And, what happens is, people just get angry. And what will happen is you'll have smart people who'll start circumventing the government and basically say to their children, this is yours at age 45 and put it in a trust - where they really try to manipulate them, and then the government won't get paid anyway. So, what's the point? They're just asking us to find ways to circumvent the process. But it's not fair. If they just simply would make it understandable.

Focus group participants, on the whole, came into the focus groups with little or no knowledge of estate recovery. Many participants had "bits and pieces" of information which they readily shared with each other in the group discussions. On the whole, participants seemed surprised that they had not heard much of anything about estate recovery prior to their participation, and stressed the need for accurate and timely information on the program to ensure they could adequately plan for their future needs.

Estate Recovery Policy: Support versus Non-Support

Support for estate recovery policy differed by research location. Site A participants were generally more supportive of estate recovery policy, whereas the Site B participants were generally non-supportive. There were, however, some differences within groups at each of the research sites which will be noted below. Regardless of whether participants agreed or disagreed with estate recovery policy, they were equally emphatic and impassioned in their opinions on the issue.

Two of the Site A groups (Groups 1 & 2) differed among themselves about estate recovery policy. Four of the Site A groups (Groups 3 through 6) supported estate recovery policy. In contrast, the majority of Site B participants did not support the policy, although “conditional support” support was discussed in one of the Site B groups related to quality of care, where three of nine participants expressed that estate recovery would be okay if they received good care.

The following exchange highlights within-group differences on estate recovery policy among participants in a Site A group:

P5: I'm a veteran. I'm a veteran and associated with the Veteran's Administration - never have been able to afford insurance. It's my opinion that if the Veteran's Administration doesn't cover it, I'll die at home. I plan on keeping that house as part of my estate.

Facilitator: So that is important to keep it as part of your estate?

P5: Yes.

Facilitator: What do others think?

A group participant joins the conversation, and challenges the former participant:

P3: You see, I don't think that's necessarily a good idea.

Facilitator: What's not a good idea?

P3: I think it's just fine for the government to take it to cover your expenses if you have to be in a long term care facility, a nursing home or whatever it happens to be. It seems to me that your assets ought to probably pay for that first. (FG1, Site A)

Discussions on inheritance also reflected participants' non-support of estate recovery. Several participants expressed concern about the importance of leaving something for their children and families. One individual from Site A expressed dismayed when she learned about estate recovery policy because, as she explained to the group, she and her husband had saved for their retirement, and wanted to leave a legacy to their children:

My main concern is I would have no inheritance to leave my children. I've always thought I was building something up so I can help them out and leave something behind that I've invested years in, I've built up, taken care of. And, I always thought that in the end, my children would benefit from that in some way. (P10: FG2, Site A)

Another participant in this group felt betrayed by estate recovery. She highlights the contributions she has made as a citizen, examining the fairness of the policy:

I paid property taxes all the way along to have to, you know, contribute to society, to the tax roll and all of that. But, I also thought that I was building this up in order to pass it onto my children or grandchildren. (P9: FG2, Site A)

Group members challenged each other within this group on leaving an estate for their children, continuing to grapple with issues of fairness and personal responsibility:

I don't know how I want to say this, but why should some people get to keep financial stuff and houses and all of those things and then let the state take care of them because they're saving it? 'Cause pretty soon, I don't know where we would be. If everybody could keep what they have for themselves, then, everybody else is going to have to make up that difference. We all would

like to keep - we have a nice big house, too, and lot of it's so the grandkids can come and swim in the pool, or whatever, but if push comes to shove - it's kind of up - you need to take care of yourself. You know, we can't always look out for somebody else to be paying our bills when we're sitting with our own means. (P7: FG2, Site A)

The issue of fairness related to estate recovery policy was also debated by one Site A participant who struggled with the issue, bringing vestiges of the “worthy” versus “unworthy” poor into the picture. This concept was raised several times in discussions on Medicaid and estate recovery. The issue of “non-homeowners” was raised again:

It's hard to judge because there are those of us – and, of course the whole group are homeowners – but there's a whole bunch of people that never have been (homeowners). They have always spent their money on vacations, or get their hair done, different things that and have no equity in anything.

She continued, angrily:

When the time comes, they're all taken care of because they *don't* have a home, where those of us that put our money in our house and in the land, so to speak, we shouldn't lose just because – I like to think of us, you know, as being more practical. And, they'd be taken care of, where we'd have to give up our inheritance because we chose a different path with our money. . . it's not fair to those of us who are homeowners cause we have to give up our home where they don't have to, to get the same benefits (P8: FG2, Site A).

Support for estate recovery policy was evident in four of the Site A groups (Groups 3 through 6) who variously stated that they didn't have a problem with estate recovery. One participant from Group 3 notes:

Why should society take care of you if you've had a really good life and you've been able to save for it - I mean this is - dying is a part of life. (P15: FG3, Site A)

Others from the same group shared similar feelings, echoing themes of social responsibility and concern for the common good:

I think it's fair. I think you *should* pay what you use, so that people coming after you will have the same benefit. I don't think - I have a problem with people who shelter their money and give it away before that and then go on the dole, and, I think that's robbing our children. That's about it. (P13: FG3, Site A)

In another group, a participant supports estate recovery policy from a “pay your own way” perspective:

We may not like it, but it is fair that if you use so much for Medicaid then they get paid back because there has to be funding coming up from somewhere other than just taxes or whatever, you know. So, to get money back from the person who used it seems perfectly fair to me. . . Basically, I think we'd want to pay our way. (P33: FG6, Site B)

Distinct from the other groups, one Site B group had a different take. This group was made of nine individuals consisting of eight females, and one male who was a respected leader within the organization. He and some of the group participants acknowledged that while they felt estate recovery was not a good policy and they were not in favor of it, there were other long-term care issues about which they were also very concerned. Primary among these was concern about the quality of care they would receive under Medicaid. “It would be all right”, noted one Site B participant, “if I got good care.” Three other individuals in this group of nine participants agreed. Seemingly paradoxically, opposition to estate recovery policy was nevertheless strong within this group, with several participants remarking that they didn't like it, and didn't think it was fair. One participant talked emphatically about the struggles of being older and needing help:

Well, we just don't have the funds to take care of our elderly or ourselves without some type of help, and I just don't think it's right that the government come in and take, you know, what our parents, or what we've worked hard for (P41: FG7, Site B).

She goes on:

You know, we got to struggle, and they want to take everything from us.”
(P41: FG7, Site B)

After learning about the Medicaid spend-down provision from other group members, another African American woman in this group shares her thoughts. Like many others in the group sessions, her comments seem to reflect misunderstanding about the differing nature of social insurance programs versus social or public assistance programs:

“Medicaid, to me, is a robber. You pay your taxes, you pay your bills. You’ve done all your duties until you get up to this age. You’re at this age, now you’re bein’ penalized because of your age and your health. And the government is like I feel about the taxes. Why do we have to pay all these taxes? What have they done with the money?” (FG7, Site B)

She continued, joined by another older woman in her group, and further expresses her anger about estate recovery:

P48: I think it’s senior citizens’ abuse.

P51: That’s right.

P48: A different kind of abuse. Nobody’s hittin’ on ya’. But they’re takin’ from ya’.

P51: But they’re still abusin’. (FG7: Site B)

The only male participant in this group, who was quite knowledgeable about programs and services for older adults, had strong opinions about government, Medicaid and estate recovery, and the status of health care for older people. He suggested that the government “back off” of estate recovery:

“I don’t know of any solution to the problem at all except for the state oughta’ step back and say – step back off the properties and maybe let the families even fight if they had to. (P42: FG7, Site B)

Site B participants in Group 8 also had negative views of estate recovery. One participant relates the issue to experiences of African Americans. She poignantly describes her feelings in this compelling narrative:

One of the things that I have watched as the next generation coming through is that old money is only old money because it’s passed from generation to generation. And each generation adds to the money that’s passed before and then subsequently passes it on. As Black people we’ve had a lot to get to the point where we’ve even had something to pass on. And, this may be narrow sighted on my part, but I almost feel like this is an attempt to keep us from having something of value to pass on. It keeps us from acquiring that old money to pass onto the next generation. (P48: FG8, Site B)

She went on to say how she was at the point where she may just hand her money over to her son now, even though she was only 55 years old, and tell him, “Here’s your inheritance. Do with it as you will.” She talked about the struggle and the sacrifice she and her son endured over the years, reflecting a sentiment shared by other group participants:

So, he, my son and I were – I was a single mother for many years. For seventeen years it was him and I. So, I feel like he worked, I mean, we balanced checkbooks, we made stews, we did without, we struggled. We celebrated some things. We had a good life. We were blessed. But it’s like he has – he won’t have anything to show for it if I encounter a major illness and it will wipe out my assets. I just don’t think that’s fair. (P48: FG8, Site B)

Differences were present across the research sites in terms of support and non-support for estate recovery policy. Generally speaking, Site A participants, with some exceptions, were supportive of estate recovery policy, stressing the notion of individual responsibility to provide for one’s own care, if possible. Many Site B

participants saw estate recovery as unfair, and felt that it was important to be able to leave an inheritance for the next generation.

Medicaid and Long-term Care

The final inquiry in the focus groups was directed towards participants' opinions about long-term care and thoughts about using Medicaid to pay for long-term care. Participants were asked: "Now that we've talked a little about homeownership and long-term care services, we would like to hear your thoughts and feelings about what you think you would do if you needed long-term care or help paying for long-term care in the future."

Discussions regarding long-term care ranged from discussions about long-term care insurance, to reverse mortgages, to concerns about corruption and greed in health care, and family versus institutional care. Themes that emerged from these discussions reflected issues of fairness and equity, views of government, politics and the economy, the importance of family, issues related to societal change, and views of aging. Participant opinions about the government were particularly negative. Seemingly paradoxically, while participants across the groups seemed generally dissatisfied with, and distrustful of government, especially its response to health care, they also seemed to wish that the government would do more.

The main findings from the discussion on Medicaid and long-term care are:

1) Medicaid is viewed as a necessary program for those who need it, and an important safety net; 2) most participants preferred to "pay their own way", if they could, in order to avoid what they saw as stigma and bureaucracy associated with

Medicaid; 3) participants believed that the health care system, including Medicaid, needs to be re-evaluated; and 4) it is perceived that older people are often disrespected within the health care system.

Medicaid: A Safety Net and a Last Resort

Five of the eight focus groups regarded the Medicaid program as necessary for those who require it, expressing concern about what would happen to people if Medicaid wasn't there. One group from Site A and two groups from Site B did not discuss advantages or positive aspects of the Medicaid program. This may be due to the dynamic nature of the group discussions which sometimes resulted in not all topics being discussed in all of the groups. The remaining groups offered many impassioned statements on the topic.

While most participants saw Medicaid as a valuable program that should be kept for those who need it, they saw it as a last resort for themselves. In addition, like other group discussions on estate recovery, some comments on the Medicaid program reflected notions of a "worthy vs. unworthy" ideology especially when it came to personal choices made by Medicaid recipients. Participants across all of the focus groups expressed concern about "welfare cheaters."

When discussing advantages to the Medicaid program, one participant shared that he thought Medicaid would enable a person to "get treatment" and some of their needs, met such as going to a nursing home. When it came to his own situation, he hoped that he would never need it. "In my case, I would not have any need for it as long as . . . unless the stock market crashes, and I lose my money. Then, it becomes a

last resort” (P2: FG1). Another participant in the same group shared how he thought Medicaid was a way to show how a society should care for its citizens:

It seems to me that if we’re going to be a humane country at all and not just have all the people laying in the streets, that it is a mandatory thing. I can’t see any alternative to it (P3: FG1, Site A).

He went on to discuss this with others in his group in the following exchange, further illuminating his perspectives on a changing society:

P3: Well, you know, I guess it depends on the kind of society that you want to live in. It concerns me that we don’t seem to have the same value for life that we used to . . .

P2: Of life?

P3: Yeah. I just think we don’t have the value of human life about now that we’ve had in the past. You know, people get shot and nobody seems to care very much . . . but you know, I think humans deserve some treatment and some respect, and then, you know, regardless of what the program costs is something we ought to have. (FG1, Site A)

In another group, a participant shared similar sentiments noting that while he agreed that “governmental programs for those who definitely need them are a good way to go”, and that Medicaid contributed to the “stability of our economy, our society, and our culture”, he was adamant about not ever wanting to use Medicaid himself: “On the basis of this discussion, I will do anything and everything I can to avoid ever needing Medicaid” (P11: FG2, Site A).

While a predominant sentiment in many of the groups reflected a sense of benevolence towards the “needy”, participants were quite reluctant to consider it for their own use. One participant stated: “For those who have nothing, or no family or anyone to depend upon, why Medicaid is the only answer as far as I know because

someone has to take care of those people (P34: FG6, Site A). He goes on to say, “It’s sort of last choice, safety net that, you know, you would hope you never have to go on Medicaid, but if you do, it’s sort of nice to know it’s there” (P34: FG6, Site A). Clearly, participants’ needs to de-identify with the Medicaid program presented an emerging pattern. The following participant’s commentary aptly summarizes the perspectives of many participants who on one hand saw advantages of Medicaid, but on the other hand, how they would not want to use it:

Because, I mean, I personally would hope that I would have enough of my finances to take care of myself till I die. But, if that should run out then it’s sort of comforting to know that something’s there, that you wouldn’t be turned out on the street. But, it’s still the kind of thing I would hate to be collecting Medicaid - like, I would not want to collect food stamps, for instance. But, I think it’s wonderful for people who can’t afford to eat. And, so, as a last resort, safety net, okay. But, you know, I certainly hope I would never have to go on Medicaid. (P33: FG6, Site A)

He goes on:

I think for the people who really are destitute it’s wonderful that Medicaid is there because, I mean there are so many children and elderly both that desperately - I mean, they have nothing. And, so it’s great that that welfare, whatever it is, is available for those who truly need it.

Reflecting views on poverty, and worthy versus non-worthy ideology, again, surfaces as he continues:

I’m always bothered terribly by when I see people using food stamps, for instance, to buy T-bone steaks, and it’s always seemed to me that along with welfare or long-term care and everything there can be some education, because I’ve seen people use welfare stamps to buy, you know, single servings of popcorn at 10 times the price of what a bag of popcorn would have sold. I don’t know if they don’t know, they don’t care, I mean, I guess they can’t buy cigarettes with welfare stamps now, but you know, when you see them paying for their groceries, and then they’ve got two cartons of cigarettes there sitting beside it, that always bothers me a little.

Some participants in another group, also discussed this, and cautioned others:

P7: I'm grateful that I have enough income and that I have insurance that I would probably never qualify. Even if I sold the house, or didn't sell the house, I probably would never get Medicaid. But for those who need it, I think they should get it.

P9: Those who need it they should really also check them – that they're really qualified that they need it. Look what happened in Katrina. (FG2: Site A)

Another group member chimed in the conversation:

P8: If there was some way to stop the abuse I think most of us would feel a lot better (FG2, Site A).

Still others reflect on welfare abuse, implicating younger people:

P41: Welfare helps, you know, not just the elderly but the younger people, but you see so much of it being abused by the younger people, but yet I feel like they tend to forget about the elderly (FG7: Site B).

Members of one group expressed how they thought people who used Medicaid were viewed and treated:

P33: Yeah. There's a stigma about people who are on Medicaid. They didn't do what they should have done or they wouldn't be doing that. I mean, it's like people not wanting welfare. I mean, it's put in the same category, you know, this is just like taking welfare. And had you done what you should have you wouldn't be here.

Facilitator: What do you think about that?

P33: I don't think it's necessarily true, but I think the feeling's out there a lot.

P36: It shouldn't be.

P33: And, as she was saying, I think that the way you're treated like if you go to a doctor's office and they know you're a Medicaid patient you're going to - they feel differently about you, is my thought, than if you're paying for it yourself. And, I think the people involved, the caregivers and so forth have a negative opinion of people who are on Medicaid (FG6, Site A).

Closely related to views of Medicaid, discussions of poverty also emerged. One group member who contended that “We’ll always have poor people,” was careful to acknowledge that, “Sometimes it’s the hand that’s dealt them, but sometimes it’s also where they don’t know how to manage money” (FG22: FG3, Site A).

Seven of the eight focus groups discussed what they saw as negative aspects of the Medicaid program. The majority of these discussions emerged from Site B groups. One group member talked about how mortgage lenders were currently encouraging people to use the equity in their homes to pay for long-term care. Reflecting on this, he noted that “a person might be better off to die a pauper than let the government come in and take everything”. He was particularly upset about the extension of the look-back period in Medicaid being extended from 3 to 5 years to qualify for Medicaid without a penalty, criticizing the government:

And in this administration, particularly, when they increase the number of years that you had to maintain that person from 3 years to 5 years. Before that, after three years you could change the property over. Five years now you have to go. Well, can you imagine maintaining somebody in your home for five years? Unassisted? (P42: FG7, Site B)

Others in his group supported him, noting that it would be “hard to do” to maintain a person in your home for five years with no assistance” (P41: FG7, Site B). Another group member followed up: “It’d be real sad. My goodness” (P44: FG7, Site B).

Discussions of long-term care and Medicaid also included thoughts about where participants would like to receive long-term care services. The overwhelming majority of participants revealed that they wished to receive care in their homes, if possible. Only two participants identified a nursing home as a place that they felt they

would like to, or “have to”, go if they needed long-term care. Participants were careful to acknowledge the burdens that care giving could place on their family members but seemed to prefer care from their families, especially since there was a great amount of concern expressed about finding trustworthy and affordable assistance.

Numerous comments about long-term care were related to the costs of care, and the cost of health care services in general. Discussions led to frequently expressed concerns about corporate greed, “Big Pharma”, and profit motives in health care. Some talked about older people they knew who went without basic necessities in order to buy medication:

I will go into any pharmacy and I will find an older person that gets up there and they say, for one little medicine, you know, three hundred dollars. . . well, let’s see do I eat? Do I get my medicine or do I eat? And why should we have to, you know, even settle for those three choices? I mean, it’s - I see it every day. It’s really sad. (P16: FG3, Site A)

In direct response to this comment, a fellow group member responded:

“It looks to me like we all need to go to Washington. Or get somebody in Washington that goes after the pharmaceutical companies and goes after all those big, big kings and queens that donate money to keep them - country going the way they like and not, you know, have to do paybacks. Cause, it’s all greed. Amounts to greed. (P18: FG3, Site A)

One person in this group who was highly informed about long-term care issues, especially long-term care insurance, suggested a remedy, while criticizing the government’s role:

But, you know, maybe we should all be paying more taxes towards long-term care for ourselves. Maybe - the long-term care industries

- nursing homes and everything - I think twenty-five percent or more the money goes to profit for millionaire owners of these things. So, if the federal government was competent and could handle all of that . . . (P19: FG3, Site A)

A quick retort to this participant's comment was offered by a group member: "Are you keeping up on which candidate's gonna' do that? Let us know" (FG3: P16, Site A). Following group laughter at this comment, he continued with more on his perceptions of political candidates: "That's very good what you said. Nobody's actually spoken about that. They say anything. You know they say anything, and then all of a sudden they change, you know. It's completely corrupt." (P19: FG3, Site A) Another group member took it one step further, offering a scathing indictment of the health care system. While this participant's comments are lengthy, they bear repeating in their entirety because they exemplify many of the tensions presented in other participants' discussions on the health care system.

Let me interject something else here. The medical profession all makes a profit. A huge profit. Insurance companies make huge profits. Doctors are in the business, we hope, to save lives. Firemen are in the business to save lives. Police are in the business to save lives. But do you ever see a profit sheet coming out of the fire department or the police department? They're not in a money-making position. (P15: FG3, Site A)

She offers an alternate stance:

And, maybe the problem is we should look at doctors and insurance companies in a different way instead of them being high-priced whatever they do - prescription writers, I think. And, the idea that they're getting kickbacks on every prescription they write, so every time you get your prescription filled, they're getting money on that. Maybe some of that should be given back or stopped or considered illegal. And, if they weren't writing so many prescriptions the insurance companies wouldn't be making, the pharmaceutical companies wouldn't be making so much money.

Maybe there needs to be a re-disposition of funds in this country. I mean, it's a different way of looking at it, but you know. Damnation. The guy who goes into a burning building to save someone's life that he doesn't know who it is, and he probably is not going to say thank you at the end of it. I just think it's wrong. (P15: FG3, Site A)

This study also sought to examine if, and how participant perspectives on estate recovery may have evolved as a result of the group interaction. Findings provided limited results on the research question: "How do perspectives on estate recovery in Medicaid evolve when participants have had a chance to explore and discuss estate recovery with a group of their peers?" There were few comments that suggested that participants' views on estate recovery had changed, or evolved via the group discussions. This may be due to the fact that most participants had limited or no knowledge of estate recovery coming into the groups and therefore, and were only able to share "bits and pieces" of information. It may also be due to the broad array of issues that were discussed, which ultimately limited the amount of time spent on each topic. There were, however, some instances were presented that suggest participants' understanding of Medicaid estate recovery had changed, or evolved during the group discussions. One common misperception a number of participants held was that a person had to sell their home and/or not be a property owner in order to qualify for Medicaid. Another participant asked: "If you're not on Medicaid and you're not receiving the benefits, will they still get your property?" (P9: FG2, Site A). Others wanted to know what would happen if their home value was greater than what was owed to the Medicaid program. One participant from Focus Group 4 who discussed

advantages of Medicaid, expressed concerns about the present value of his home, what it might be in the future, and how Medicaid fit into that picture:

P24: Well, an advantage would be that the dollars that you use today are at today's rate. And when you go to sell your house in the future, your house will hopefully have increased in value. And the charges will be from the current rate rather than the inflated rate. I mean, do they charge interest on the money? I mean, how does that work? That's a good question. Is the bill - if it costs me \$26 this year, and it costs me \$30 next year - are they gonna' increase the value? Kind of like the can of beans that sits there and they keep raising the price? Or, you know, I agree with you - I just don't trust that the money's gonna' be there but there's the inflated value. Who determines the value of my home? Who determines what I owe? How do they keep the books? Do they charge interest? (FG4, Site A)

Due to the complexity of the Medicaid program and estate recovery, and the dynamic nature of focus groups, many of the questions posed by participants were not fully answered within the focus group discussions. A number of participants did share, however, especially at the member check meetings, that their participation in the groups allowed them to at least have initial exposure to estate recovery. In some of the focus group discussions, and in the member check meetings as well, many participants noted that they would follow up with the appropriate agencies and organizations to get further information so they could adequately plan ahead for their futures.

Summary

This chapter has presented participants' responses to the primary research question in this study which was aimed at exploring a diverse group of older adult homeowners' perspectives on the Medicaid estate recovery program. Related topics on the meaning of home, advantages and disadvantages of homeownership, support

and non-support of estate recovery policy, and thoughts about Medicaid and long-term care were discussed. Themes involving the need for knowledge and information, views of government, politics and economics, the importance of family, perspectives on a changing society, and views on individual versus public responsibility for long-term care have emerged from the discussions.

CHAPTER 5

DISCUSSION, IMPLICATIONS AND CONCLUSION

Discussion

This qualitative study employed focus group methods to gather perspectives of a diverse group of older adult homeowners on their thoughts and feelings about the Medicaid Estate Recovery Program. The findings from this study offer a number of possibilities for social work practice, policy, and research. First, I will provide a brief summary and discussion of the study's major findings. Then, I will present implications of the study followed by concluding remarks.

Findings and Discussion: Homeownership

The primary findings from this study show that participants across all of the focus groups were pleased with their status as homeowners and the benefits it offered, despite negative aspects they identified such as maintenance, property taxes, and other costs associated with home owning. Consistent with the literature on the benefits of homeownership, participants invariably expressed positive sentiments which spanned the areas of economic, social, psychological/emotional, and health-related benefits. The ability to build financial security, being part of a neighborhood and community, having "something that's yours", a place to raise a family, and the freedom and independence "to do what you want" were some of the reasons participants gave for why homeownership was beneficial and why it was preferred over non-home owning.

Participant perspectives on homeownership clearly align with tenets of social constructionism, reflecting the multiple meanings and realities people hold about their homes. Discussions about what it was like to be a home owner brought a wide range of feelings and perspectives. Importantly, participants reflected on the nature of time and how their lives have changed over the course of their tenure as homeowners. Consistent with social constructionist thought, participant exchanges demonstrated how the meaning of home evolved over time as they raised children, built a financial foundation, and became attached to their homes and neighborhoods. When they were younger, they struggled to make the mortgage payment and to make ends meet. One Site B participant described her journey as a homeowner: “I mean, we balanced checkbooks, we made stews, we did without. We struggled. We celebrated some things. We had a good life. We were blessed.” (P48: FG7, Site B). Looking back, a sense of satisfaction for their discipline and hard work seemed to have paid off. This sentiment of gratitude and feeling “blessed” was common.

In spite of many positive reflections on homeownership, thoughts about an uncertain future and a rapidly changing society did not escape the discussions among focus group participants. The unpredictability of the market economy, the vulnerabilities they faced as older people, and concerns they held about the status of health care made them uneasy, despite the fact that they were generally pleased about their home ownership status. As one gentleman from Site A noted about his home: “I suppose you could lose it somehow” (P1: FG1) reflecting on the vicissitudes of the market economy. Given the current foreclosure crisis and declining home values

across the United States at the time of this writing, his comment was somewhat prescient.

Findings and Discussion: Estate Recovery

Perspectives on Medicaid and estate recovery were different both within and across the groups, but most notably between research Site A and Site B. While more groups, overall, expressed support of estate recovery policy than I anticipated at the outset of this research, the finding that the Site B groups were more strongly opposed to estate recovery than were the Site A groups is not particularly surprising given the stark differences in economic and other socio-demographic characteristics between the two. Not unexpectedly, discussions about estate recovery were inextricably tied to participants' views on the importance or non-importance of inheritance.

Several factors may contribute to the difference of opinion between Site A and Site B on support versus non-support of estate recovery policy. First, however, it is important to note that how people think and feel about estate recovery provisions may be very different when they are faced with an imminent need to make long-term care decisions, as opposed to merely reflecting on a future state, as was the case in these discussions. Secondly, it may be that having more detailed information on estate recovery would have the potential to change people's views on the issue.

Site A groups consisted primarily of White individuals who resided in various metropolitan communities within a major Midwestern city. Forty percent of Site A group members resided in a county with a poverty rate of 3.6% with the remaining participants residing in areas where poverty levels ranged from 14.6% to 17.4%. In

terms of income, nearly 75% of participants in Site A reported income levels of mid (\$19, 001 to \$39,999) to high (\$40,000 or more). Overall, Site A participants were more educated and had higher incomes than their Site B counterparts. To my surprise, and contrary to my social work practice wisdom and contentions on estate recovery cited in the literature, most of the Site A groups expressed support for estate recovery policy, although there were several participants within two Site A groups expressed opposition to estate recovery. Those that supported estate recovery contended that inheritance for their children or heirs was less important than their responsibility to “pay their own way”, reflecting notions of an individualistic value system. However, they were also proponents of the “common good”, and felt that it was important to use their own resources first in order to preserve the Medicaid program for those who were less fortunate and “need it more”. Furthermore, many in the Site A groups expressed disapproval of those who would protect their assets to qualify for Medicaid, as well as disapproval of “welfare cheaters.”

Interestingly, participants across the groups highlighted the importance of keeping the Medicaid program for those who needed it, yet most participants, when it came themselves, did not want to be associated with Medicaid, seeing it only as a “last resort.” While they expressed concerns about stigmatization of people on “welfare”, noting how they were often treated poorly in the Medicaid system, they simultaneously disparaged those who behaved in ways that were not deemed appropriate for people on Medicaid, such as purchasing cigarettes or T-bone steaks. These seemingly contradictory views reflect philosophical differences about the

nature of publicly funded programs such as Medicaid. According to Handler and Hasenfeld (2006), notions of “deserving” and “undeserving” individuals have historically been the bedrock of U.S. welfare policy and tied to ensuring that people who could contribute to their own survival should do so through the labor market. They contend that when we view welfare recipients in negative ways, and define poverty in terms of individual behaviors as opposed to structural and systemic issues, we ignore having to address social and economic conditions that lead to inequality and poverty (Handler & Hasenfeld, 2006).

Group participants in Site A continued to wrestle with issues of fairness and equity, and debated the issues among themselves. While some believed that Medicaid should be available to everyone, others struggled with why some should work hard and save for a home and be penalized by estate recovery, when others would still be able to have Medicaid coverage when they hadn’t saved, or had otherwise spent their money foolishly. Some reminded other group participants that they “shouldn’t judge” because they didn’t really know the reasons why people “ended up” like they did. It may also be that views from participants in Site A participants that supported estate recovery may be related to higher levels of education and income, predisposing individuals to more liberal views regarding social justice issues. A future study focusing on working class individuals’ views of this issue may yield different perspectives.

In discussions on inheritance, Site A participants who had children and grandchildren noted that their children were “doing well” and they didn’t necessarily

need their inheritance. They discussed several instances where they had been able to help their children along the way, either paying for their educational expenses, or lending them money for various reasons from parental resources like home equity. Leading scholars note that these efforts, referred to as “en vivo” inheritance, are often overlooked in discussions of inheritance as it is usually thought of as a post-death transfer (Butler, 2001; Shapiro, 2004). In the case of assisting with children’s education, for example, en vivo transfers may confer the advantage of avoiding student loan debt. Shapiro (2004) notes that these types of transfers can be thought of as “head start assets” (p. 13) which boost people beyond their own means, and which are not usually available to poor and minority families. Down payment assistance is another form of en vivo inheritance that allows access to homeownership, improved educational opportunities, a chance to live in a better community, and increased social status (Beverly, Sherraden, Zhan, Shanks & Nam, 2008; Shapiro, 2004). Low-income families, on the other hand, are less likely to receive down payment assistance (Shapiro, 2004).

Site B groups comprised of older African Americans who, like Site A participants, resided in a large Midwestern metropolitan area. All of the Site B participants resided in a county that held the second highest poverty level in the state at 17.6% (U.S. Census Bureau, 2006). Income and educational levels of Site B participants were significantly less than their Site A counterparts with nearly early two-thirds of Site B participants having an annual household income of \$19,999 or less.

Like the Site A groups, Site B individuals were willing to pay their share of long-term care costs if they could, but opposed estate recovery policy because they felt they should be able to pass their estates onto their children and grandchildren. A number of Site B participants expressed that they had worked hard, paid their taxes, and had been “good citizens”, yet it seemingly it “got them nowhere” if they could not pass on what they had worked so hard to earn onto their children or grandchildren. This likely reflects the fact that homeownership comprises their only held asset.

One Site B participant saw estate recovery as a punishment for being getting old and having poor health. “Medicaid to me is a robber”, noted one African American elder. Some in her group likened Medicaid estate recovery to senior citizen abuse: “. . . nobody’s hittin’ on ya’. But they’re takin’ from ya’.” (P48:FG7, Site B). Another participant suggested that estate recovery seemed like an attempt to keep Black people from gaining wealth, or “old money”, to pass on to future generations, again, reflecting themes of fairness and equity. Some of the discussions in the Site B groups reflected a sense of dismay about the Medicaid process and many participants felt it was unfair that people had to impoverish themselves in the spend-down process, losing what little joy they found from previous hobbies or activities since money spent on such items could not be counted towards spend-down. Like Curry (2000) found in her study of Medicaid estate planning, participants from Site B also seemed to hold a sense of fatalism.

Furthermore, while Site B participants were opposed to estate recovery, their experience seemed to reflect, in a perverse sort of way, what economists refer to as

“opportunity costs” (Jensen, 1982). Opportunity costs refer to what might be missed by choosing one alternative over another. In other words, what might a person be giving up by the choices they make? What is the next highest-valued alternative? The next highest valued alternative to receiving care under Medicaid (and subsequently having to comply with estate recovery) from the perspectives of this group, was the issue of quality of care. Participants in one of the two Site B groups felt that estate recovery was “moot” because they believed that quality of care was the most important, and from an opportunity costs perspective, the highest value alternative. Importantly, however, they did not believe that they would actually be able to *get* quality long-term care services. Based on their experiences with family members and others they knew who had received long-term care services in various settings, they were convinced that the quality of care people received was a more pressing issue than considerations of estate recovery. They told how they had known people who hired long-term care help at home who had their money stolen from the workers, or those who were abused and neglected in long-term care settings. They also cited how the medical profession didn’t seem to care about older people, noting, “You’re just a throw-away person.” Clearly, this group expressed sentiments reflecting marginalization, not surprising given the historical legacy of discrimination and oppression experienced by African Americans. They seemed to be saying that not only would they lose their estate if they used Medicaid, but on top of it, they would not receive good care anyway. Some participants in one Site B group said that estate recovery would be “okay if you got good care”, (P41:FG7) but they clearly did not

believe that was going to happen. Furthermore, they seemed to attribute poor quality of care issue to the “profit motive” in the current health care system, noting, like some Site A participants, that if the profit motive in health care were removed, health care may improve.

I was particularly struck by the lack of discussion on advantages or positive aspects of Medicaid by Site B groups. To be fair, one group from Site A did not discuss advantages, either. Obviously, the dynamic nature of focus group discussions does not allow for inclusion of every aspect that is covered by other groups. Overall, the perspectives shared by Site B participants about estate recovery and Medicaid reflected voices that seemed distrustful and sadly resigned, lacking faith in what they saw as the federal government’s willingness and ability to make meaningful change. Distrust of government by minority groups is not surprising. In a recent study by the National Public Radio (NPR), a Kaiser Family Foundation, and Harvard University’s Kennedy School of Government (1999), African Americans were significantly less likely to trust their government to “do what was right” (p. 1) and to solve problems than were Whites and Latinos.

Discussion on participants’ views of estate recovery are incomplete without some exploration of issues of differential inheritance rates between Whites and African Americans, institutional supports and barriers to wealth acquisition, and discussions on asset-based policy. Given these considerations, it is not difficult to understand why African American focus group participants expressed opposition to estate recovery policy.

Data on inheritance presented by Shapiro (2004) shows stark differences in the amounts of inheritance between African Americans and Whites. Shapiro notes that Whites receive at least three times larger amounts of inheritance than do African Americans. He further notes that among 45-60 year olds, this figure increases to nearly 20 times more among Whites than African Americans. He also shows that the median inheritance for African Americans is less than \$1,000, whereas more than one-half of White inheritances were \$10,000 or more. He further notes, “. . . family inheritances, especially financial resources, are the primary means of passing class and race advantages from one generation to another ” (p. 61). When considering these figures, it is easy to see how one might question the fairness of estate recovery policy.

Furthermore, the case can be made that lower income and minority individuals, like those who participated in the Site B focus groups, could actually benefit *more* from inheritance. They may be more adversely affected by estate recovery policy because, with limited incomes, they have less money to save, and therefore, less potential to build wealth. Moreover, as noted by Beverly and colleagues (2008), minority individuals are more likely to live in neighborhoods where property values offer lower returns on investment. Furthermore, as noted by a number of scholars in the field, many minority individuals and families are left out of the mainstream institutional structures that support wealth accumulation, such as benefits accrued via the U.S. tax code. Lower income and minority individuals often do not benefit from these incentives because they have little or no tax liability, and therefore, do not itemize deductions - a necessary requirement to claim exemptions like the

home mortgage tax deduction (Beverly, Sherraden, Zahn, Shanks & Nam, 2008; Shapiro, 2004). Glaeser and Shapiro (2002) also note that only 13% of homeowners in the bottom 40 percent of the income distribution are known to itemize deductions, essentially leaving out a large group of people, many of whom are low-income homeowners. Shapiro (2004) also notes that a typical African American home buyer will pay lending institutions nearly \$12,000 more in interest over the life of a mortgage than the average White home buyer due to differential lending rates.

It should be noted that the asset levels of participants in both research sites employed in this study, aside from their status as homeowners, is unknown, and therefore, assumptions cannot be made that lower income group participants in this study were necessarily asset poor. It is worthy of consideration, however, that asset poverty, which refers to the ability of a family to maintain a poverty level of living for up to three months, disproportionately affects African Americans in the United States (Haveman & Wolff, 2004). Furthermore, poverty rates among elderly blacks are approximately tripe than those of Whites (Butrica, 2008). According to Haveman and Wolff (2004), about one-third of all Americans lack sufficient net worth to do this. They also note that some groups are more disadvantaged than others in this regard. Notably, in 2001, using the net worth standard, they note that African Americans showed an asset poverty rate of 62 percent. For individuals with less than a high school education, the asset poverty rate was 60 percent (Haveman & Wolff, 2004).

Findings and Discussion: Knowledge and Information Needed

Site A and Site B groups all expressed a need for further education and information about the Medicaid Estate Recovery Program, with many participants astonished, and some angered, at having first learned about the program in the focus group discussions. Participants in all of the focus groups had many questions about Medicaid and Estate recovery policy, with many only having bits and pieces of information, if any, prior to coming to the focus group discussions. While some group members stood out in both Sites A and B in terms of their greater level of knowledge of Medicaid, long-term care and estate recovery, most had little information, or no information, on estate recovery. Many participants across both research sites suggested that the government should be more forthcoming about estate recovery: “ . . . we should *not* be in this forum discussin’ it. We should have known about it before we walked in” (P48: FG7, Site B).

In the AARP and ABA report, “Medicaid Estate Recovery: A 2004 Survey of State Programs and Practices”, the authors note that lack of information about estate recovery has been a pressing concern since the federal estate recovery mandate began in 1993 (Karp, Sabatino & Wood, 2005). As cited in their report, timely, clear and accurate information about estate recovery is necessary, yet many states offer little information to the public. While some states presently use mechanisms like brochures, web sites, toll-free telephone numbers, and trained staff to educate the public, it is not readily known how this information is utilized and distributed (Klem & Wood, 2007).

As stated in Chapter 2, each state is required under guidelines issued by the Centers for Medicare and Medicaid (CMS), to provide a “general notice” of estate recovery at the time of Medicaid application. While most states meet this requirement, the manner in which they do so is often inadequate, leaving some individuals and their families without critical information. Oftentimes states provide only a simple one line description of estate recovery within a Medicaid application that is filled with other important beneficiary information. This method of delivery makes it difficult for individuals who apply for Medicaid to discern what is important, or even to miss the information altogether, especially since many who apply for Medicaid may be under stress, sick, or physically impaired. It is vitally important that when applicants enroll in the Medicaid program, that they are aware that they are agreeing to pay back to the state the amount equal to the care that they received (Klem & Wood, 2007). Implications of not having this information can be profound. Some of the consequences may be not learning about the right to appeal an estate recovery claim; being unaware of exemptions or deferrals for which individuals may be eligible; not being made aware of about the minimum claim value of an estate; not being informed about important lien provisions of Medicaid; and, not being informed about undue hardship criteria. Knowing about undue hardship provisions may be especially important in cases where an estate consists of an income-producing asset, which would cause a loss of livelihood for survivors (Klem & Wood, 2007). Clearly, findings from this study suggest that participants are ill-informed about estate recovery policy, and draw attention to the inaccuracies in neo-classical economy

theory that assumes people have perfect knowledge of market factors upon which to make decisions (Beverly, Sherraden, Zhan, Shanks & Nam, 2008).

To encourage informed decision-making, early and accurate information about estate recovery is essential. Making materials available in multiple languages, using reader-friendly language and readable materials are paramount, especially given the anticipated surge in minority populations throughout the United States (U.S. Census, 2000). In addition, providing user-friendly web sites, and clear application notices and explanations of estate recovery at the point of eligibility, and training eligibility and other staff can enhance the likelihood that individuals are informed in the best manner possible (Wood & Klem, 2007).

Finally, a primary concern regarding information on estate recovery concerns transfer of asset provisions of the Medicaid program. While the rules regarding asset transfers to qualify for Medicaid have changed as a result of the federal Deficit Reduction Act of 2005, it is not illegal to transfer assets to qualify for Medicaid, although as previously discussed, a penalty period is imposed. Individuals who are poor, socially isolated, or sick may have little access to information about this option, or less likely to be able to afford legal consultation regarding appropriate distribution of their assets, or their legal rights under the federal Medicaid program (State of West Virginia, 2005; Karp, Sabatino & Wood, 2005). Wood and Klem (2007) in their most recent report on estate recovery, show that public information and notification on key aspects of the program continue to vary widely by state in terms of content and clarity, nearly fifteen years after the initiation of estate recovery policy.

Implications

Implications for Social Work Practice

Several important implications for social work practice emerge from the findings in this study. First of all, social workers must have up-to-date and accurate information about the Medicaid program and estate recovery. They must also be willing and able to relay this information to clients and their families in a manner that is clear and understandable. Social workers may be reluctant to inform clients about estate recovery for fear that clients may forego needed services once they learn about the program, yet clearly, social workers have an ethical responsibility to inform clients so they can make their own decisions as to whether or not Medicaid is a choice they wish to pursue. Social workers should also be prepared to advocate for clients rights to self-determination during the process of applying for Medicaid benefits, especially with vulnerable older individuals who may be facing a loss of control in many facets of their lives.

Social workers should also advocate for improvements in, and access to, public information about estate recovery, recognizing the need for timely, readable, and language-appropriate materials for all ages. That clients are provided with more than superficial information on the program is essential. One way this could be done is through local involvement with human service organizations, aging network providers, and multi-disciplinary coalition groups. Social workers could also advocate with state and federal level policy leaders to advocate for non-discriminatory policies.

Social work practice should include a thorough assessment of client's values and perspectives on the importance of inheritance and legacy, the meaning of home, and their views of Medicaid and estate recovery program. As well, social workers should pay special attention to promoting open dialogue with clients and their families about estate recovery, recognizing that there may be widely varying views on the topic. Social workers should be cognizant in assessment practices and interactions with clients, that estate recovery may have the potential to be a barrier to use of Medicaid services, and understand that the possibility exists that clients may feel coerced into protecting their estates by family members or others and thereby deny Medicaid services. Social workers should be able to provide clients with contact information and resources to obtain legal assistance related to estate recovery so that all clients have the opportunity to learn more about their legal options and rights. This may include assisting clients and their families with referrals to elder law attorneys who specialize in Medicaid issues.

When possible, social workers should engage in, and promote research efforts that aim to increase understanding and knowledge about estate recovery, relying on practice wisdom as an adjunct to sound empirical studies. Finally, social workers should strive to rebuke practices that silence the voices of those who are marginalized, particularly those of minority individuals who may be adversely affected by estate recovery policy. This may be accomplished in several arenas such as at the organizational level through day-to-day interaction with social work peers

and others involved in the client delivery system, as well as at state and federal policy levels which will be discussed further below.

Implications for Social Policy

Consistent with discussions in the empirical literature on estate recovery, Medicaid policies should include a requirement that all states provide clear and easily accessible information on estate recovery (Klem & Wood, 2007). As noted previously, there is wide variation among the states on how this is done.

Another area of concern for social policy regarding estate recovery relates to issues of consumer protections. Because estate recovery is essentially a loan that must be paid back, basic protections of informed consent processes (Reamer, 2002) should be mandated. Federal policies should consider incorporation of true informed consent standards in Medicaid estate recovery policy to ensure that basic rights of due process and informed consent are respected. These policies should include commonly accepted standards of informed consent which include recognition of voluntary participation, competence, and full disclosure (Reamer, 2002). Focus group participants in this study discussed how decisions concerning their estates were made *for them* by virtue of this estate recovery policy which they very much resented. Kapp (2006) contends this violates individual rights to choose how they wish to handle their estates, and interferes with their fundamental rights to liberty and ultimately self-determination under the constitution.

Alternative policy approaches to estate recovery should also be explored in order to enhance the opportunity for intergenerational wealth transfer, especially for

low-income and minority individuals. Examples could be drawn from the state of Michigan's proposal which suggested for a five dollar per year surcharge on mortgage holders which would essentially have eliminated estate recovery. States could also raise the minimum estate value threshold to reflect median home values in respective states. As discussed earlier, states have varying thresholds under which they will not recover for Medicaid services. Some states will recover a minimum homestead value of \$50 (Wisconsin), whereas other states have a higher threshold. The state of Alaska, for example, exempts the first \$75,000 of the estate value from recovery, and the state of Kansas sets its threshold at \$10,000 of real property and \$2,000 personal property for an exemption to recovery (Karp, Sabatino & Wood, 2005).

Social workers also have a role in the social policy arena. By virtue of the profession's commitment to social justice, social workers have a responsibility to advocate for fair and just social policy. Indeed, as noted by Weick (2000), social work's commitment to poverty and the needs of marginalized groups is not highly acclaimed in the public's mind, nor are the needs of those most vulnerable and discriminated against. Weick wisely reminds social workers that they must "give adequate voice to the skills that distinguish them from other helping professions" (p. 400) in order to be effective client advocates.

Implications for Research

Empirical studies are needed to gather more information about the estate recovery program including investigation of whether estate recovery serves as a barrier to the receipt of Medicaid services, and the extent to which low-income and minority households are impacted by estate recovery. While the states are required by CMS to report the number of estates against which recovery was completed (Klem & Wood, 2006) information about the racial and ethnic composition of beneficiaries whose estates are affected by estate recovery is not required, nor is it collected by the states. Given the current U.S. mortgage crisis and the apparent differential impact of this phenomenon on minority groups, more studies are needed that explore the effects of lending and foreclosure practices on minority homeowners (New York Times, 2008). An additional area for research relates to whether or not estate recovery is cost-effective. Many states have grappled with whether or not the costs of administration and recovery outweigh the modest amounts states receive, but little reliable data is available (Karp, Sabatino, & Wood, 2005).

Limitations

Several limitations to this study should be noted. First, this study was confined to one geographic area only, and views of participants may not reflect those of individuals in other areas. Broadening the scope of the study to include individuals from other parts of the country may yield different information. Secondly, there were an unequal number of groups in this study when considering characteristics of race and ethnicity. Six groups were conducted, that nearly exclusive participation by

Whites, and only two groups were held with African American individuals. Future studies should consider equalizing the number of groups to ensure adequate representation of all voices.

An additional limitation of this study is has to do with screening criteria. Participants in this study were selected based on their status as homeowners and their age. It was ascertained that most participants were at a stage in their lives when they would be thinking about their future needs, rather than being actively engaged in making long-term care decisions, or being a present beneficiary of long-term care services. It could be that people would feel differently about estate recovery policy when they are actually faced with having to make decisions about long term care as opposed to just thinking about it as a likely future event. It can also be problematic, as noted by Morgan (1988), to rely on focus group interaction as a source of data because it would be difficult to know whether or not group data would mirror the behavior of individuals outside of the group.

Finally, because of the enormous complexity of Medicaid and the Estate Recovery Program, it was difficult for group facilitators to respond in sufficient detail to questions posed by participants without interfering with the group process. Therefore, facilitators sometimes delayed providing direct answers to participants' queries, steering them instead to the handouts provided at the end of the sessions and community experts on the issue for further follow-up.

Conclusion

This study makes a number of important contributions to the existing literature on homeownership, estate recovery, and intergenerational wealth transfer. Primarily, virtually no empirical studies have brought together the literature on homeownership, estate recovery, inheritance, and the racial wealth gap, nor has the issue been raised as to whether or not African American individuals may be differentially affected by estate recovery practices given historical and present day discrimination and disadvantages faced by this minority group. As noted previously, data collection on estate recovery varies widely among the states, and no program data is available, at least publicly, if at all, that identifies recoveries of estates in relation to race and ethnicity (Vasquez, 2007). Therefore, this study provides an important first step in raising awareness on this critical issue.

Secondly, consistent with other empirical studies (Karp, Sabatino, & Wood, 2005; Wood & Klem, 2007), findings from this study reinforce the need for accurate and timely information about the Medicaid estate recovery program. Participants in this study had little, if any, knowledge of estate recovery at a time when they were beginning to explore options for long-term care, and were eager to learn more. Indeed, as discussed earlier, some were outraged about first having learned about estate recovery as a result of their participation in this study. Having access to information is particularly critical for minority and social isolated individuals who are often left out of the mainstream social and political structures that offer opportunities for asset accumulation.

In closing, I would like to present a heartfelt comment that was expressed to me by an 89 year old African American woman who approached me following one of the focus group sessions. This articulate older woman made a special effort to let me know that she appreciated the opportunity to be a part of the group, and that she had learned a lot in the process. She said that she was especially pleased because, *“Nobody ever asks us what we think.”* To me, this message serves as a reminder of our mission of service on behalf of those most vulnerable and discriminated against. Her sincere statement should compel us to further seek out and closely listen to the voices of those who have been silenced and ignored.

REFERENCES

- Achenbaum, W.A. (1983). *Shades of gray: Old age, American values, and federal policies since 1920*. Boston, MA: Little/Brown.
- American Veterinary Medical Association (2007). *U.S. pet ownership - 2007*. Retrieved May 30, 2008 from <http://www.avma.org/>
- Applebaum, W.A. (1978). *Old age in the new land: The American experience since 1790*. Baltimore, MD: Johns Hopkins University Press.
- Baker, D., & Taylor, H. (1997). The relationship between condition specific morbidity, social support and material deprivation in pregnancy and early motherhood. *Social Science and Medicine*, 45, 1325-1336.
- Baker, M. (1996). Ethical dilemmas in implementing Medicaid eligibility and estate recovery policies: Four case examples. *Generations*, 20, 88-91.
- Barker, Robert L. (1999). *Social work dictionary* (4th ed.). Washington, DC: NASW.
- Berger, P.L. & Luckman, T. (1967). *The social construction of reality: A treatise in the sociology of knowledge*. New York, NY: Anchor Books.
- Berkman, B., Gardner, D., Zodikoff, D., & Harooytan, L. (2005). Social work in health care with older adults: Future challenges. *Families in Society*, 86 (3), 329-338.
- Beverly, S., Sherraden, M., Zhan, M., Shanks, T.R., & Nam, Y. (2008). *Determinants of asset building. A report in the series poor finances: Assets and low-income households*. St. Louis, MO: Washington University.
- Blau, P. M. (1964). *Exchange and power in social life*. New York, NY: John Wiley & Sons, Inc.
- Blum, T., & Kingston, P. (1984). Homeownership and social attachment. *Sociological Perspectives*, 27, 159-180.
- Blundo, R., & Greene, R. (1999). Social construction. In Greene (Ed.), *Human Behavior Theory and Social Work Practice* (2nd ed.). 309-340. Cambridge, MA: Blackwell.

- Boehm, P. T., & Schlottmann, A. M. (2004). The dynamics of race, income and homeownership. *Journal of Urban Economics*, 55(1), 113-130.
- Boehm, P. T., & Schlottmann, A. M. (1999). Does homeownership by parents have an economic impact on their children? *Journal of Housing Economics*, 8(3), 217-232.
- Borglin, G., Edberg, A., & Hallberg, I. (2005). The experience of quality of life among older people. *Journal of Aging Studies*, 19(2), 201-217.
- Bradley, E. H., Curry, L. A., McGraw, S. A., Webster, T.R., Kasl, S. V., & Andersen, R. (2004). Intended use of informal long-term care: The role of race and ethnicity. *Ethnicity and Health*, 9(1), 37-54.
- Bradley, E. H., McGraw, S. A., Curry, L., Buckser, A., King, K., Kasl, S. (2002). Expanding the Andersen model: The role of psychosocial factors in long-term care use. *Health Services Research*, 37(5), 1221-1242.
- Brown, J.B. (1999). The use of focus groups in clinical research. In *Doing Qualitative Research* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Brown, L. J., Kuttner, R., & Shapiro, T. (2005). *Building a real "ownership society"*. New York, NY: The Century Foundation Press.
- Burr, V. (1995). *An introduction to social constructionism*. London: Routledge.
- Burwell, B. & Crown, W. (1996). Medicaid eligibility policy and asset transfers: Does any of this make sense? *Generations* 20,(3),78-84.
- Butler, E. & Kaiser, E. (1971). Prediction of residential movement and spatial allocation." *Urban Affairs Quarterly*, 6(4), 477-494.
- Butrica, A. (2008). Do assets change the racial profile of poverty among older adults? Retrieved March 4, 2008 from http://www.urban.org/UploadedPDF/411620_racial_poverty.pdf
- Carstensen, L. (1996). Studying the strengths of older Americans. *The Chronicle of Higher Education*, B1-3.
- Chapin, R. (2008). *Social policy for effective practice: A strengths approach*. New York, NY: McGraw-Hill.

- Citizens for Better Care (CBC). (2004). *Estate Recovery, Medicaid to take back long term care benefits*. Retrieved September 2, 2004 from http://www.cbcmi.org/publications/est_rec.htm
- Cobb, A., & Forbes, S. (2003). Qualitative research: What does it have to offer to the gerontologist? *Journal of Gerontology*, 57A(4), M197-M201.
- Connell, C.M., & Gibson, G.D. (1997). Racial, ethnic, and cultural differences in dementia care giving: Review and analysis. *The Gerontologist*, 37(3), 355-364.
- Crabtree, B., & Miller, W. (1999). *Doing qualitative research* (2nd ed.). Newbury Park, CA: Sage Publications.
- Creswell, J. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.
- Curry, L., Gruman, C., & Robison, J. (2001). Medicaid estate planning: Perceptions of morality and necessity. *Gerontologist*, 41(1), 34-42.
- Curry, L. (2000). Responsibilities for financing nursing home care: Individual Motivations for Material Wealth Transfer. *Dissertation Abstracts International*, (UMI No. 9963274).
- Dahlgren, P. (1988). What's the meaning of this? Viewers' plural sense-making of TV news. *Media, Culture and Society*, 10, 285-301.
- Denzin, N. K., & Lincoln, Y. S. (2000). *Handbook of qualitative research* (2nd ed.) Thousand Oaks, CA: Sage Publications.
- Devers, L. K. (1999). How will we know "good" qualitative research when we see it: Beginning the dialogue in health services research. *Health Services Research*, 34(5 Part II), 1153-1188.
- Diener, E. (2000). Subjective well-being: The science of happiness and a proposal for a national index. *American Psychologist*, 55(1), 34-43.
- Dobrof, R., & Moody, H. (1996). Philanthropy and legacy: Who will say Kaddish for me? *Generations*, 20(3), 26-29.
- Domowitz, I., & Sartain, R. (1999). Determinants of the consumer bankruptcy decision. *Journal of Finance*, 45, 403-420.

- Ekerdt, D., J., Kosloski, K., & DeViney, S. (2000). The normative anticipation of retirement by older workers. *Research on Aging*, 22(1), 3-22.
- Erikson, E. (1980). *Identity and the life cycle*. New York, NY: W.W. Norton & Company.
- Family Caregiver Alliance. (2005). *Selected long-term care statistics*. Retrieved March 26, 2005 from <http://www.caregiver.org>
- Federal Agency Forum on Aging-Related Statistics. (2004). Older Americans 2004: Key indicators of well-being. Washington, DC: U.S. Government Printing Office.
- Fischer, C. (1982). *To dwell among friends: Personal networks in town and country*. Chicago, IL: University of Chicago Press.
- Franklin K., & Lowry, C. (2001). Computer-mediated focus group sessions: naturalistic inquiry in a networked environment. *Qualitative Research*, 1(2), 169-184.
- Frolik, L. (1996). Legacies of possessions: Passing property at death. *Generations*, 20, 9-12.
- Georgetown University (2007). Medicaid's long-term care spousal impoverishment protections. Long term care financing project. Retrieved June 2, 2008 from <http://ltc.georgetown.edu/pdfs/spousal0207.pdf>
- Gergen, K.J. (1999). *An invitation to social construction*. Thousand Oaks, CA: Sage Publications.
- Germain, C.B., & Gitterman, A. (1996). *The life model of social work practice: Advances in theory and practice*, (2nd ed.). New York, NY: Columbia University Press.
- Glaeser, E. L., & Shapiro, J. (2002). *The benefits of the home mortgage interest deduction*. Cambridge, MA: Harvard Institute of Economic Research.
- Goggins, L. (1997). When practitioners assist elders in accessing Medicaid for long-term care: Implications of eligibility, transfer of assets, and estate recovery. *Dissertation Abstracts International*, (UMI No. 9817702).
- Goss, E., & Phillips, I. (1997). The effect of state economic development agency spending on state income and employment growth. *Economic Development Quarterly*, 11, 88-96.

- Gouldner, A.W. (1960). The norm of reciprocity: A preliminary statement. *American Sociological Review*, 25, 161-178.
- Gotham, K. F. (2002). *Race, real estate, and uneven development: The Kansas City Experience, 1900-2000*. Albany, NY: State University of New York Press.
- Greater Kansas City Community Foundation, 2005. Retrieved August 1, 2008 from <https://www.donoredge.org/viewAnonymousReport.do;jsessionid=6980DA64C05D63121E7A4578115E54C5?organizationId=1002928>
- Green, R.K., & White, M.J. (1997). Measuring the benefits of homeownership: Effects on children. *Journal of Urban Economics*, 41(3), 441-61.
- Greene, V., & Ondrich, J. (1990). Risk factors for nursing home admissions and exits: A discrete time hazard function approach. *Journals of Gerontology*, 45, S250-S258, 574-79.
- Harrington, C., & LeBlanc, A., & Tonner, C. (2001). Medicaid 1915(c) home and community-based services waivers across the states. *Health Care Financing Review*, (22)2, 159-174.
- Handler J. F. & Hasenfeld, Y. (2006). *Blame welfare, ignore poverty and inequality*. Cambridge, MA: Cambridge University Press.
- Hermans, C. (personal communication), March 6, 2007.
- Hooyman, N., & Kijak, H.A. (2002). *Social gerontology: A multidisciplinary perspective* (4th ed.). Needham Heights, MA: Allyn & Bacon.
- Haveman, R., & Wolff, E. (2004). The concept and measurement of asset poverty: Levels, trends and composition for the U.S., 1983-2001. *Journal of Economic Inequality*, 2, 145-169.
- Hillman, J. (1992). *We've had a hundred years of psychotherapy and the world's getting worse*. San Francisco, CA: Harper.
- Jarrett, R. (1993). Focus group interviewing with low-income minority populations: a research experience. In D. Mordan (ed.) *Successful Focus Groups: Advancing the State of the Art*, (pp. 184-201). Newbury Park, CA: Sage Publications.
- Jensen, O. W. (1982). Opportunity costs: Their place in the theory and practice of production. *Managerial and Decision Economics*, 3(1), 48-51.

- Kaiser Family Foundation (2006). Deficit Reduction Act of 2005: Implications for Medicaid. Retrieved June 10, 2008 from http://www.aucd.org/docs/policy/medicaid/kaiser_medicaid_dra_2005_020106.pdf
- Kaiser Family Foundation (2006). *Medicaid and long-term care*. The Kaiser Family Foundation. Retrieved July 1, 2005 from <http://www.kfg.org>
- Kane, R. (1996). From generation to generation: Thoughts on legacy. *Generations*, 20, 5-9.
- Kane, T. J. (1994). College entry by Blacks since 1970: The role of college costs, family background, and the returns to education. *Journal of Political Economy*, 102, 878-907.
- Kapp, M. B. (2006). Medicaid planning, estate recovery, and alternatives for long-term care financing: Identifying the ethical issues. *Care Management Journals*, 7(2), 73-78.
- Karp, N., Sabatino, C., & Wood, E. (2005). Medicaid Estate Recovery: A 2004 survey of state programs and practices. Washington, DC: American Association of Retired Persons.
- Kendig, H., Browning, C., & Teshuva, K. (1998). Health actions and social class among older Australians. *Australian and New Zealand Journal of Public Health*, 22, 808-813.
- Kidd, P. S., & Parshall, M. B. (2000). Getting the focus and the group: Enhancing analytical rigor in focus group research. *Qualitative Health Research*, 10(3), 293-308.
- Kitzinger, J. (1994). The methodology of focus groups: The importance of interaction between research participants. *Sociology of Health & Illness*, 16(1), 103-121.
- Kivnick, H. (1996). Remembering and being remembered: The reciprocity of psychosocial legacy. *Generations*, 20, 49-53.
- Kotre, J., & Kotre, K. (1998). Intergenerational buffers: The damage stops here. In McAdams & de St. Aubin, eds. *Generativity and adult development: How and why we care for the next generation* (pp. 367-389). Washington, DC: American Psychological Association.
- Kotre, J. (1984). *Outliving the self: Generativity and the interpretation of lives*. Baltimore, MD: Johns Hopkins University Press.

- Krueger, R. A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). Thousand Oaks, CA: Sage Publications.
- Krueger, R. A., & Casey, M. A. (2000). *Focus groups: A practical guide for applied research*, (3rd ed.). Thousand Oaks, CA: Sage Publications.
- Lee, J., Hyungsoo, K., & Tanbenbaum, S. (2006). Medicaid and family wealth transfer. *The Gerontologist*, 46(1), 6-13.
- Leonard-Wright, B., Lui, M., Mota, G., Muhammad, D., & Voukydis, M. (2005). *State of the dream 2005: Disowned in the ownership society*. Boston, MA: United for a Fair Economy.
- Lincoln, Y., & Guba, E. (1985). *Naturalistic inquiry*. Newbury Park, CA: Sage Publications.
- Luong, V.H. (2000). Theoretical explanations of differences in community-based long-term care use between black and white elders. Unpublished manuscript. Retrieved June 10, 2006 from http://64.233.167.104/search?q=cache:zBqaoKWl_rcJ:www.rcgd.isr.umich.edu/prba/perspectives/springsummer2000/vluong.pdf+van+h.+luong+theoretical+explanations&hl=en&ct=clnk&cd=1&gl=us
- Madriz, I. (1998). Using focus groups with lower socioeconomic status Latina women. *Qualitative Inquiry*, 4, 114-128.
- Maines, D. (2000). Charting futures for sociology: Culture and meaning. The social construction of meaning. *Contemporary Sociology*, 29(4), 577-584.
- Mallett, S. (2004). Understanding home: A critical review of the literature. *The Sociological Review*, 52(1), 62-89.
- McAdams, D., Hart, H., & Maruna, S. (1998). The anatomy of generativity. In *Generativity and adult development: How and why we care for the next generation* (pp. 7-43). McAdams & de St. Aubin (Eds.). Washington, D.C.: American Psychological Association.
- McAdams, D., & de St. Aubin (1998). *Generativity and adult development: How and why we care for the next generation*. Washington, DC: American Psychological Association Press.
- Merton, R. K., Fiske, M., & Kendall, P. L. (1956). *The focused interview*. Glencoe, IL: Free Press.

- Merriam, S. B. (1998). *Qualitative research and case study application in education* (Rev. ed.). San Francisco: Jossey-Bass.
- Miller, C. J., & Montalto, C. P. (1998). Comparison of economic status of elderly households: non-metropolitan versus metropolitan residence. *Family Economic & Nutrition Review*, 11(4), 19-35.
- Miller, R. K., & McNamee, S. J. (1998). *Inheritance and wealth in America*. New York, NY: Plenum Press.
- Milligan, M. (1998). Interactional past and potential: The social construction of place attachment. *Symbolic Interaction*, 21(1), 1-33.
- Mirowski, J., & Ross, C. (1999). Economic hardship across the life course. *American Sociological Review*, 64(4), 548-569.
- Moody, H.R. (2006). *Aging concepts and controversies* (5th ed.). Thousand Oaks, CA: Pine Forge Press.
- Moody, H.R. (1994). The return of the repressed: The ethics of assets and inheritance. Conference proceedings, June 7, 1994.
- Morgan, D. L. (1997). *Focus groups as qualitative research*. Thousand Oaks, CA: Sage Publications.
- Morgan, D. L. (1996). Focus groups. *Annual Review of Sociology*, 22, 129-152.
- Morgan, D.L. (1988). *Focus groups as qualitative research*. Thousand Oaks, CA: Sage Publications.
- Morgan, D. & Krueger, R. (1993). When to use focus groups and why. In D. Morgan (Ed.), *Successful focus groups: Advancing the state of the art* (pp. 3-20). Newbury Park, CA: Sage.
- Mui, A., Choi, N., & Monk, A. (1998). *Long term care and ethnicity*. Westport, CT: Auburn House.
- National Association of Social Workers (1996). *NASW code of ethics*. Washington, DC: Author.
- National Public Radio, Kennedy School of Government, & Harvard University (1999). *Attitudes towards government*. Retrieved July 1, 2008 from <http://www.npr.org/programs/specials/poll/govt/gov.toplines.pdf>

- New York Times, October 17, 2007. Editorial. *Subprime in black and white*. Retrieved October 30, 2007 from <http://www.nytimes.com/2007/10/17/opinion/17wed2.html>
- O'Bryant, S. (1983). The subjective value of "home" to older homeowners. *Journal of Housing for the Elderly*, 1(1), 29-43.
- Oliver, M., & Shapiro, T. (2006). *Black wealth/White wealth: A new perspective on racial inequality*. New York, NY: Routledge.
- Oppenheim, I.S., & Moschella, A. L. (2005). National perspective on expanded estate recovery: Case law analysis, emerging legislative trends and responsive strategies for the elder law attorney. *National Academy of Elder Law Attorneys Journal*, 1(1), 7-39.
- Opoku, A., Mauldin, T., Sweaney, A., Bachtel, D., Atilas, J., & Eaves, C. (2006). Predisposing, enabling, and need predictors of community versus institutional long-term care. *Journal of Housing for the Elderly*, 20(1/2), 133-154.
- Padgett, D. K. (1998). *Qualitative methods in social work*. Thousand Oaks: Sage Publications.
- Padgett, D. K. (1998). *Qualitative Methods in Social Work Research: Challenges and Rewards*. Thousand Oaks, CA: Sage Publications.
- Padgett, D. K., Matthew, R., & Conte, S. (2004). Peer debriefing and support groups: Formation, care and maintenance. In D. Padgett (Ed.), *The Qualitative Researcher Experience* (pp. 225-235). New York, NY: Thomson.
- Page-Adams, D., & Scanlon, E. (2001). Assets, health and well-being: Neighborhoods, families, children and youth. Research background paper. St. Louis: Washington University, Center for Social Development. Retrieved February 1, 2006 from <http://gwbweb.wustl.edu/csd/>
- Page-Adams, D. (1995). Economic resources and marital violence. *Dissertation Abstracts International*, (UMI No. 9616375).
- Patton, M. Q. (2002). *Qualitative research & evaluation methods* (3rd ed.). Thousand Oaks: Sage Publications.
- Pletsch, P., Doerr, B., & Irwin, D. (2001). Focus group interviews: A method for creating partnerships with African-American women in the design of research informed consent. *Journal of National Black Nurses Association*, 12(1), 42-47.

- Pope, A. (2002). The elderly in modern society: A cultural psychological reading. *Janus Head*, online version. Retrieved January 10, 2006 from <http://www.janushead.org>
- Rakoff, R. (1977). Ideology in everyday life: The meaning of the house. *Politics and Society*, 7, 85-104.
- Reamer, F. (2002). *The social work ethics audit: A risk management tool*. Washington, DC: NASW Press.
- Relph, E. (1976). *Place and placelessness*. London: Pion Limited.
- Robert, S., & House, J. (1996). SES differentials in health by age and alternative indicators of SES. *Journal of Aging & Health*, 8(3), 359-389.
- Rodwell, M. K. (1987). Naturalistic inquiry: An alternative model for social work assessment. *Social Service Review*, 61(2), 231-246.
- Rodwell, M. K. (1998). *Social work constructivist research*. New York: Garland Publishing.
- Rohe, W., & Basolo, V. (1997). Long-term effects of homeownership on the self-perceptions and social interaction of low-income persons. *Environment and Behavior*, 29(6), 793-827.
- Rohe, W., & Stewart, L. (1996). Homeownership and neighborhood stability. *Housing Policy Debate*, 9, 37-81.
- Rossi, P., & Weber, E. (1996). The social benefits of homeownership: Empirical evidence from national surveys. *Housing Policy Debate*, 7(1), 1-35).
- Rowles, G., & Ohta, R., (Eds.). (1983). *Aging and milieu: Environmental perspectives on growing old*. New York: Academic Press.
- Rubinstein, R., & Parmelee, P. (1992). Attachment to place and the representations of the life course by the elderly. In I. Altman & S. Low (Eds.), *Place attachment*. New York: Plenum Press, 139-163.
- Rutman, D., & Freedman, J. (1987). Anticipating relocation: Coping strategies and the meaning of home for older people. *Canadian Journal on Aging*, 7(1), 17-31.

- Saleebey, D. (2004). The power of place: Another look at the environment. *Families in Society*, 85(1), 7-16.
- Sandelowski, M., Holditch, D., Davis, B., Harris, B. (1989). Writing the proposal for research in the naturalist paradigm. *Research in Nursing & Health*, 12(2), 77-84.
- Saunders, P. (1978). Beyond housing classes: The sociological significance of private property rights in means of consumption. *International Journal of Urban and Regional Research*, 18(2), 202-227.
- Scanlon, E., & Page-Adams, D. (2000). Homeownership and youth well-being: An empirical test of asset-based welfare. Center for Social Development. St. Louis, MO: Washington University.
- Shapiro, T. (2004). *The hidden cost of being African American: How wealth perpetuates inequality*. New York, NY: Oxford University Press.
- Shapiro, T., & Wolff, E. (2001). *Assets for the poor: The benefits of spreading asset ownership*. New York, NY: Russell Sage Foundation.
- Sherraden, M., (Ed.). (2005). *Inclusion in the American dream: Assets, poverty and public policy*. New York, NY: Oxford University Press.
- Sisco, S., Volland, P., & Gorin, S. (2005). Social work leadership and aging: Meeting the demographic imperative. *Health & Social Work*, 30(4), 344-348.
- State of Pennsylvania, (2002). *2002 Medicaid state recovery work group report to the Pennsylvania Intra-Governmental Council on Long-term Care*. Retrieved July 1, 2006 from [http://www. http://aspe.hhs.gov/daltcp/reports/estreccol.htm](http://www.aspe.hhs.gov/daltcp/reports/estreccol.htm)
- State of West Virginia (2006). Medicaid estate recovery: What seniors should know. Darrell V. McGraw, Attorney General. Charleston, W.VA: Office of the Attorney General.
- Steinberger, P. (1981). Political participation and community: A cultural/interpersonal approach. *Rural Sociology*, 46(1), 17-19.
- Stone, J. (2004). *Medicaid: Eligibility for the aged and disabled*. Hauppauge, NY: Novinka Books.
- Stronks, K., van de Mheen, H., van de Bos, J., & Mackenbach, J. (1997). The interrelationship between income, health, and employment status. *International Journal of Epidemiology*, 26, 592-600.

- Stum, M. (2001). Financing long term care: Examining decision outcomes and systemic influences from the perspective of family members. *Journal of Family and Economic Issues*, 22(1), 25-53.
- Stum, M. (1998). The meaning and experience of spending down to Medicaid in later life. *Advancing the Consumer Interest*, 10(2), 23-34.
- Swarns, R. L. (2008). Rising renters erasing gains for ownership. New York Times, June 21, 2008 retrieved June 22, 2008 from <http://www.nytimes.com/2008/06/21/us/21renters.html>
- Swenson, M. (1998). The meaning of home to five elderly women. *Health Care for Women International*, 19, 381-393.
- Takacs, T., & McGuffey, D. (2002). Medicaid planning: Can it be justified? Legal and ethical implications of Medicaid planning. *William Mitchell Law Review*, 29, 111-158.
- United States Census Bureau (2006). American Community Survey. Retrieved April 3, 2008 from <http://factfinder.census.gov>
- United States Census Bureau. (2005). Housing vacancies and homeownership. Retrieved September 10, 2006 from <http://www.census.gov/hhes/www/housing/hvs/annual05/>
- United States Census Bureau (2004). U.S. interim projections by age, sex, race, and Hispanic origin. Retrieved October 15, 2007 from <http://www.census.gov>
- United States Census Bureau (2003). The Older Population in the United States: March 2002. Retrieved September 1, 2006 from <http://www.census.gov/prod/2003pubs/p20-546.pdf>
- United States Congressional Record, Senate S5229, May 21, 2001. Amendment No. 724. Retrieved September 2, 2004 from www.gpoaccess.gov/record/
- United States Court of Appeals. (2002). *State of West Virginia v. U.S. Department of Health & Human Services*. Retrieved February 1, 2005 from pacer.ca4.uscourts.gov/opinion.pdf/011442.P.pdf
- United States Department of Health and Human Services. (2006). *Medicaid estate recovery*. Retrieved April 10, 2006 from <http://www.hhs.gov>

- United States Department of Health and Human Services, Administration on Aging. (2003). *A profile of older Americans: 2003*. Retrieved September 7, 2004, from <http://www.aoa.dhhs.gov/prof/Statistics/profile/profiles.asp>
- United States Department of Health and Human Services. (2004). Centers for Medicare & Medicaid Services. *Estate Recovery*. Retrieved September 1, 2005 from <http://www.cms.hhs.gov/default.asp?>
- United States Government Accountability Office (GAO). (2000). *42 USC 1396 p, Social Security, Subchapter XIX, Grants to states for Medical Assistance programs, liens, adjustments and recoveries and transfers of assets*. Supplement 5. Retrieved July 8, 2008 from <http://www.gpoaccess.gov/uscode/index.html>
- Vasquez, B. E-mail communication. October, 2007.
- Vosler, N., & Page-Adams, D. (1996). Predictors of depression among workers at the time of a plant closing. *Journal of Sociology and Social Welfare*, 13(4), 25-42.
- Wallace, S., Levy-Storms, L., Kington, R., & Andersen, R. (1998). The persistence of race and ethnicity in the use of long term care. *Journal of Gerontology: Social Sciences*, 53(2), S100004-112.
- Walker, L., Gruman, C., Robison, J. (1998). Medicaid estate planning: Practices and perceptions of Medicaid workers, elder law attorneys and certified financial planners. *The Gerontologist*, 38(4), 405-411.
- Walker, L., Gruman, C., & Robison, J. (1999). Medicaid eligibility workers discuss Medicaid estate planning for nursing home care. *The Gerontologist*, 39(2), 201-209.
- Wardaugh, J. (1999). The unaccommodated woman: Home, homelessness and identity. *Sociological Review*, 47(1), 91-109.
- Wegner, E., & Yuan, S. (2002). Legal welfare fraud among middle-class families. *American Behavioral Scientist*, 47(11), 1406-1418.
- Weick, A. (2000). Hidden voices. *Social Work*, 45(5), 395-402.
- Weiner, J. (1996). Public policies on Medicaid asset transfer and estate recovery: How much money to be saved? *Generations*, 20, 72-77.

- Wilkinson, S. (1999). How useful are focus groups in feminist research? In R.S. Barbour & J. Kitzinger (Eds.), *Developing focus group research*, 64-78. Thousand Oaks, CA: Sage Publications.
- Williams, L., Mehta, K., & Lin, S. (1999). Intergenerational influence in Singapore and Taiwan: The role of the elderly in family decisions. *Journal of Cross Cultural Gerontology*, 14, 291-322.
- Wood, E. F., & Klem, E. M. (2007). *Protections in Medicaid estate recovery: Findings, promising practices, and model notices*. Research report. Washington, DC: American Association of Retired Persons.
- Yegidis, B., & Weinbach, R. (2006). *Research methods for social workers* (5th ed.). Boston, MA: Pearson Education, Inc.

APPENDIX A HUMAN SUBJECTS APPROVAL

The University of Kansas Medical Center

Human Research Protection Program

May 29, 2007

Project Number: 10924
Project Title: The Role Of Estate Recovery In Medicaid Long-Term Care: Perspectives Of Older Adult Homeowners
Sponsor: None
Protocol Number: N/A
Primary Investigator: Deborah Adams, Ph.D
Department: Social Welfare
Meeting Date: 5/22/2007
HSC Approval Date: 5/29/2007
HSC Expiration Date: 5/28/2008
Type of Approval: Expedited #7

Dear Investigator:

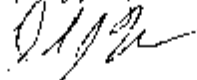
This is to certify that your research proposal involving human subject participants has been reviewed and approved by the KUMC Human Subjects Committee (HSC). This approval is based upon the assurance that you will protect the rights and welfare of the research participants, employ approved methods of securing informed consent from these individuals, and not involve undue risk to the human subjects in light of potential benefits that can be derived from participation. It is the investigator's responsibility to only use those informed consent documents bearing the correct approval and expiration dates when obtaining informed consent from research participants.

Approval of this research is contingent upon your agreement to:

- (1) Adhere to all KUMC Policies and Procedures Relating to Human Subjects, as written in accordance with the Code of Federal Regulations (45 CFR 46).
- (2) Maintain copies of all pertinent information related to the research study including, but not limited to, video and audio tapes, instruments, copies of written informed consent agreements, and any other supportive documents in accordance with the KUMC Research Records Retention Policy.
- (3) Report unanticipated problems to the HSC by completing the Internal or External HSC Unanticipated Problem/Adverse Event reporting form, as applicable.
- (4) Submit deviations from previously approved research activities which were necessary to eliminate apparent and immediate dangers to the subjects by using the KUMC Protocol Deviation Report.
- (5) Submit Amendments to the HSC for any proposed changes from the previously approved project using the Request for Amendment form. Changes may not be initiated without prior HSC review and approval, unless a delay in implementation would place subjects at risk.
- (6) Submit Continuing Review Form (CR Form) to the KUMC HSC before the expiration date. Federal regulations and HSC policies require continuing review of research at intervals appropriate to the degree of risk, but not less than once per year.

If you have any questions regarding the human subject protection process, please do not hesitate to contact our office.

Very truly yours,



Daniel J. Vnse, M.S., J.D.
IRB Administrator

Mail-Stop 1032, 3501 Rainbow Blvd. Kansas City, KS 66160
Phone: (913) 588-1240 Fax: (913) 588-5771 humansubjects@kumc.edu

The University of Kansas Medical Center

Human Research Protection Program

August 13, 2007

Project Number: 10924
Project Title: The Role Of Estate Recovery In Medicaid Long-Term Care: Perspectives Of Older Adult Homeowners
Sponsor: None
Protocol Number: N/A
Primary Investigator: Deborah Adams, P.h.D
Department: Social Welfare
Meeting Date: 8/14/2007
HSC Approval Date: 8/13/2007
HSC Expiration Date: 5/28/2008
Study Action: Addition of Study Site (Vernon MultiPurpose Senior Center)
Recruitment Flyer
Consent Form Revisions
Type of Approval: Expedited Review under §46.110

Dear Investigator:

Your amendment request dated **July 23, 2007** was reviewed, and the KUMC Human Subjects Committee (HSC) has determined that you are **APPROVED** to continue the above-referenced human subject research project with the incorporated revision(s). Any additional revisions to the research must be reported to, and approved by, the HSC prior to implementing those revisions.

If applicable to this amendment, you will find enclosed an approved stamped copy of the revised consent form that supersedes any previously approved consent form. A copy of it needs to be kept with all other documentation pertaining to the above research project. Only a copy of this most current approved stamped consent form may be used to consent subjects.

If you have any questions regarding the human subject protection process, please do not hesitate to contact our office.

Very truly yours,



Daniel J. Voss, M.S., J.D.
IRB Administrator

Mail-Stop 1032, 3901 Rainbow Blvd., Kansas City, KS 66160
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APPENDIX B
INFORMED CONSENT

CONSENT FORM

**TITLE: The Role of Estate Recovery in Medicaid Long-term Care:
Perspectives of Older Adult Homeowners**

INTRODUCTION

As an older adult homeowner, you are being invited to participate in a focus group study about Medicaid and long-term care. This research study will be conducted at the University of Kansas Medical Center with Deborah Adams, Ph.D. as the principal investigator. Doreen Higgins, MSSW, a doctoral candidate at the University of Kansas, School of Social Welfare will lead the focus group discussions. Approximately 60 subjects will be enrolled in the study which will be conducted at the Landon Center on Aging at the KUMC.

You do not have to participate in this research study. Before you make a decision to participate, you should read the rest of this form. The main purpose of research is to benefit older adults and society in general. You might get personal benefit from participating in this study, but you should understand that the purpose of research is to create new knowledge.

BACKGROUND

As people grow older, many find that they may need assistance paying for long-term care services such as meal preparation, transportation, or other activities of daily living. Others may need help paying for skilled nursing care or nursing home care. One of the most common ways older people pay for long-term care is through the federal Medicaid program. Understanding how older people think and feel about using Medicaid to pay for long-term care may help us understand how Medicaid policy affects older people.

PURPOSE

The purpose of this focus group study is to gain understanding about your perspectives as an adult home owner, age 55 and older, on using Medicaid to pay for long-term care services. This may include some discussions about home ownership, inheritance, and the Medicaid Estate Recovery Program. Your perspectives are important because they will contribute to an overall

understanding of how Medicaid long-term care policy affects older people.

PROCEDURES

If you are eligible and decide to participate in this study, your participation in the focus group will last approximately 1 to 1 ½ hours. Your participation will involve attendance at one focus group consisting of 8-10 other older adults. You will be given an opportunity to attend a follow-up meeting to discuss the study's findings, but this is not required. The follow-up meeting will also be held at the Landon Center on Aging and it will last approximately one hour. What you say in the focus group is confidential and no one other than the research team will have access to it. The group discussions will be recorded to allow accurate transcription so that the information from the meeting can be thoroughly analyzed. The tapes and the transcriptions will be kept in a locked office at the university for a period of six (6) years after the submission of the final report and close-out procedures on the research study.

RISKS

There are no known risks associated with participating in this study.

NEW FINDINGS STATEMENT

You will be informed if any significant new findings develop during the course of the study that may affect your willingness to participate in this study.

BENEFITS

You may benefit from the opportunity to share your perspectives on this issue. Your participation in this study may benefit others by contributing to our understanding of Medicaid long-term care policy.

ALTERNATIVES

Your participation in this study is voluntary and you may withdraw from the study at any time. You may refuse to answer any focus group questions that you wish. Deciding not to participate will have no effect on the care or services you receive at University of Kansas Medical Center.

COSTS

There are no costs to you for participation in this study.

PAYMENT TO SUBJECTS

If you decide to participate in the focus group, you will be paid \$20 at the end of the meeting as a token of appreciation for your time and effort. The investigator may ask for your Social Security number to comply with federal and state tax and accounting records. The KUMC Research Institute will be given your name, address, social security number, and the title of this study to allow them to write checks for your study payments. Study payments are taxable income. A Form 1099 will be sent to you and to the Internal Revenue Service if your payments are \$600 or more in a calendar year.

INSTITUTIONAL DISCLAIMER STATEMENT

If you believe you have been injured as a result of participating in research at Kansas University Medical Center (KUMC), you should contact the Director, Human Research Protection Program, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160. Compensation to persons who are injured as a result of participating in research at KUMC may be available, under certain conditions, as determined by state law or the Kansas Tort Claims Act.

CONFIDENTIALITY AUTHORIZATION

Efforts will be made to keep your personal information confidential. Researchers cannot guarantee absolute confidentiality. If the results of this study are published or presented in public, information that identifies you will be removed. No information will be included in the final report or any other related publications that could identify you or be linked to any specific individual.

QUESTIONS

I have read the information in this form. My questions have been answered to my satisfaction. I am aware that if I have any more questions, concerns or complaints after signing this you may contact Deborah Adams, Ph.D., principal investigator at (913) 897-8444, 210 Regents Center, KU Edwards Campus, 12600 Quivira Rd., Overland Park, KS 66213. If you have any questions about your rights as a research subject, you may call (913) 588-1240 or write the Human Subjects Committee, Mail Stop #1032, University of Kansas Medical Center, 3901 Rainbow Blvd., Kansas City, KS 66160.

SUBJECT RIGHTS AND WITHDRAWAL FROM THE STUDY

Your participation in this study is voluntary and that the choice not to participate or to quit at any time can be made without penalty or loss of benefits. Not participating or quitting will have no effect upon the medical care or treatment you receive now or in the future at the University of Kansas

Medical center. The entire study may be discontinued for any reason without your consent by the investigator conducting the study.

CONSENT

Doreen Higgins, MSSW, and doctoral candidate has given you information about this research study. She has explained what will be done and how long it will take. They explained any inconvenience, discomfort or risks that may be experienced during this study.

I freely and voluntarily consent to participate in this research study. I have read and understand the information in this form and have had an opportunity to ask questions and have them answered. **I will be given a signed copy of the consent form to keep for my records.**

Type/Print Subject's Name

Signature of Subject

Time Date

Type/Print Name of Witness

Signature of Witness

Date

Type/Print Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Date

APPENDIX C

GUIDED QUESTIONS

Guided Questions for Focus Group Discussions

Facilitator: “Thank you all for coming. We appreciate that you are willing to share your views with us today.” Facilitators will introduce themselves, briefly review details of the group discussion including the length of the session, confidentiality, tape recording, and informed consent forms.

The facilitator will inform participants that there are no “right or wrong” answers, the importance of respecting others’ opinions, and the importance of speaking one at a time so that everyone’s contribution can be successfully recorded.

Facilitator: “We’re having several meetings like this one over the next few weeks so that people who own their own homes can discuss their thoughts and feelings about long-term care. As people get older, many find that they need assistance with daily activities like preparing a meal, taking a bath, or getting to doctor’s appointments. Others may need more help such as regular skilled nursing care and require nursing home care. Many older people may also need help paying for assistance, whether it is provided at home or in a nursing home. One of the most common ways that older people pay for long-term care is through the federal Medicaid program. Today, we’d like to hear your thoughts about long-term care, what you would do if you needed long term care in the future, and what ideas you might have on how the costs of long-term care for older adults should be covered.”

Guided Questions

1. One of the things that everyone here today has in common is homeownership. “We’ll start by asking you to talk together about owning your own homes. Can someone get our discussion started by sharing what it means to you to be a home owner?”

Probes

Advantages and disadvantages of homeownership

- Objective – such as financial benefits; the costs of caring for one’s own house and yard;

- Subjective - such as sense of security and well-being or the stress of home maintenance, neighborhood/home value decline, estate planning (i.e. which of the kids gets the house?)
2. For many families, a home is the most valuable thing they own. If the need arises for long-term care when a person gets older, many people with limited income and assets apply for Medicaid to help pay for that care. Usually, the Medicaid program requires a recipient to agree to give the government the proceeds from selling his or her home after death in return for getting long-term care services. This provision of Medicaid policy is called “estate recovery” and we’d like to turn now to your thoughts and feelings about estate recovery in Medicaid.

Probes

- Some people know about estate recovery, but many people have very little information about this policy.
 - What, if anything, had you heard about estate recovery for long-term care services through Medicaid before you came to this meeting today?
 - Participants should be reminded again that there are no right or wrong answers to these questions and that they may respectfully disagree with others in the group.
3. Now that we’ve talked a little about homeownership and long-term care services, we would like to hear your thoughts and feelings about what you think you would do if you needed long-term care or help paying for long-term care in the future. We’re interested in things like who you would want to provide care for you, and where you would like to get this care. We would also like you to share your thoughts about how you might pay for long-term care.

Probes

- What would be some advantages and some disadvantages for each of you in applying for Medicaid assistance to help pay for long-term care?
4. Are there any comments that you haven’t had a chance to make? Is there anything about long-term care and estate recovery through Medicaid that you would be interested in hearing the group discuss together before we end the meeting?

Facilitator: “Thank you all very much for coming. Please remember that the ideas and opinions that were shared today are confidential and should not be shared outside of the group. Also, we would like to remind you that you will not be identified in any of the documents or correspondence that is produced from this group discussion. Each of you will receive a printed copy of the group discussion.”

Participants will be reminded of the resource table available that has information about community resources for older adults, as well as provided a reminder that they will be contacted in several weeks to reconvene for the member check meetings.

APPENDIX D

NOTE TAKING FORM

The Role of Estate Recovery in Medicaid
Long-term Care: Perspectives of Older Adult Homeowners
HSC 10924
University of Kansas Medical Center/Landon Center on Aging/Vernon Center
Doreen Higgins, Doctoral Candidate, MSSW
Deborah Adams, Ph.D., Principal Investigator

Focus Group Notes

Location _____ Date _____

Group Number _____

Begin Time _____

End Time _____

Number in Group: Total _____ Female _____ Male _____ Facilitator _____

Notetaker _____

Q1: What it means to own your own home

Participant #	Brief Summary of Participants' Comments

Q2: Thoughts and feelings about estate recovery in Medicaid

Participant #	Brief Summary of Participants' Comments

Q3: What would you do if you need long-term care and/or help paying for long term care?

Participant #	Brief Summary of Participants' Comments

Q4: Other comments about long term care and estate recovery?

Participant #	Brief Summary of Participants' Comments

Q5: Wrap-up

Participant #	Brief Summary of Participants' Comments

APPENDIX E

SOCIO-DEMOGRAPHIC INFORMATION FORM

Demographic Information

Today's Date: _____

Name: _____ Age: _____

Mailing Address: _____ Zip Code: _____

(Optional: Please provide if you would like me to mail you a summary of the focus group findings at the end of the study)

Phone Number: _____

(Optional: Please provide if you would like a call inviting you to come to a follow-up meeting where I will describe the focus group findings at the end of the study).

1. What is your gender?

_____ Female _____ Male

2. What is the highest educational level you have achieved? Please check one.

_____ No formal education	_____ High school graduate
_____ Elementary school	_____ Some college
_____ Junior high school	_____ College Graduate
_____ Some high school	_____ Graduate School

3. What is your race/ethnicity?

_____ African American
_____ White
_____ Latino/Hispanic
_____ Other, please specify: _____

4. What is your marital status?

_____ Single/never married
_____ Married
_____ Divorced or separated
_____ Widowed

5. For how many years have you been a homeowner?

_____ Less than 1 year
_____ 2-5 years
_____ 6-10 years
_____ 11-15 years
_____ 16-20 years
_____ 21 or more years

Demographic Information (Continued)

6. What is your annual household income? (Your best guess is fine!)

- ☐ Less than \$10,999
- ☐ \$11,000 to \$19,999
- ☐ \$20,000 to \$29,999
- ☐ \$30,000 to \$39,999
- ☐ \$40,000 to \$49,999
- ☐ \$50,000 or more

APPENDIX F

DEBRIEFING FORM

**“The Role of Estate Recovery in Medicaid
Long-term Care: Perspectives of Older Adult Homeowners”**

HSC 10924

University of Kansas Medical Center/Landon Center on Aging

Doreen Higgins, Doctoral Candidate, MSSW

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Focus Group Debriefing Form

Date of Focus Group: _____ Team Members: _____

Site: _____

1. Discuss how you think things went. What went well? What were your first impressions?
2. Discuss areas of concern and what you think needs to be changed or improved upon.
3. Go over the interview guide, question by question. Review trends, questions and comments for each question; consider the major issues that emerged. What are the key themes that emerged from the data so far?
4. Were there any surprises?
5. What was going on in terms of body language?

Debriefing Form (Continued)

6. Were there power dynamics in the group that may have influenced responses?
7. What questions were not answered? What additional questions or methods would enhance understanding?
8. Other comments/observations:

*Adapted in part from “Tips for Debriefing Data Collection Activities”, retrieved on May 20, 2007 from http://www.girlsbestfriend.org/downloads/debriefing_data_collection_tips.doc

APPENDIX G

CODING FACE SHEET

The Role of Estate Recovery in Medicaid Long-term Care: Perspectives of Older Adult Homeowners/D. Higgins/University of Kansas/Transcript Review Form

Group # _____ Date: _____ # Participants: _____ Location: _____

Q1: What is it like to be a homeowner:	Advantages	Disadvantages	Quotes	Examples of Group Interaction	Reviewer Comments	Themes

Q2: What have you heard about E.R.	Heard of It	Not Heard of It	Quotes	Examples of Group Interaction	Reviewer Comments	Themes
2a. Is E.R. a Barrier to using Medicaid for LTC?						

Q3: What would you do if you needed long-term care?	Where would you like to receive it?	How you would pay for it?	Who would you like to provide it?	Quotes	Examples of Group Interaction	Reviewer Comments	Themes

Q4: Other thoughts about Medicaid, E.R./LTC?	Quotes	Examples of Group Interaction	Reviewer Comments	Themes

APPENDIX H

THEMATIC TEMPLATE

"The Role of Estate Recovery in Medicaid Long-term Care: Perspectives of Older Adult Homeowners"

Focus Group # ____ Location: _____ Date: _____
 Participants: ____ group members; male; female; age range; other _____
 General Comments: _____

Within Group/Across Group Themes

Research Question 1: When given an opportunity to learn about and discuss estate recovery, how do older adult homeowners describe their perspectives on using Medicaid for long-term care?

Subquestion: What is it like to be a homeowner? (Meaning of Home)

Advantages/disadvantages of H.O.	Quote
Meaning of Home	Quote
RQ1/Subquestion #2: Thoughts and feelings about Estate Recovery? RQ1/Subquestion #3: What have you heard about Estate Recovery?	
Medicaid Estate Recovery & Inheritance	Quote
RQ1/Subquestion #4: What would you do if you needed long-term care or help paying for long-term care in the future? RQ1/Subquestion #5: Where would you like to receive it; who would you like to provide it? How would you pay for it? Would estate recovery impact your decision to use Medicaid for LTC?	

Long-term Care Needs & Preferences	Quotes
Importance of Family	Quote
Getting Older	Quote
A Changing Society	Quotes
Knowledge & Information	Quotes
Views of Government	Quotes
Social vs. Individualist Views	Quotes

APPENDIX I

ACROSS GROUP THEMATIC COMPARISONS

Major Theme	FG1	FG2	FG3	FG4	FG5	FG6	FG7	FG8
Social vs. Individual Responsibility								
Fairness & Equity								
Views of Government, Politics & Market Economy								
Getting Older								
A Changing Society								
The Importance of Family								
Need for Education & Information								