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**Wealth Building in Rural America**



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George Warren Brown School of Social Work

# **Asset-Building Programs for People with Disabilities in Rural Areas: Including Independent Living and Long-Term Care Planning Education**

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*Asset building programs for people with disabilities in rural areas:  
Including independent living and long-term care planning education*

*Abstract*

*This paper presents findings from a case study of individuals with multiple sclerosis examining their planning and preparation activities for their future independent living and long-term care needs. Data collected from a representative sample of National Multiple Sclerosis Society members in the greater metropolitan St. Louis and eastern Illinois area indicate significant differences in income, assets, education, health and functional limitation status between individuals living in rural versus urban areas. Additionally, findings show respondents with greater levels of education and assets, and those living in urban areas, are more likely to have saved for retirement, made legal preparations, or engaged in planning activities for future needs. Recommendations for asset building programs include incorporating education and training on planning for independent living and long-term care into financial planning curriculum, particularly for people with disabilities living in rural areas.*

*Keywords: disability, assets, rural, financial planning, independent living, long-term care*

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Disability is a prevalent phenomenon in the United States. Across the country, nearly 50 million people reported experiencing some type of disability in the 2000 U.S. Census (U.S. Census Bureau, 2003). Twenty-eight percent of those individuals, or nearly fourteen million, were over the age of sixty-five while thirty-three million fall between the ages of eighteen and sixty-four. Additionally, 2.6 million children between the ages of five and fifteen experience disability. Overall, almost 1 in 5 Americans is a person with a disability.

There is much diversity with the disability experience related to differences in particular mental and physical conditions, levels of severity of impairment, and social, economic, and environmental factors. These analyses center on financial distinctions and resultant preparedness for future independent living and long-term care needs between persons with disabilities living in rural areas compared to those in suburban or urban areas. The intent of this work is to better understand the interactions between geography and planning activities. Findings add to the existing knowledge base on asset building needs of people with disabilities and supplies recommendations for asset development policies and program as they relate to people with disabilities.

### Disability in Rural Areas

Living with a disability in a rural area can be quite different than living with a disability in a suburban or urban area. Some principal differences are community size, opportunities to participate in community life, and nature and availability of community resources to facilitate participation (Jang, Mortimer, Haley & Graves, 2004, Williams, Ehde, Smith, Czernieck, Hoffman & Robinson, 2004). However for the most part,

similar barriers to community participation exist regardless of region or community size. These include limited employment opportunities (Shur, 2002, Randolph, 2004, Lustig, Weems & Strauser, 2004), lack of appropriate healthcare services (Iezzoni, Davis, Soukup & O'Day, 2002), inaccessible building and physical environments and poor public transportation accommodations (National Council on Disability, 2003, Kaye, 2001, National Organization on Disability, 2001). The consequence of these barriers contribute to identifying disability as a contributor to rural poverty (Fischer, 2004), people with disabilities in rural counties having higher rates of unemployment than those in more urbanized areas (Beale, 2004, Szalda-Petree, Seekins & Innes, 1999), difficulty in accessing health care specialists and rehabilitation services (Johnstone, Nossaman, Schopp, Holmquist & Rupright, 2002, Auchincloss, Van Nostrand & Ronsaville, 2001) and difficulty in securing accessible transportation (Rowley, 2003). Additionally, people with disabilities living in rural communities often have fewer assistive technology supports (Johnson, 2004), advanced education supports for vocational training or attendance of college courses (Eldar, 2001), and peer supports as the closest center for independent living may be located in a distant metropolitan area (RTC, 2004a).

In the year 2000, nearly 20% of the U.S. population (approximately 44.5 million people) lived in non-metropolitan counties. About 22% of these individuals (just over 9.5 million) reported experiencing disability (RTC, 2004b). This estimate includes individuals with physical and mental impairments ranging from spinal cord injury to osteoarthritis to traumatic brain injury. General health trends for the rural segment of the disability population suggest increased incidence and prevalence of mental health conditions such as depression compared to non-rural counterparts (Wang, 2004) and a

pattern of increased difficulty in engaging in community life corresponding to increased levels of functional limitation and disability (Rowley, 2003). In sum, for a person experiencing disability living in a rural area, quality of community participation or active engagement in community life is a significant concern (Seekins, 2001a).

The picture painted here of experiencing disability in a rural community should not be viewed pessimistically. In general, rural community members often have greater social resources than persons living in suburban and urban areas including greater knowledge of their communities, broader and stronger community social networks, and longer individual or familial histories within their communities (Martinez-Brawley, 2000). Additionally, unique phenomena often arise in communities viewed as having “limitations”. In rural areas, one such phenomenon includes the above average percentage of individuals with disability who are self-employed (Seekins, 2001b). Contributing to this trend are low start up costs and the potential of earnings from self-employment to significantly raise a household’s income level (Arnold, Seekins & Spas, 2001). At both the local and national levels, community organizations and institutions such as centers for independent living, economic development organizations, and colleges and universities are working to utilize existing resources in combination with rural community characteristics and existing trends to improve both the quality of life and the quality of participation of persons with disabilities. Small business development is one primary strategy (Ipsen & Arnold, 2002). Other needs and opportunities include obtaining additional education and training, financing assistive technology and equipment, purchasing homes, and modifying homes, and personal businesses for

accessibility. Asset development is a significant part of all of these strategies to increase overall quality of community participation.

A substantial challenge in undertaking this work, however, is the lack of information about the financial status, asset holdings, level of financial training, and amount of financial planning of the population of persons with disabilities. There is much theoretical and empirical work to be done to develop foundational knowledge in this area (Putnam, Sherraden, Edwards, Porterfiled, Wittenberg & Welch, in press). As this work progresses, portions of the asset development community are beginning to develop policy agendas to address the needs of people with disabilities at national, state, and local levels (With Equity and Assets For All, 2003). As a contribution to both knowledge and policy development in the in this area, we report empirical findings from a case example of persons living with multiple sclerosis in the St. Louis, Missouri metropolitan area. As part of a larger survey of independent living and long-term care needs, questions related to financial status, asset holds, financial education and planning were asked of respondents. Specifically, our questions were 1) what is the financial status (including wealth) of persons with multiple sclerosis, 2) what variances is there in level of financial education and planning for future needs related to living with disability, and 3) what differences are there in these characteristics based on rural, suburban and urban location?

## Methods

### *Survey Instrument*

Data for this study come from the Independent Living and Long-Term Care Survey conducted by Washington University in St. Louis and the National Multiple Sclerosis Society, Gateway Area Chapter. The survey was jointly developed by the research subcommittee of the Gateway Area Chapter's Long-Term Care Task Force for the purpose of planning future services for chapter members. Survey content reflected the interests of the task force and included: history of multiple sclerosis, use of medical care, current and future independent living and long-terms needs, financial preparation for future needs and personal background information. When possible, questions were borrowed from existing surveys including the 1996 Aging with Disability Survey conducted by the Rehabilitation Research and Training Centers on Aging with Disability and Aging with Spinal Cord Injury (Campbell & Sheets, 1996) and AARP's 2001 survey on public perceptions of long-term care costs (AARP, 2001). In some cases modified to be more applicable to persons with MS. New questions were created when needed. The survey was piloted with chapter volunteers who have MS, resulting in minor modifications to improve readability and survey format.

### *Sample*

The sample base for the survey was the membership of the National Multiple Sclerosis Society, Gateway Area Chapter. The chapter has approximately 5000 members in the greater metropolitan St. Louis and southeastern Illinois area. Membership in the



chapter is limited to individuals diagnosed with multiple sclerosis. Family members and other interested individuals are eligible to participate in chapter activities but are not included as part of the membership rolls. Two thousand names were randomly selected for the survey from the membership listing, with representative proportions drawn from urban (70%) and rural (30%) regions. Regional designations were determined based on zip code and closely followed 2000 U.S. Census Bureau definitions with urban participants designated as living in *urban areas* (“core census block groups or blocks with a population density of at least 1,000 people per square mile”) or *urban clusters* (“surrounding census blocks that have an overall density of at least 500 people per square mile”) (U.S. Census Bureau, 2002). Rural was defined as “all territory, population, and housing units located outside of urban areas and urban clusters” (U.S. Census Bureau, 2002).

### *Data Collection*

Data collection took place from February to March 2004. Surveys were printed in fourteen-point, Times New Roman font and assembled into booklet form. This format was deemed most accessible to chapter members. Surveys were mailed to sample members along with postage-paid return envelopes. Reminder notices were sent to non-respondents after two weeks and again after four weeks. A letter from the Gateway Area Chapter program director and the principal investigator was printed on the booklet cover explaining the purpose of the project. The letter instructed sample members of the option to complete either the paper version of the survey or an internet-based version posted through the Gateway Area Chapter’s website. This offering of an electronic option was

designed to increase accessibility for sample members who utilize electronic technology to assist in reading and/or writing. Recent research in the field of health research has shown no difference in reliability of instruments administered via the internet versus paper (Ritter, Lorig, Maurent, & Matthews, 2004). However there is significant variation in response rates (Braithwaite, Emery, DeLusignan, & Sutton, 2004) with evidence indicating that when given the option of completing a paper or Web-based survey, response rates of the Web-based survey are both higher (McCabe, 2004, Schleyer & Forrest, 2000) and lower (Leece, Bhandari, Sprague, et. al., 2004, Raziano, Jayadevappa, Valenzula, Weiner & Lavizzo-Mourey, 2001, Jones & Pitt, 1999) than paper surveys. Addition of an electronic version of this survey follows the National Institute of Disability and Rehabilitation Research's guidelines for conducting inclusive and accessible research (National Center for the Dissemination of Disability Research, 2001). The letter also included a toll-free telephone number for sample members to call to receive assistance in filling out the survey, should that be their preferred method of accommodation. Volunteers were trained to assist callers, however no sample members called for assistance. Finally, the letter offered as an incentive for survey completion entrance into a drawing for the chance to win one of eight gift certificates. The front inside cover of the booklet contained informed consent information.

The total number of respondents was 576 yielding a total response rate of 29%. Forty-nine respondents completed the electronic version of the survey (9% of all respondents). Geographically, 29% of respondents lived in "non-metro" areas and 71% in "metro" areas, mirroring the regional distribution of chapter members.

### *Data Analysis*

We conducted a series of t-test and chi-square analyses to assess whether there were differences between rural and urban areas in demographics, service uses, and long-term care planning and preparation among persons diagnosed with multiple sclerosis (MS). We used logistic and multiple regressions to examine the factors associated with current use of, perceived need for, and engagement in planning for independent living and long-term care (IL/LTC) needs by rural and urban geographies.

### Findings

Table 1 shows the demographic background and disability characteristics of persons diagnosed with MS (N = 576). Consistent with patterns of MS diagnosis, the vast majority of respondents were female who identified their race as white. Approximately 70% were married and lived with a spouse. Their average age was just over fifty years. Less than 40% were formally employed. Most respondents reported having relapsing/remitting MS with an average age of diagnosis of roughly thirty-five years. Average numbers of functional limitations were just under two. Functional limitation scores were constructed by summing activities of daily living and instrumental activities of daily living scores creating a range of 0-17.

Statistically significant differences by geographies were found in financial and health status. Compared with people with MS in urban areas, individuals living in rural areas had lower average household incomes and assets; level of educational attainment was lower as well. Self-rated physical and mental health of rural community members was lower than the ratings by their urban counterparts. About 61% of rural residents

identified the status of their MS to be moderate, 30% mild and about 10% said it was severe. Comparatively, 46% of urban residents described their current MS status as being moderate, 40% reported it as mild and about 14% severe.

Insert Table 1 here

In terms of service utilizations, there were no geographic differences in the use of assistive technology and personal assistance. Slightly over half of all respondents reported using assistive technology with an average of about 2 devices used. A similar percentage employed personal assistance, with almost 38% receiving help for 6 years or more. Thirty-two percent receive 16 or more hours of assistance a week. Differences were found in formal service use. Compared with urban residents, respondents diagnosed with MS living in rural areas reported more formal service use (10.6% vs. 18.1%), especially chore service (13.2%) (See Table 2). Geographic variance was also noted in the type of insurance individuals held. Generally, urban respondents were more likely to have insurance (98.4%), particularly private insurance (76.9%). In comparison, rural respondents tended to be insured by Medicare (43.1%) and/or Medicaid (23.9%).

Insert Table 2 here

Little difference was observed in independent living and long-term care (IL/LTC) planning and preparation by geography. Only a small percentage of respondents had engaged in independent living or long-term care planning (23%) or had received

information about it (36%). More rural (44%) than urban respondents (31%) felt informed or somewhat informed about IL/LTC services in their communities. There were no differences in feelings of confidence in locating services or knowing the cost of services. More urban than rural respondents had a will (59% vs. 40%), although there was no differences by geography in holding long-term care insurance, advance directives, or a power of attorney. Utilization of all of these preparatory mechanisms was limited. In regards to saving for retirement, urban residents were more likely to have saved or currently be saving for retirement or for other purposes; their spouses were more likely to save in comparison as well.

Insert Table 3 here

Logistic regressions indicate which factors are associated with formal, personal, and assistive service uses. The findings show that asset and geographic location (urban vs. rural), as well as education, health insurance, general and financial planning information about IL/LTC are not significant predictors of service utilizations (Table 5). Functional status is one of the most predictive factors that are associated with service uses across three models. Respondents with more difficulty in performing ADLs and IADLs were 3.4 times as likely to use formal service, in terms of odds (OR = 3.4, 95% CI = 2.3 – 5.0,  $p < .0001$ ), about 6.6 times as likely to use personal services (OR = 6.6, 95% CI = 4.2 – 10.3,  $p < .0001$ ), and about 12 times as likely to use assistive service (OR = 12.1, 95% CI = 7.1 – 20.4,  $p < .0001$ ). Compared with those living alone, respondents living with spouses are 70% less likely to use formal services, in terms of odds. Age,

employment status, and living arrangement were significantly related to personal service use. Age and employment status were also associated with assistive service use.

Insert Table 4 here

Table 5 shows the results of cumulative logistic regressions that predict IL/LTC preparation. Geographic location is significantly related to how informed the respondents feel about the types and availability of independent living and long-term care services, but not confidence in finding them or knowledge about their costs. Rural respondents were 40% less likely, in terms of odds, to feel informed about the formal services (OR = 0.6, 95% CI = 0.4 – 0.9,  $p = .01$ ). Increased age and having received information/education about formal service were significant predictors of being informed about services and their costs as were asset holdings having information about independent living and long-term care planning. People with more assets were 1.6 times as likely, in terms of odds, to feel informed about IL/LTC cost (OR = 1.6, CI = 1.1 – 2.3,  $p = .02$ ) than those with fewer assets. Additionally, having this long-term care planning information increased the likelihood respondents felt confident about being able to locate independent living and long-term care services.

Insert Table 5 here

Respondents having greater assets were more likely to feel prepared and have engaged in activities to prepare to pay for future IL/LTC needs. Those with more assets were 1.5 as

likely to feel financially prepared than those with fewer assets (OR = 1.5, CI = 1.0 – 2.2,  $p = .04$ ). Additionally characteristics including being older, more educated, having received information about IL/LTC services and planning were significantly associated with feeling prepared to finance future needs as well. These characteristics, with the exception of receiving information or education about IL/LTC planning, also increase the likelihood respondents have engaged in future preparation activities defined as purchasing IL/LTC insurance, having a will, health care advanced directive, or power of attorney. Future preparation for IL/LTC needs is created by summing up IL/LTC coverage purchase, having a will, health care advanced directive, and power of attorney, ranging from 0 – 4. Multivariate regression shows that asset was significantly related to future preparation ( $b = 0.3, t = 2.5, p = .03$ ).

In regards to saving for retirement, asset holdings and geographic location were important. Respondents with more assets were 2.2 times as likely to currently save for retirement than those with fewer assets (OR = 2.2, CI = 1.4 – 3.7,  $p = .002$ ); urban respondents were 1.7 times as likely to save than rural respondents (OR = 1.7, CI = 1.0 – 2.7,  $p = .05$ ). Being employed full or part-time employment, living with a spouse, and having received information about IL/LTC service and planning were also significant factors in saving.

Insert Table 6 here

In sum, findings from this case study show rural respondents are in worse health, and more reliant on public insurance than urban respondents. Additionally, they have fewer personal resources, as measured in terms of income, wealth, and education. Utilization of personal, technological and formal independent living and long-term care

services is similar across geographies indicating that where you live is not determinant of the nature of assistance you receive. In both instances, respondents rely heavily on personal and technological assistance and less so on formal services. Thus rural respondents have significant social and technological resources, equivalent to those of urban respondents and utilize them at a similar frequency.

Across geographies, few respondents reported engaging in planning or preparation for future independent living or long-term care needs. Those that had were more likely to be of greater wealth or education or perhaps be closer to being in need of these resources being of more advanced age or having received information or education about independent living or long-term care. Compared to urban respondents, rural respondents were more aware of resource and services in their community. This may be related to their smaller sizes of their communities or greater familiarity with a broader range of community members. Urban respondents were more likely to have formalized their plans in terms of purchasing insurance and obtaining legal documents.

Wealth, as measured by asset holdings, is related to both feeling prepared and engaging in financial preparation activities for future independent living and long-term care needs. This may not be unexpected as individuals in households of greater financial status may have more opportunity to save and plan for the future. Equally important then, may be receipt of independent living information and education in general and financial planning relating specifically to future needs. In this analysis both having greater assets and more information and education are significant.



## Discussion

Findings from this study reinforce, in many ways, what is already known about people with disabilities living in rural communities. Fiscally, resources for these individuals are more limited. Additionally, their health and functional status in general is worse. This is likely due in part to the nature of rural economies which often generate lower wages (US. Department of Agriculture, 2003, 2004) and to rural health care networks which commonly are found to be inadequately prepared to address the medical needs of people with disabilities, lacking in both knowledgeable staff and adequate and appropriate services (Vanek, 2002, Eldar, 2001). However, informal resources within rural communities are shown to be as strong as those in urban areas, identified in this case example through utilization of personal assistance and assistive technology employed by individuals to help achieve their daily objectives. Knowledge of community resources for independent living and long-term care is higher in rural communities, also supporting the premise that natural helping networks that integrate personal and professional resources exist in rural communities (Watkins, 2004). These distinctions are significant in understanding the nature of geographic differences in the experience of living with disability and provide some ability to hypothesize about potential variances in community participation. For instance rural dwellers may have fewer opportunities to participate at the levels they desire in their communities due to health limitations or accessibility restrictions that require significant financial resources to address.

In this case example of individuals living with multiple sclerosis, preparation for future needs in terms of independent living and long-term cares services that will improve or sustain community participation as well as individual health is limited. In this way, persons aging with MS are not very different than the general population of adults which is generally uninformed about the costs of long-term care (AARP, 2001) and engages in limited planning activities for future health and disability related needs (San Antonio & Rubinstein, 2004). What distinguishes these individuals from their peers without MS is the “known” trajectory of their condition and the greater likelihood that they will need assistance in the future. Although the disease trajectory of MS is unpredictable and symptoms of MS, mainly functional and sometimes mental limitations, often subside or stabilize, a significant percentage of adults with MS are reliant on assistance to perform daily tasks and maintain community participation.

In this study, over half of all respondents meet daily needs with the assistance of another person or assistive technology. The average age of respondents in this case example is fifty and most live within a family unit. Multiple sclerosis itself, is not known to shorten the average lifespan. Thus it is expected that people with MS will age into older adulthood similarly to their generational peers who do not have MS. However, if these individuals require the same or greater amount of assistance as they age, as might be anticipated, then it is not much of a stretch to imagine they may be in need of additional support or formal services. Recent research in the area of aging with MS indicates worse health and greater functional limitations are predictive of assistive technology use (Finlayson, Guglielmello & Liefer, 2000). Additionally, heavy reliance on family caregivers by persons aging with MS often results in a high level of caregiver

burden (Aronson, Cleghorn & Goldenberg, 1996). When caregiver “thresholds” are at their limit in terms of time, skill, and energy, caregivers for persons with MS often turn to formal supports or institutionalization (Caron, Loos, Pacolet, Versieck & Vlietinck, 2000). Institutionalization is a real fear for many individuals with MS (Finlayson, 2004). However it is based in reality. If the compositions of personal assistance support change through children moving out of the family home, divorce, illness, or death of a spouse, sibling, parent or friend, individuals with MS may find the need to assemble a new or modified network of support. Additionally, financial capacity to purchase informal assistance such as assistive technology can have a significant influence on maintaining functional independence (Mathieson, Kronenfeld & Keith, 2002). Thus within these scenarios, planning and financially preparing for future needs is important to assuring persons with MS in this study are able to meet their individual daily goals and objectives. However, as previously noted, few participants have done so.

Significant for the field of asset building, in this study, respondents with MS who have greater assets and those who have received information about independent living and long term needs and services and related financial planning, are more prepared for the future. This creates two distinct hypotheses and potential implications for asset development programs. First, there is substance to the argument that assisting individuals with disabilities in developing greater assets may lead to greater planning for future independent living and long-term care needs. This being said, the two developments may not naturally coincide and it may be factors other than asset accumulation that lead individuals to plan for their futures such as education, employer or community-sponsored program, advancing age, or relative need of the individual. Second, if asset accumulation

and future planning are related, providing training and education on planning for independent living and long-term care needs as part of the financial curriculum offered to asset development program participants may help facilitate this connection.

### *Study limitations*

As with any case study, there are limitations in generalizing results. In this study we focus only on adults with multiple sclerosis and as discussed in the introduction, disability is a varied experience. It may be that individuals with diagnostic conditions that are traditionally viewed as more stable, like spinal cord injury, may not feel the same impetus to plan for future needs as individuals with more potentially progressive diseases. However, there are physiological, social, and economic factors that indicate planning for future independent living and long-term care needs may be prudent for all persons experiencing disability. Those include relatively recent advancement in medical research that suggest many people aging with long-term impairments such as polio will experience “post-onset” conditions (Williams, 2000, Trojan & Cashman, 2005) or as in the case of spinal cord injury, where aging-related changes (Charlifue, Lammertse & Adkins, 2004, Capoor & Stein, 2005) may increase level of impairment. Additionally, secondary conditions related to primary injuries or illnesses often contribute to or exacerbate disability (Kinne, Patrick & Doyle, 2004). Changes in social support, as mentioned previously along with employment conditions and health insurance coverage, among other factors, may heavily impact an individual’s need for and ability to secure the needed supports to sustain desired levels of community participation. Other limitations

include the small response rate and sample bias related to membership in the Gateway Area Chapter and ability to complete the survey.

### Conclusion

This analysis contributes to a wider body of knowledge about people with disabilities living in rural areas. Specifically, it adds to the very limited amount of empirically-based literature on asset building and people with disabilities. There is much work to be done in this field to fully understand what is needed and desired by persons with disabilities generally and programmatically in terms of asset building. As efforts in this area progress, rural communities have many resources to offer including independent living centers, university centers, small business development agencies, community development organizations and most importantly people with disabilities themselves. Their existing work in improving and advancing opportunities for community participation of people with disabilities have laid a foundation in many rural areas for the acceptance and inclusion of persons with disabilities that will be crucial for asset building efforts to succeed. The next step forward in program and policy development may be to begin building alliances and sharing information to develop relevant policies and program materials to contribute not only to the current economic advancement of people with disabilities living in rural areas but the planning of their futures as well. A next step for research is to increase our understanding of how different segments of the population of people with disabilities value, seek, and utilize independent living and long-term care education and planning information through asset development programs. Both efforts will be important to effectively creating educational materials and targeting asset building

programs to what may be varying needs among the population of people with disabilities in rural areas.

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Table 1. Demographics and disability traits by locality

|                        | Total<br>(N = 576) | Rural<br>(n = 170) | Urban<br>(n = 390) | Test statistics                    |
|------------------------|--------------------|--------------------|--------------------|------------------------------------|
| Age (yrs)              | 50.2               | 51.1               | 49.7               | $t(542) = 1.4$                     |
| Gender                 |                    |                    |                    |                                    |
| Male (%)               | 20.6               | 17.7               | 21.9               | $\chi^2 = (1, N = 548) = 1.2$      |
| Female (%)             | 79.4               | 82.3               | 78.1               |                                    |
| Race                   |                    |                    |                    |                                    |
| White                  | 92.1               | 93.9               | 91.6               | $\chi^2 = (1, N = 544) = 0.8$      |
| Non-White              | 7.9                | 6.1                | 8.4                |                                    |
| Marital status         |                    |                    |                    |                                    |
| Married                | 69.9               | 66.5               | 71.1               | $\chi^2 = (1, N = 545) = 1.2$      |
| Not married            | 30.1               | 33.5               | 28.9               |                                    |
| Highest education      |                    |                    |                    |                                    |
| High school            | 47.0               | 55.2               | 43.6               | $\chi^2 = (1, N = 546) = 6.2^*$    |
| College and above      | 53.0               | 44.8               | 56.4               |                                    |
| Employment status      |                    |                    |                    |                                    |
| Employed               | 37.1               | 33.5               | 39.3               | $\chi^2 = (3, N = 540) = 3.5$      |
| Homemaker              | 11.3               | 9.9                | 11.4               |                                    |
| Retired and unemployed | 20.4               | 19.9               | 20.6               |                                    |
| Disability leave       | 31.3               | 36.7               | 28.8               |                                    |
| Living arrangement     |                    |                    |                    |                                    |
| Live alone             | 14.0               | 18.0               | 12.6               | $\chi^2 = (2, N = 533) = 3.1$      |
| Live with spouse       | 71.0               | 65.8               | 72.6               |                                    |
| Live with others       | 15.0               | 16.2               | 14.8               |                                    |
| Household income       | 3.7                | 3.1                | 3.9                | $t(467) = -4.6^{***}$              |
| Assets                 | 5.4                | 4.4                | 5.8                | $t(431) = -4.7^{***}$              |
| MS status              |                    |                    |                    |                                    |
| Mild                   | 36.1               | 29.7               | 39.6               | $\chi^2 = (2, N = 546) = 9.6^{**}$ |
| Moderate               | 50.8               | 60.6               | 46.2               |                                    |
| Severe                 | 13.1               | 9.7                | 14.2               |                                    |
| MS types               |                    |                    |                    |                                    |
| Relapsing/remitting    | 61.2               | 57.8               | 63.9               | $\chi^2 = (3, N = 545) = 2.6$      |
| Secondary progressive  | 15.2               | 16.3               | 14.8               |                                    |
| Primary progressive    | 12.2               | 12.1               | 11.6               |                                    |
| Not sure               | 11.3               | 13.8               | 9.8                |                                    |
| Age of diagnosis (yrs) | 35.3               | 36.5               | 34.7               | $t(554) = 1.5$                     |
| Duration of MS (yrs)   | 13.4               | 13.8               | 13.6               | $t(554) = 0.1$                     |
| Physical health status | 3.1                | 3.3                | 3.0                | $t(551) = 3.3^{**}$                |
| Mental health status   | 2.8                | 3.0                | 2.8                | $t(551) = 2.2^*$                   |
| Functional status      | 1.9                | 2.0                | 1.9                | $t(551) = 1.6$                     |

$p < .05$ ,  $** p < .01$ ;  $*** p < .001$

Table 2. Service use by locality.

|                                   | Total<br>(N = 576) | Rural<br>(n = 170) | Urban<br>(n = 390) | Test statistics                      |
|-----------------------------------|--------------------|--------------------|--------------------|--------------------------------------|
| <b>Assistive technology</b>       |                    |                    |                    |                                      |
| Use (yes %) <sup>1</sup>          | 53.9               | 56.6               | 51.4               | $\chi^2 = (1, N = 551) = 1.3$        |
| Mean # use                        | 1.9                | 2.0                | 1.8                | $t (554) = 0.8$                      |
| <b>Personal assistance</b>        |                    |                    |                    |                                      |
| Use (yes %) <sup>1</sup>          | 54.6               | 57.1               | 52.6               | $\chi^2 = (1, N = 543) = 0.9$        |
| Duration of use (%) <sup>1</sup>  |                    |                    |                    |                                      |
| Less than 1 year                  | 9.9                | 12.8               | 8.7                | $\chi^2 = (3, N = 300) = 5.1$        |
| 1-5 years                         | 52.5               | 53.2               | 51.9               |                                      |
| 6-10 years                        | 22.0               | 24.5               | 20.4               |                                      |
| 10 + years                        | 15.6               | 9.6                | 18.9               |                                      |
| Frequency of use (%) <sup>1</sup> |                    |                    |                    |                                      |
| 5 hours or less/wk                | 41.0               | 44.0               | 39.1               | $\chi^2 = (3, N = 288) = 0.7$        |
| 6-15 hrs/wk                       | 27.0               | 25.3               | 27.4               |                                      |
| 16-30 hrs/wk                      | 10.7               | 11.0               | 11.2               |                                      |
| 31+ hrs/wk                        | 21.3               | 19.8               | 22.3               |                                      |
| <b>Formal service</b>             |                    |                    |                    |                                      |
| Current use (yes %) <sup>1</sup>  | 12.9               | 18.1               | 10.6               | $\chi^2 = (1, N = 554) = 5.9^*$      |
| Past use (yes %) <sup>1</sup>     | 15.5               | 18.3               | 14.0               | $\chi^2 = (1, N = 550) = 1.6$        |
| Mean # services used              | 0.2                | 2.4                | 2.3                | $t (554) = 0.9$                      |
| Transportation service            | 4.0                | 4.8                | 3.1                | $\chi^2 = (1, N = 556) = 1.0$        |
| Chore service                     | 8.0                | 13.2               | 5.9                | $\chi^2 = (1, N = 556) = 8.3^{**}$   |
| Home health service               | 3.3                | 4.2                | 2.8                | $\chi^2 = (1, N = 556) = 0.7$        |
| Adult day care service            | 0.4                | 0                  | 0.5                | $\chi^2 = (1, N = 556) = 0.9$        |
| Assisted living residence         | 0.4                | 0.6                | 0.3                | $\chi^2 = (1, N = 556) = 0.4$        |
| Skilled nursing facility          | 1.6                | 1.2                | 1.8                | $\chi^2 = (1, N = 556) = 0.3$        |
| <b>Insurance</b>                  |                    |                    |                    |                                      |
| Insurance (yes %)                 | 96.8               | 92.6               | 98.4               | $\chi^2 = (1, N = 543) = 11.9^{***}$ |
| Private insurance                 | 71.5               | 58.7               | 76.9               | $\chi^2 = (1, N = 556) = 18.9^{***}$ |
| Medicare                          | 36.1               | 43.1               | 32.4               | $\chi^2 = (1, N = 556) = 5.9^*$      |
| Medicaid                          | 13.4               | 23.9               | 9.0                | $\chi^2 = (1, N = 556) = 22.4^{***}$ |
| VA                                | 4.0                | 3.0                | 4.6                | $\chi^2 = (1, N = 556) = 0.8$        |
| More than one insurance           | 26.7               | 32.3               | 23.9               | $\chi^2 = (2, N = 556) = 5.4$        |

<sup>1</sup> Percentage within locality is reported.

$p < .05$ ,  $** p < .01$ ;  $*** p < .001$

Table 3. Planning and preparation.

|                                    | Total<br>(N = 576) | Rural<br>(n = 170) | Urban<br>(n = 390) | Test statistics                      |
|------------------------------------|--------------------|--------------------|--------------------|--------------------------------------|
| LTC planning (yes %)               | 22.8               | 24.1               | 21.5               | $\chi^2 = (1, N = 547) = 0.4$        |
| LTC information (yes %)            | 36.0               | 30.0               | 38.4               | $\chi^2 = (1, N = 535) = 3.5$        |
| <b>Feel informed</b>               |                    |                    |                    |                                      |
| Very informed                      | 6.9                | 6.6                | 6.9                | $\chi^2 = (3, N = 545) = 1.27^{**}$  |
| Somewhat informed                  | 29.2               | 37.7               | 24.3               |                                      |
| Not very informed                  | 36.9               | 36.5               | 38.6               |                                      |
| Not at all informed                | 27.0               | 19.2               | 30.2               |                                      |
| <b>Feel confident</b>              |                    |                    |                    |                                      |
| Very confident                     | 16.4               | 15.6               | 17.2               | $\chi^2 = (3, N = 546) = 0.5$        |
| Somewhat confident                 | 48.0               | 46.7               | 47.8               |                                      |
| Not very confident                 | 22.1               | 23.9               | 21.4               |                                      |
| Not at all confident               | 13.6               | 13.8               | 13.7               |                                      |
| <b>Cost informed</b>               |                    |                    |                    |                                      |
| Very informed                      | 9.7                | 9.6                | 9.8                | $\chi^2 = (3, N = 546) = 0.4$        |
| Somewhat informed                  | 29.1               | 29.3               | 28.8               |                                      |
| Not very informed                  | 34.2               | 35.9               | 34.0               |                                      |
| Not at all informed                | 27.0               | 25.2               | 27.4               |                                      |
| <b>Finance preparedness</b>        |                    |                    |                    |                                      |
| Very prepared                      | 4.3                | 3.0                | 4.8                | $\chi^2 = (3, N = 543) = 5.1$        |
| Somewhat prepared                  | 27.7               | 21.7               | 29.4               |                                      |
| Not very prepared                  | 31.9               | 33.7               | 30.8               |                                      |
| Not at all prepared                | 36.2               | 41.6               | 35.0               |                                      |
| <b>LTC preparedness</b>            |                    |                    |                    |                                      |
| IL/LTC coverage                    | 14.7               | 14.4               | 14.5               | $\chi^2 = (1, N = 499) = 0.0$        |
| Will                               | 47.1               | 39.0               | 49.9               | $\chi^2 = (1, N = 545) = 5.4^*$      |
| Advance directive                  | 36.9               | 39.2               | 36.1               | $\chi^2 = (1, N = 497) = 0.5$        |
| Power of attorney                  | 38.0               | 38.9               | 37.3               | $\chi^2 = (1, N = 529) = 0.1$        |
| Total (mean, SD)                   | 1.3 (1.3)          | 1.3                | 1.3                | $t(547) = -0.5$                      |
| <b>Saving</b>                      |                    |                    |                    |                                      |
| <b>Saved for retirement</b>        | 59.6               | 48.8               | 63.5               | $\chi^2 = (1, N = 537) = 10.1^{**}$  |
| <b>Saving for retirement</b>       | 53.5               | 40.4               | 59.0               | $\chi^2 = (1, N = 532) = 15.7^{***}$ |
| <b>Saving for other goals</b>      | 45.7               | 35.4               | 49.9               | $\chi^2 = (1, N = 517) = 9.2^{**}$   |
| <b>Spouse saved for retirement</b> | 61.4               | 50.7               | 64.9               | $\chi^2 = (1, N = 474) = 8.4^{**}$   |
| <b>Could save more</b>             | 23.2               | 19.4               | 25.4               | $\chi^2 = (1, N = 543) = 2.3$        |

$p < .05$ ,  $** p < .01$ ;  $*** p < .001$



Table 4. Logistic regression models predicting assistive, personal, and formal service uses (N=576).

|                                 | Formal service use |      |            | Personal service use |      |            | Assistive service use |      |            |
|---------------------------------|--------------------|------|------------|----------------------|------|------------|-----------------------|------|------------|
|                                 | Beta               | SE   | Chi-square | Beta                 | SE   | Chi-square | Beta                  | SE   | Chi-square |
| Age                             | 0.03               | 0.02 | 3.38       | 0.03                 | 0.01 | 4.25*      | 0.07                  | 0.02 | 19.93***   |
| Education                       | -0.25              | 0.39 | 0.43       | -0.21                | 0.26 | 0.67       | 0.42                  | 0.29 | 2.20       |
| Employment <sup>a</sup>         |                    |      |            |                      |      |            |                       |      |            |
| Full- or part-time worker       | -1.05              | 0.62 | 2.90       | -1.10                | 0.32 | 11.81***   | -0.95                 | 0.34 | 7.65**     |
| Homemaker & volunteer           | -0.46              | 0.66 | 0.49       | -0.29                | 0.43 | 0.45       | -0.32                 | 0.47 | 0.47       |
| Unemployed & retired            | -0.41              | 0.47 | 0.78       | -1.18                | 0.39 | 9.06**     | -1.03                 | 0.43 | 5.77*      |
| Living arrangement <sup>b</sup> |                    |      |            |                      |      |            |                       |      |            |
| Living w/ spouse                | -1.16              | 0.45 | 6.70**     | 0.77                 | 0.39 | 3.87*      | -0.13                 | 0.41 | 0.11       |
| Living w/ others                | -0.09              | 0.53 | 0.03       | 1.06                 | 0.50 | 4.60*      | 0.17                  | 0.51 | 0.11       |
| Functional status               | 1.22               | 0.20 | 38.48***   | 1.88                 | 0.23 | 67.24***   | 2.49                  | 0.28 | 80.99***   |
| Health insurance                | 0.40               | 0.87 | 0.21       | -0.76                | 0.78 | 0.95       | 0.05                  | 0.78 | 0.00       |
| LTC info/education              | 0.34               | 0.39 | 0.76       | 0.61                 | 0.32 | 3.71       | 0.51                  | 0.34 | 2.24       |
| LTC financial planning info     | 0.62               | 0.42 | 2.23       | -0.24                | 0.27 | 0.77       | -0.17                 | 0.30 | 0.31       |
| Asset                           | -0.86              | 0.50 | 2.93       | 0.02                 | 0.28 | 0.01       | -0.24                 | 0.30 | 0.63       |
| Area /rural                     | -0.54              | 0.36 | 2.23       | 0.19                 | 0.27 | 0.50       | 0.13                  | 0.29 | 0.19       |

<sup>a</sup> Those on temporary or permanent leave is the reference variable.

<sup>b</sup> Living alone is the reference variable.

$p < .05$ , \*\*  $p < .01$ ; \*\*\*  $p < .001$

Table 5. Cumulative logistic regression models predicting independent living and long-term care preparation (N=576).

|                                 | Informed about LTC |      |            | Confidence about LTC |      |            | Informed about LTC cost |      |            |
|---------------------------------|--------------------|------|------------|----------------------|------|------------|-------------------------|------|------------|
|                                 | Beta               | SE   | Chi-square | Beta                 | SE   | Chi-square | Beta                    | SE   | Chi-square |
| Age                             | 0.03               | 0.01 | 6.75**     | -0.00                | 0.01 | 0.04       | 0.03                    | 0.01 | 8.08**     |
| Education                       | 0.30               | 0.19 | 2.57       | 0.21                 | 0.18 | 1.34       | 0.18                    | 0.18 | 0.98       |
| Employment <sup>a</sup>         |                    |      |            |                      |      |            |                         |      |            |
| Full- or part-time worker       | 0.19               | 0.24 | 0.68       | 0.35                 | 0.23 | 2.18       | 0.36                    | 0.23 | 2.41       |
| Homemaker & volunteer           | -0.06              | 0.31 | 0.04       | 0.26                 | 0.31 | 0.69       | -0.29                   | 0.32 | 0.87       |
| Unemployed & retired            | -0.49              | 0.27 | 3.37       | 0.05                 | 0.27 | 0.04       | -0.07                   | 0.27 | 0.07       |
| Living arrangement <sup>b</sup> |                    |      |            |                      |      |            |                         |      |            |
| Living w/ spouse                | -0.15              | 0.26 | 0.31       | -0.06                | 0.26 | 0.05       | -0.17                   | 0.26 | 0.41       |
| Living w/ others                | -0.01              | 0.33 | 0.00       | 0.15                 | 0.32 | 0.21       | -0.07                   | 0.33 | 0.05       |
| Functional status               | 0.13               | 0.11 | 1.29       | 0.07                 | 0.11 | 0.44       | 0.11                    | 0.11 | 1.06       |
| Health insurance                | -0.95              | 0.49 | 3.80       | 0.17                 | 0.48 | 0.12       | -0.30                   | 0.49 | 0.37       |
| Duration of MS                  | 0.00               | 0.01 | 0.00       | -0.01                | 0.01 | 0.48       | 0.02                    | 0.01 | 4.05*      |
| LTC info/education              | 1.57               | 0.22 | 49.18***   | 0.39                 | 0.21 | 3.35       | 1.57                    | 0.22 | 50.01***   |
| LTC financial planning info     | 0.27               | 0.19 | 2.01       | 0.60                 | 0.20 | 9.33**     | 0.52                    | 0.19 | 7.40**     |
| Asset                           | 0.05               | 0.20 | 0.07       | 0.25                 | 0.20 | 1.61       | 0.45                    | 0.20 | 5.05*      |
| Area /rural                     | -0.46              | 0.19 | 6.04*      | -0.04                | 0.19 | 0.05       | -0.20                   | 0.19 | 1.16       |

<sup>a</sup> Those on temporary or permanent leave is the reference variable.

<sup>b</sup> Living alone is the reference variable.

$p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$

Table 6. Cumulative logistic /Binary logistic/multivariate regression models predicting independent living and long-term care financial preparation (N=576).

|                                 | How prepared to finance LTC |      |            | Saving for retirement |      |            | Future preparation |      |         |
|---------------------------------|-----------------------------|------|------------|-----------------------|------|------------|--------------------|------|---------|
|                                 | Beta                        | SE   | Chi-square | Beta                  | SE   | Chi-square | Beta               | SE   | t       |
| Age                             | 0.03                        | 0.01 | 10.66**    | 0.02                  | 0.01 | 1.53       | 0.03               | 0.01 | 5.73*** |
| Education                       | 0.49                        | 0.19 | 6.73**     | 0.24                  | 0.24 | 0.97       | 0.28               | 0.11 | 2.47*   |
| Employment <sup>a</sup>         |                             |      |            |                       |      |            |                    |      |         |
| Full- or part-time worker       | 0.40                        | 0.24 | 2.73       | 1.70                  | 0.31 | 29.66***   | 0.26               | 0.14 | 1.81    |
| Homemaker & volunteer           | 0.59                        | 0.32 | 3.42       | -0.02                 | 0.40 | 0.00       | -0.05              | 0.19 | -0.25   |
| Unemployed & retired            | -0.01                       | 0.27 | 0.00       | 0.19                  | 0.34 | 0.32       | 0.13               | 0.16 | 0.77    |
| Living arrangement <sup>b</sup> |                             |      |            |                       |      |            |                    |      |         |
| Living w/ spouse                | 0.18                        | 0.27 | 0.45       | 0.88                  | 0.36 | 6.07*      | 0.04               | 0.16 | 0.22    |
| Living w/ others                | 0.01                        | 0.34 | 0.00       | 0.29                  | 0.45 | 0.43       | -0.01              | 0.20 | -0.05   |
| Functional status               | -0.04                       | 0.11 | 0.13       | -0.31                 | 0.15 | 4.35*      | 0.11               | 0.07 | 1.67    |
| Health insurance                | 0.27                        | 0.55 | 0.24       | 0.03                  | 0.72 | 0.00       | -0.40              | 0.31 | -1.30   |
| Duration of MS                  | 0.00                        | 0.01 | 0.20       | 0.00                  | 0.01 | 0.02       | 0.00               | 0.01 | 0.23    |
| LTC info/education              | 0.57                        | 0.22 | 6.97**     | -0.59                 | 0.30 | 3.95*      | 0.21               | 0.13 | 1.61    |
| LTC financial planning info     | 1.23                        | 0.20 | 38.33***   | 1.57                  | 0.27 | 22.23***   | 0.26               | 0.12 | 4.75*** |
| Asset                           | 0.41                        | 0.20 | 4.16*      | 0.81                  | 0.26 | 9.93**     | 0.27               | 0.12 | 2.25*   |
| Area /rural                     | 0.11                        | 0.19 | 0.33       | 0.51                  | 0.25 | 4.01*      | 0.04               | 0.11 | 0.35    |

<sup>a</sup> Those on temporary or permanent leave is the reference variable.

<sup>b</sup> Living alone is the reference variable.

$p < .05$ , \*\*  $p < .01$ , \*\*\*  $p < .001$