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Medicaid Home and Community-Based Services for Older People and Persons with Physical Disabilities: Beneficiary Satisfaction, Service Use and Expenditures

Final Report

Submitted to

Lisa Maria B. Alecxih
The Lewin Group, Inc.
3130 Fairview Park Dr., Suite 800
Falls Church, VA 22042

Prepared for
Susan Radke
Centers for Medicare & Medicaid Services
Office of Research, Development, and Information
Mail Stop C3-19-26
7500 Security Boulevard
Baltimore, MD 21244-1850

Prepared by
Joshua M. Wiener, Ph.D.
Wayne L. Anderson, Ph.D.
Galina Khatutsky, M.S.
Judith Shinogle, Ph.D.
RTI International
Health, Social, and Economics Research
701 13th Street, NW
Suite 750
Washington, DC 20005

RTI Project Number 09123.001

MEDICAID HOME AND COMMUNITY-BASED SERVICES FOR OLDER PEOPLE AND PERSONS WITH PHYSICAL DISABILITIES: BENEFICIARY SATISFACTION, SERVICE USE AND EXPENDITURES

Final Report

Authors: Joshua M. Wiener, Ph.D.
Wayne L. Anderson, Ph.D.
Galina Khatutsky, M.S.
Judith Shinogle, Ph.D.

Elderly and Physically Disabled Medicaid HCBS Beneficiaries
Project Director: Joshua M. Wiener, Ph.D.

Overall Project Director: Lisa Maria B. Alecxih

Federal Project Officer: Susan Radke

RTI International[*]

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EXECUTIVE SUMMARY

ES.1 Study Goals

This report is a product of a large CMS-funded project conducted by The Lewin Group and its subcontractors, RTI International, the University of Minnesota's Research and Training Center on Community Living, Mathematica Policy Resource, and the Medstat Group. The study's primary goals were to examine the financing and delivery of Medicaid home and community-based services (HCBS) and to study selected programs to assess their effects on quality of care, utilization of services, and cost. The project had two major study populations—older people and young people with physical disabilities were one group and people with intellectual disabilities/developmental disabilities were the second group. This report addresses older people and younger persons with physical disabilities.

The overall study had two components. The first component of the project involved case studies of the range of the services, coverage, financing, administration, and quality assurance systems in the seven states—Alabama, Indiana, Kentucky, Maryland, Michigan, Washington and Wisconsin (Wiener, Tilly, and Alecxih, 2002; Wiener et al., 2002; Wiener and Goldenson, 2001; Wiener and Lutzky, 2001a, 2001b; Tilly and Goldenson, 2001; Tilly, 2001; Tilly and Kasten, 2001a, 2001b). The second component of the study involved analyzing a survey of aged/physically disabled beneficiaries who used Medicaid home and community services and their Medicaid claims. This report presents findings from several studies that used the data from the Survey of Aged and Physically Disabled Medicaid Beneficiaries.

In analyzing the Survey of Aged and Physically Disabled Medicaid Beneficiaries and associated Medicaid claims data, RTI had the overarching goal of providing comprehensive descriptive information about Medicaid HCBS beneficiaries in the six study states (no survey was conducted in Indiana since the budget could only sustain drawing a sample in six states). In addition, the study objectives were to the following:

- Develop a survey-based measure of satisfaction with paid personal assistance
- Identify overall predictors of satisfaction for older adults and young persons with disabilities
- Examine the effect of workforce issues on consumer satisfaction
- Evaluate differences in satisfaction between persons using agency-directed and consumer-directed services
- Investigate correlates of prescription drug use among HCBS recipients
- Analyze the role of HCBS in Medicaid utilization and expenditure patterns.

Because of the wide diversity of study topics that may be of interest to a wide variety of audiences, each chapter/study is written as a stand alone document that can be understood by itself without reference to the other chapters.

ES.2 Methodology

The studies presented in this report analyze a survey of aged and physically disabled Medicaid beneficiaries who used Medicaid home and community-based services and their associated Medicaid claims. As part of our analysis, we constructed a measure of satisfaction with personal care services.

The Survey of Aged and Physically Disabled Medicaid Beneficiaries

The Survey of Aged and Disabled Medicaid Beneficiaries collected survey data on older people aged 65 and over and younger persons with physical disabilities (those under 65) who used Medicaid HCBS. The survey was conducted by Mathematica Policy Research, Inc (Snell et al., 2005). The survey obtained information on the demographic composition of beneficiaries, their health and functional status, the extent of informal support, as well as detailed data on the scope and types of paid personal care received. Other topics of interest included consumer satisfaction with paid care, consumer control over personal care services, and demographic characteristics of primary paid helpers.

The study used survey data gathered from 2,597 community-residing Medicaid beneficiaries receiving HCBS in six states—Alabama, Kentucky, Maryland, Wisconsin, Washington, and Michigan. The sample of Medicaid HCBS beneficiaries represented the following distribution by state:

Alabama	$n = 326$
Kentucky	$n = 680$
Maryland	$n = 213$
Washington	$n = 601$
Wisconsin	$n = 173$
Michigan	$n = 604$

The states were chosen to represent a range of developed and developing HCBS systems. The survey was fielded between May 2003 and June 2004, with the sample allocated proportionally among states based on the number of HCBS beneficiaries. From a sample frame of 87,322 community-residing Medicaid HCBS recipients, a simple random sample was selected in each of the six states, yielding a sample of 5,405 individuals, of which 2,601[1] responded to the survey; 1,864 individuals were ineligible, and 939 beneficiaries were nonrespondents (Snell, et al., 2005). Because of the major policy interest in differences between older and younger persons with physical disabilities, the survey sample was stratified by age (under age 65 versus age 65 or over). The survey, which took about 36 minutes to complete, was conducted primarily through telephone interviews using a computer-assisted telephone interviewing (CATI) system (n = 2,458) with some in-person interviews (n = 143).[2] The overall survey response rate was 72

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[1] Four observations were later determined to be duplicates and were alter removed from the sample resulting in the final sample of 2,597 of survey respondents.

[2] Four observations were later determined to be duplicates and were removed from the analysis.

percent, with 28 percent of respondents using a proxy (Snell et al., 2005). Most of the proxy responses were provided by unpaid caregivers.

Satisfaction with Paid Personal Assistance Scale

To examine satisfaction with paid personal assistance, a subsample of 2,325 self-respondents and unpaid caregiver proxies who provided responses to eight survey items was selected to construct the Satisfaction with Paid Personal Assistance Scale (SPPAS). These items measure overall satisfaction, as well as interpersonal aspects of care provided by paid caregivers, such as communication with paid caregivers, how problems get resolved, how often paid caregivers get impatient or angry, and how well paid caregivers are trained. This measure was used in 3 project studies.

Medicaid Claims

Medicaid claims for survey participants were used to study survey respondents' HCBS and non-HCBS utilization and expenditure patterns. The Medstat Group obtained Medicaid eligibility and claims files through CMS's Medicaid Statistical Information System (MSIS). Although Mathematica Policy Research, Inc. surveyed persons in six states, RTI was not able to obtain needed Medicaid claims data from Maryland and Michigan, so the claims analyses were limited to four states: Alabama, Kentucky, Washington and Wisconsin. The match rate between the claims data and the survey averaged approximately 99 percent across the four states in the analysis.

ES.3 Describing Medicaid Home and Community-Based Services Beneficiaries in Six Study States

The purpose of this analysis was to develop a chart book to provide basic descriptive information about Medicaid beneficiaries and their experiences using HCBS. The principal findings of the study are the following:

- In terms of demographic characteristics, survey respondents included a significant proportion of minority beneficiaries, were mostly female, and had low levels of education. The majority of respondents were not married and had very low income.

- To qualify for personal care assistance, either though Medicaid HCBS waivers or state plan services, a person needs to have substantial health problems and functional limitations. The survey found high levels of poor or fair health status, substantial functional impairment and significant amounts of pain. Pressure sores were also relatively common. Judging by a high proportion of proxy responses, a significant portion of participants experienced cognitive impairment. Given these significant health issues, the relatively low level of unmet need for ADL/IADL assistance reported in the survey was surprising.

- The great majority of the Medicaid HCBS beneficiaries in the six surveyed states reported high overall satisfaction with paid personal care and positively rated their relationship with paid helpers. A majority of respondents were satisfied with the amount of choice and control over scheduling and tasks performed, but a significant minority reported that they wanted more hours of personal care.

- In arranging and receiving personal care, beneficiaries reported several challenges. Sometimes they reported having difficulty finding a replacement worker and experienced lack of paid help on weekends. They also reported that some of the paid personal care workers were showing up late, not showing up on scheduled days, or not working hard enough.

ES.4 Personal Care Satisfaction among Aged and Physically Disabled Medicaid Beneficiaries

The purpose of this study was to develop a measure of satisfaction with personal care services and to use it to identify correlates of satisfaction among Medicaid beneficiaries. Assessing satisfaction of HCBS consumers with the paid personal assistance is important because it is a key component in measuring quality of care. The principal findings of the study are the following:

- Overall, HCBS Medicaid recipients are very satisfied with the personal assistance services.
- Race concordance between clients and paid caregivers is a positive and significant predictor of satisfaction with paid personal assistance.
- Unmet need for activities of daily living/instrumental activities of daily living (ADL/IADL) assistance is associated with lower satisfaction with paid personal assistance.
- For physically disabled persons under age 65, residing in group settings rather than in their own homes is associated with substantially lower satisfaction with their paid personal care.

ES.5 Workforce Issues and Consumer Satisfaction

The purpose of this study was to identify the extent of workforce problems in services to Medicaid HCBS beneficiaries and to identify correlates of satisfaction. The principal findings are the following:

- Workforce-related issues are powerful predictors of client satisfaction, stronger than any other demographic and health factors
- Among workforce issues, recruitment is more important than retention:
  - Having problems with replacing a worker or having workers not show up or show up late are more important than having a lot of different workers over time.
  - Having services performed by any number of different workers is better than having no services at all.

- Having well-trained workers was valued as much as having no recruitment problems.

- Problems with mistreatment rarely occurred, but when they did, they had the strongest effect of any variable estimated.

- Worker respect was associated with satisfaction scores for older Medicaid beneficiaries, but not younger persons with physical disabilities.

ES.6 Consumer Direction and Satisfaction with Paid Personal Assistance in Washington State

The purpose of this study was to compare consumer satisfaction with consumer-directed and agency-directed care in Washington. Skeptics of consumer-directed care argue that satisfaction in consumer-directed care is lower than for agency-directed care. The principal findings of this study are the following:

- Consumer-directed home care in Washington is used by a broad range of people with disabilities. It is used by older as well as younger people, by persons with severe disabilities as well as people with minor and moderate disabilities, and by minorities as well as Whites.

- Satisfaction with paid personal care is no worse for persons enrolled in consumer-directed programs than for those participating in traditional agency-directed home and community-based care.

- Medicaid beneficiaries aged 65 and over using consumer-directed home and community-based care are more satisfied than those using traditional agency-directed care.

- There was no statistically significant difference in satisfaction with paid personal care for physically disabled persons under age 65 enrolled in consumer-directed or agency-directed programs.

ES.7 Medication Use among Medicaid Users of Home and Community Based Services

The purpose of this study was to estimate the extent to which Medicaid HCBS beneficiaries received medications and to identify the correlates of unmet needs for prescription drugs. This research highlights the need to study the interaction of Medicaid, social services programs, and financial barriers for the aged and physically disabled Medicaid population. The principal findings are the following:

- A large majority of physically disabled and aged Medicaid HCBS recipients receive the prescription medications they need.

- A majority of physically disabled and aged Medicaid HCBS recipients receive needed assistance in taking their medications.

- However, 6.3 percent of study participants report unmet medication needs and list financial barriers as the primary reason for not having access to medications.

- Lack of transportation increases the probability of unmet need for prescription drugs.

- Increased satisfaction with paid personal help decreases the probability of unmet need for prescription drugs. This may be because HCBS links individuals to the service system.

ES.8 Understanding the Relationship Between Medicaid Home and Community Based Services and Medicaid Inpatient, Outpatient, Prescription Drug and DME Use

The purpose of this study was to examine the effect of Medicaid utilization of HCBS on a broad range of Medicaid outpatient service use and the use of prescription drugs and durable medical equipment (DME). The principal findings are the following:

Inpatient Services

- Controlling for a variety of health status variables, use of HCBS is associated with an increase in the number of inpatient discharges.
    - Waiver services were associated with a statistically significant change in the number of discharges.
    - We did not include a variable for state plan home health use in this regression because of the potential for endogeneity.

- *Marginal effects*: Waiver services had a statistically significant effect on the number of inpatient discharges, increasing discharges by 0.16 discharges per year..
    - We did not calculate a marginal effect for state plan home health use because of the potential for endogeneity.

Outpatient Services

- Controlling for a variety of health status variables, use of HCBS is associated with higher use of any outpatient services:
    - Home health use is a significant and positive predictor of the use of any outpatient services for the total study sample and for young persons with disabilities.
    - State plan personal care use is a positive but weak predictor of any use for beneficiaries aged 65 and over.
    - Most individual waiver services are significant and positive predictors of any outpatient utilization both for the total sample and for age groups of interest.

- Marginal effects:

  - Waiver services have the largest marginal effect. Medicaid beneficiaries receiving at least one Medicaid HCBS waiver service had a 12.8 percentage point higher outpatient care use.

  - Receipt of any state plan personal care or any state plan home health services has a smaller but also a statistically significant positive effect on outpatient use (4.8 percentage points and 2.1 percentage points respectively).

Prescription Drugs and DME

- Both state plan personal care and home health are significant and positive predictors of prescription drug and DME utilization for the total sample and for both age groups.

- Of individual HCBS services, personal care and nursing/therapies/other services appear to be the most consistently significant and positive predictors for the total sample and both age groups.

- Although receiving state plan home health and personal care is associated with a higher monthly number of prescription drug/DME claims for the total sample, only home health is a significant predictor for both people with disabilities under age 65 and older people. It is an especially strong predictor for young persons with disabilities, where receiving Medicaid state plan home health benefit increases the number of claims by about one per month.

- Use of HCBS waiver services are associated with more monthly prescription drug/DME claims.

- *Marginal effects.* Receipt of any of the three types of HCBS has a positive and significant effect on any use of prescription drugs/DME but no positive effect on the number of average prescription drug/DME claims:

  - Receiving versus not receiving HCBS waiver services of any kind is associated with an almost 20 percentage point increase in any prescription drug/DME use. The likelihood of consumers using any prescription drugs and durable medical equipment is almost 10 percentage points higher for beneficiaries using state plan personal care, and almost 5 percentage points higher for beneficiaries using state plan home health

  - There was no corresponding significant change in the number of monthly prescription drug/DME claims.

  - There was almost no change in the net combined effect of the HCBS use on prescription drug/DME use.

ES.9 The Association between Home and Community-Based Services and Medicaid Spending

The purpose of this study was to examine the effect of Medicaid HCBS spending on non-HCBS expenditures. The principal findings are the following:

Non-HCBS Services

- Among users, for most services, non-HCBS Medicaid expenditures were higher for young persons with disabilities than for those aged 65 and over:
  - Inpatient Medicaid expenditures. Younger persons with disabilities had 2.5 times the amount of non-HCBS Medicaid expenditures as older persons ($50,290 vs. $20,025).
  - Nursing facility Medicaid expenditures. These expenditures were about the same for young persons with physical disabilities and those aged 65 and over ($38,060 vs. $34,478).
  - Outpatient Medicaid expenditures. Younger persons with physical disabilities had 45 percent higher expenditures than older persons ($6,186 vs. $4,251).
  - Prescription drug/DME expenditures. Younger persons with physical disabilities had 73 percent higher expenditures than older persons ($6,702 vs. $3,218).
  - Total Medicaid expenditures. Younger persons with physical disabilities had almost 1.5 times the amount of Medicaid expenditures as older persons ($23,227 vs. $15,823). These expenditures do not include Medicare spending for dual eligibles.

HCBS Services

- While there was little differences in the probability of use by age group for the three HCBS services analyzed in the study, among those with positive expenditures, physically disabled persons under age 65 consistently had higher mean expenditures than older persons for each HCBS program:
  - State plan personal care ($14,818 vs. $11,228)
  - State plan home health ($6,616 vs. $5,798)
  - HCBS waiver ($10,050 vs. $8,570).
- Approximately three-quarters of waiver respondents used either waiver personal care or waiver home health and therapies. The great majority of waiver recipients used some of the broad array of less medically oriented services offered under the waiver.

Overall Effect of HCBS Spending on Medicaid Expenditures

- The association of HCBS spending on other Medicaid expenditures is minimal. A $100 monthly increase in any of the three HCBS services analyzed resulted in changes of less than 1 percent in other Medicaid expenditures. HCBS recipients may be gaining greater access to other Medicaid services, but the absolute change in expenditures is small.

- Medicaid home and community-based services do not increase or decrease total non-HCBS Medicaid expenditures.

ES.10 Summary and Conclusions

One of the major changes in long-term care over the last decade has been the growth in use of and expenditures for HCBS, especially through the Medicaid program. Despite this growth, little research has been done on who uses services and on the experiences of Medicaid beneficiaries who do. As a result, policymakers have had little data on which to make their policy decisions.

This report documents a major research effort to examine Medicaid HCBS for older adults and younger people with physical disabilities. A companion component of the study examined HCBS for persons with intellectual disabilities or developmental disabilities.

In the first component of the older adults and younger people with physical disabilities component of the project, case studies of the home and community-based service system were conducted in Alabama, Indiana, Kentucky, Maryland, Michigan, Washington, and Wisconsin. In the second phases of the study, surveys were conducted of Medicaid HCBS beneficiaries in all of the case study states except for Indiana. In the third and final phase of the project, Medicaid claims data was matched to the survey respondents in Alabama, Kentucky, Washington, and Wisconsin. Medicaid claims data were not available in time for Maryland, and Michigan's capitated payment system did not allow for a detailed analysis of use and expenditures.

The surveys, with and without merged Medicaid claims data, were used to analyze several issues of importance to federal and state policymakers, including a descriptive analysis of HCBS beneficiaries and their experiences, satisfaction with personal assistance services, workforce issues, consumer-directed services, medication use, and the effect of HCBS on Medicaid expenditures and use of acute care services. The results of these studies provide a rich set of findings that aid in understanding these growing services.

From the studies presented in this report, the following implications can be drawn:

- Medicaid home and community-based services are serving a population that it was designed to serve—beneficiaries with fairly high levels of functional and cognitive disabilities and with fair and poor health. Despite state options to provide eligibility for somewhat higher income persons, the vast majority of Medicaid home and community-based services beneficiaries were very low income. Of substantial policy concern is that pain were very prevalent and pressure sores were relatively common, both of these problems could be areas for additional focus by Medicaid officials.

- Medicaid beneficiaries express high levels of satisfaction with Medicaid home and community-based services, an important measure of program success. The study findings regarding racial concordance underline the importance of cultural competence in long-term care. In addition, the lower level of satisfaction by younger people with disabilities with group living arrangements, such as residential care facilities, suggests the need for some caution regarding expanding those waiver services.

- Satisfaction with long-term care depends heavily on the people who provide the services, most of which are hands on and often highly intimate and personal. Again, while not without problems, Medicaid beneficiaries expressed high levels of general satisfaction with their direct care workers. Overall, Medicaid beneficiaries' satisfaction was more related to having somebody provide needed services than necessarily having continuity with the same person overtime.

- One of the most contentious issues in consumer-directed home care is whether the quality of care is as high as it is for agency-directed care. Consumer-directed care typically lacks the training requirements and the professional supervision that is more common in agency-directed care. Our study of Washington state finds no statistical evidence that satisfaction with consumer-directed care is lower than with agency-directed care. In fact, older people with disabilities are more satisfied with consumer-directed care than with agency-directed care. While satisfaction is not synonymous with quality, it is an important component of quality.

- The hallmark of modern care of chronic illnesses is treatment with prescription drugs. A large majority of Medicaid home and community-based services beneficiaries report that they receive the medications that they need and most have help in taking their medications. For the minority of people not receiving the medications they need, perceptions of cost and transportation problems are key variables. These results underscore the need to monitor the effect of cost sharing on Part D use by the "extra help" population and the importance of social services in linking people to the use of prescription drugs.

- Federal and state policymakers are concerned about the health care use of people with disabilities both from the perspective of its high costs and the problems of access that they often have. Using versus not using Medicaid HCBS services appears to improve access to outpatient services, broadly defined, prescription drugs and DME, and inpatient services. At least for prescription drugs, the improvement in access is offset by a reduction in the number of prescription/DME claims by at least a portion of the population resulting in no net change in monthly prescription/DME claims. For inpatient services, HCBS waiver services are associated with an increase in hospital discharges, suggesting that the services function to link beneficiaries to services.

- One of the goals of home and community-based services is to reduce other Medicaid expenditures so that there are no net costs. This study found that using versus not using HCBS services has a very small impact on non-HCBS expenditures. Thus, using versus not using HCBS services does not increase or decrease total non-HCBS Medicaid services.

CHAPTER 1
INTRODUCTION AND METHODOLOGY

1.1 Study Goals

Home and community-based services, such as home health care, personal care, adult day care, respite care, and assisted living facilities, have grown in importance to the long-term care (LTC) system over the past two decades. In 2000, Medicaid non-institutional LTC services constituted 25 percent of total Medicaid LTC expenditures, up from about 10 percent in 1988. (The Lewin Group, 2000). Among the older population, home and community-based services were estimated to constitute about 30 percent of total LTC expenditures in that same year (U.S. Congressional Budget Office, 1999). Despite rapidly growing expenditures for these services, there is a dearth of research documenting the effects of these services on cost, quality of care, or quality of life of both recipients and their families (Lutzky et al., 2000).

In the coming years, it is likely that expenditures and utilization of home and community-based services will increase substantially for both demographic and policy reasons. Demographically, largely because of the aging of the population, the number of people with disabilities will increase substantially. Using the 1994 National Health Interview Survey, Rice (1996) projected that the number of people age 65 or over with activity limitations will increase from 12 million in 1994 to 28 million in 2030.

From a policy perspective, creation of a more balanced delivery system by expanding home and community-based services is a major policy goal in almost all States. States' rationales for this shift are that people want to remain in their own homes rather than enter institutions, that the quality of care at home is better than in nursing homes and other institutions, and the belief that these services will save money. In addition, consumer groups for both older people and younger adults with physical disabilities, have pushed for more noninstitutional services. The U.S. Supreme Court's Olmstead decision (*Olmstead* v. *L.C. ex. rel. Rimring*, 119 S. Ct. 2176 [1999]) found that inappropriate institutionalization was illegal under the Americans with Disabilities Act and established a limited right to home and community-based services, thus providing additional impetus for this policy choice (Rosenbaum, 2000).

This report is a product of a large CMS-funded project conducted by The Lewin Group and its subcontractors, RTI International, the University of Minnesota's Research and Training Center on Community Living, Mathematica Policy Resource and the Medstat Group (Wiener, Tilly, & Alecxih, 2002). The study's primary goals are to examine the financing and delivery of Medicaid home and community-based services and to study selected programs to assess their effects on quality of care, utilization of services and cost. The first component of the project involved case studies of the range of the services, coverage, financing, administration, and quality assurance systems in the six states (Wiener et al., 2002; Wiener and Goldenson, 2001; Wiener and Lutzky, 2001a,b; Tilly and Goldenson, 2001; Tilly, 2001; Tilly and Kasten, 2001a,b). The second component of the study involved analyzing surveys of older people and persons with physical disabilities and ID/DD beneficiaries who used Medicaid home and community services in Alabama, Kentucky, Maryland, Michigan, Washington and Wisconsin.

This report presents findings from the several studies that used the data from the Survey of Aged and Physically Disabled Medicaid Beneficiaries and Medicaid claims data.

In analyzing the Survey of Aged and Physically Disabled Medicaid Beneficiaries, RTI had several study objectives:

- Provide comprehensive descriptive information about Medicaid home and community-based services beneficiaries in the six study states.
- Develop a survey-based measure of satisfaction with paid personal assistance.
- Identify overall predictors of satisfaction for older adults and young persons with disabilities.
- Examine the effect of workforce issues on consumer satisfaction.
- Assess differences in satisfaction between persons using agency-directed and consumer directed services.
- Investigate correlates of prescription drug use among HCBS recipients.
- Examine Medicaid claims for survey participants to study the effect of various HCBS benefits on acute care utilization and expenditure patterns.

Because of the wide diversity of study topics that may be of interest to a wide variety of audiences, each chapter/study is written as a stand alone document that can be understood by itself without reference to the other chapters.

1.2 Survey Methodology

The Survey of Aged and Disabled Medicaid Beneficiaries collected survey data on older people aged 65 and over and younger persons with physical disabilities (those under 65 years old) who used Medicaid home and community-based services. The survey instrument is presented in Appendix A. The survey obtained information on the demographic composition of beneficiaries, their health and functional status, the extent of informal support, as well as detailed data on the scope and types of paid personal care received. Other topics of interest included consumer satisfaction with paid care, consumer control over personal care services, and demographic characteristics of primary paid helpers.

The study used survey data gathered from 2,597 community-residing Medicaid beneficiaries receiving HCBS in six states—Alabama, Kentucky, Maryland, Wisconsin, Washington, and Michigan.[3] The States were chosen to represent a range of developed and developing HCBS systems. The survey was conducted by Mathematica Policy Research, Inc. (Wiener, Tilly, and Alecxih, 2002). The survey was fielded between May 2003 and June 2004,

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[3] Wisconsin home care beneficiaries residing in counties participating in the Family Care demonstration were excluded from the sampling frame.

with the sample allocated proportionally among States based on the number of HCBS beneficiaries. The sample frame included older persons and younger people with physical disabilities. Because of the major policy interest in differences between older and younger persons with physical disabilities, the survey sample was stratified by age (under age 65 versus age 65 or over).

This survey provides a rare opportunity for highly frail individuals to voice their concerns and describe their satisfaction with personal assistance services. Surveying such impaired populations is known to be difficult, and to ensure that data collected were of high quality, special modifications to survey design and procedures, including proxies and frequent fatigue probes were used. Respondents participated in the survey directly or via proxy (paid and unpaid caregivers) and included participants living in their own homes and residents of assisted living facilities and other group settings. The survey, which took about 36 minutes to complete, was conducted primarily through telephone interviews using a computer-assisted telephone interviewing (CATI) system ($N = 2{,}458$) with some in-person interviews ($N = 143$).[4] The overall survey response rate was 72 percent, with 28 percent of respondents using a proxy. Most of the proxy responses were provided by unpaid caregivers.

The sample of Medicaid home and community-based services beneficiaries represented the following distribution by state:

Alabama	N=326
Kentucky	N=680
Maryland	N=213
Washington	N=601
Wisconsin	N=173
Michigan	N=604

1.3 Medicaid Claims

The Medstat Group obtained Medicaid eligibility and claims files through CMS's Medicaid Statistical Information System (MSIS) for each sample state. While Mathematica Policy Research, Inc., surveyed persons in the six states, RTI was not able to obtain needed claims data from Maryland on a timely basis, and Michigan claims contain capitated expenditures, which did not allow for an analysis of utilization of services or individual expenditures. As a result, the claims analyses were limited to four states: Alabama, Kentucky, Washington and Wisconsin.

We were able to obtain claims data for only four of the six states in the sample. While this was not desirable, it did not have major consequences for the study. Sample respondents in the two states for which we did not have claims data, Michigan and Maryland, were from each state's optional personal care program, for which we had adequate numbers of respondents in Washington and Wisconsin to represent this service in the analysis. In addition, we did not incur a significant loss in power for significance testing due to the loss of the sample members in

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[4] Four observations were later determined to be duplicates and were removed from the sample.

Michigan and Maryland. Our sample of approximately 18,000 persons provided substantial power in both the overall sample and in subgroup analysis.

Medicaid claims files contain Medicaid expenditures organized by site of service (inpatient, other institutional, and outpatient services, and prescription and durable medical equipment) and contain eligibility data on consumers (periods of eligibility, dual eligibility with Medicare, and whether receiving cash assistance). Medstat matched respondents from the survey data with one year of their Medicaid claims, spanning a period 6 months before and after they were surveyed. The survey month was counted as one of the 6 pre-survey months.

These claims are dated by date of service, although claims payment and state processing of MSIS claims can lag dates of service. The match rate between the claims data and the survey averaged approximately 99 percent across the four states in the analysis.[5] Research using both the survey data and Medicaid claims is presented in chapters 7 and 8.

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[5] Only 368 of 601 survey respondents in Washington state gave their permission to match their survey responses to claims data. We found no differences on important demographic and health-related factors between those respondents who did and did not give their permission.

CHAPTER 2
KEY SURVEY FINDINGS

2.1 Chart Book Methodology

The *Medicaid Home and Community-Based Services: Survey of Aged and Disabled Medicaid Beneficiaries Chart Book* (Khatutsky, Akhmerova, Anderson, and Wiener, 2006) presents descriptive data from the survey in a bar chart format for all variables by domain. Results are presented for the total sample (blue bars), and then separately for physically disabled persons under age 65 (red bars) and for people aged 65 and over (green bars). The results are unweighted. We present proportions for categorical variables and means for continuous variables. For some variables, the categories were collapsed for easier presentation. Corresponding variable names are listed at the bottom of each chart. The graphs were produced using STATA/ SE version 9 software. Excerpts from the chart book are presented in chapter 2.

2.2 Demographics

Figures 1 through 5 present demographic characteristics of the sample. In terms of demographic characteristics, survey respondents included a significant proportion of minority beneficiaries, were mostly female, and had low levels of education. The majority of respondents was not married and had very low income.

Figure 1. Race

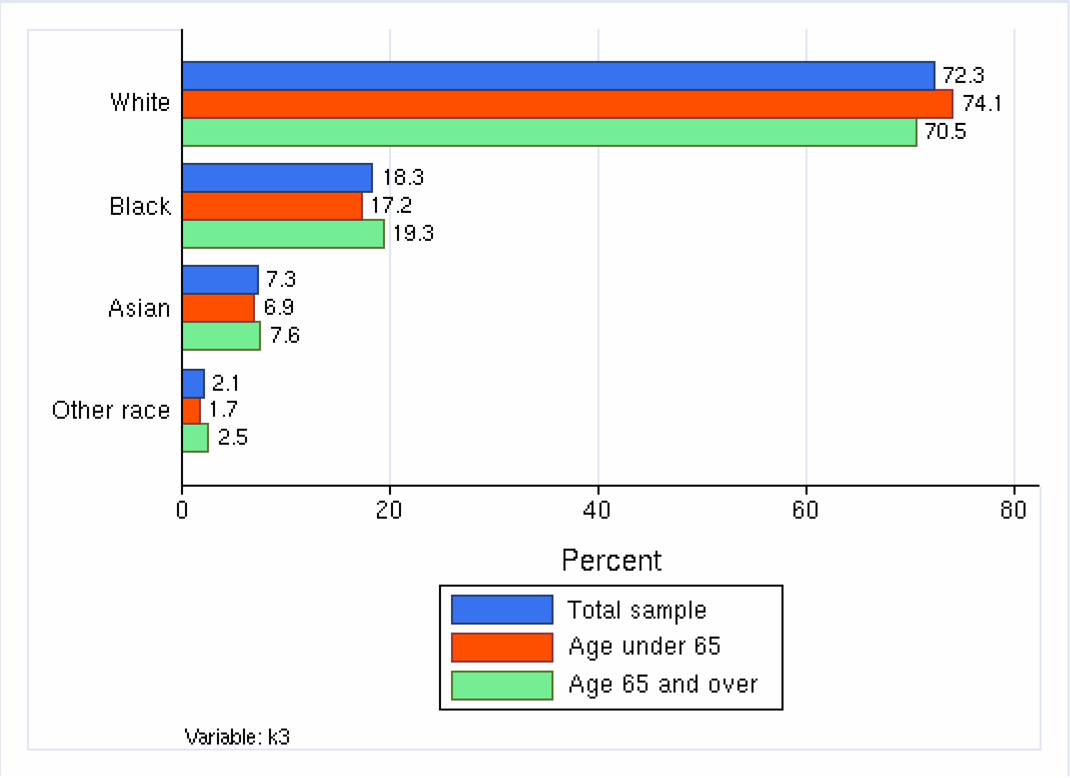


Figure 2. Gender

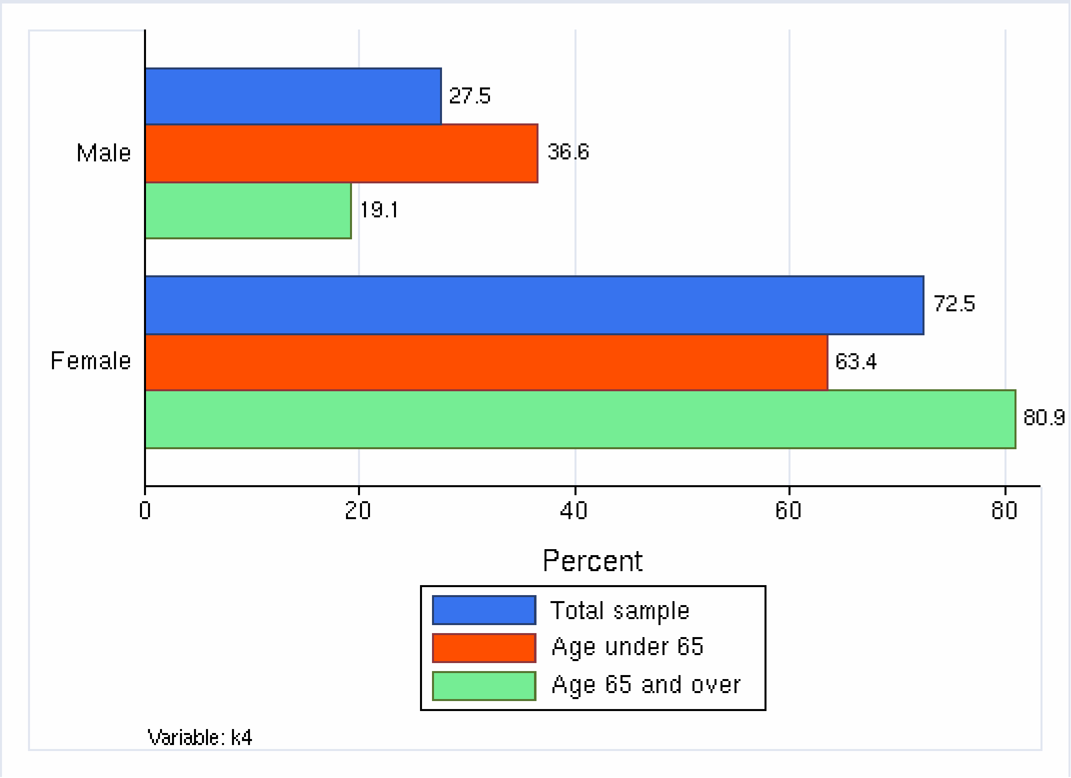


Figure 3. Education: Highest grade/level of school completed

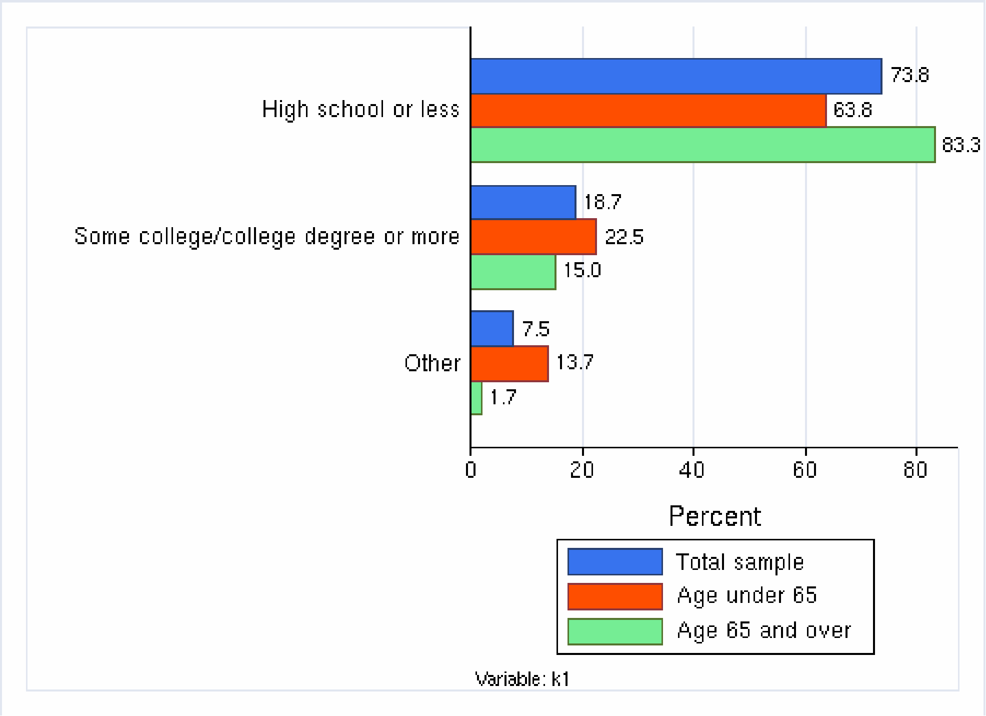


Figure 4. Marital status

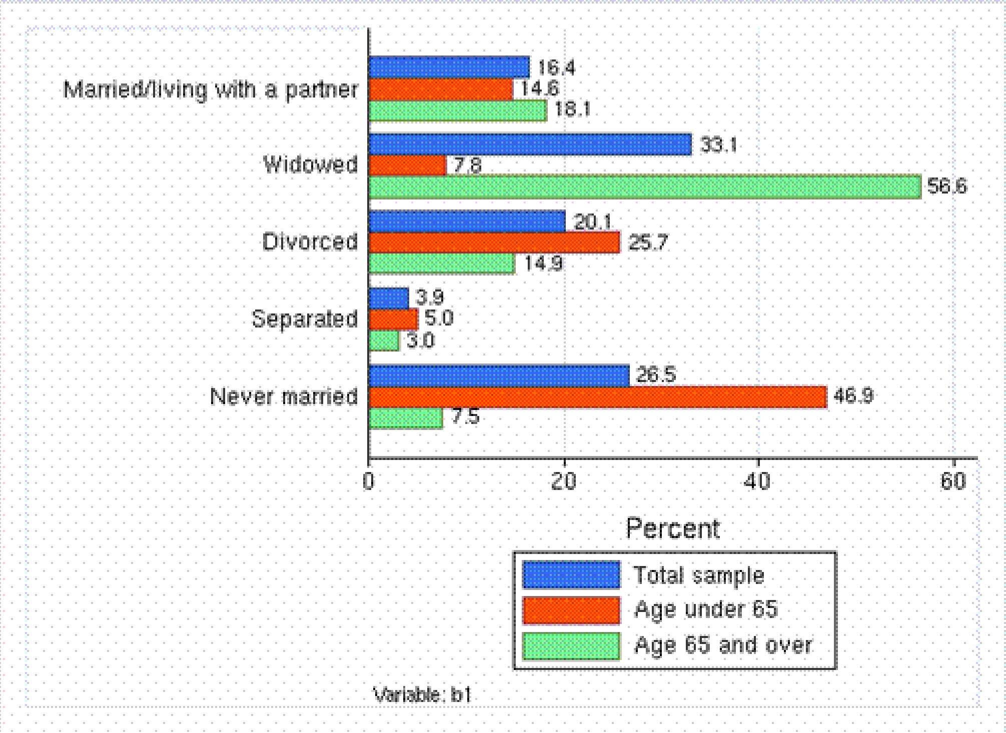
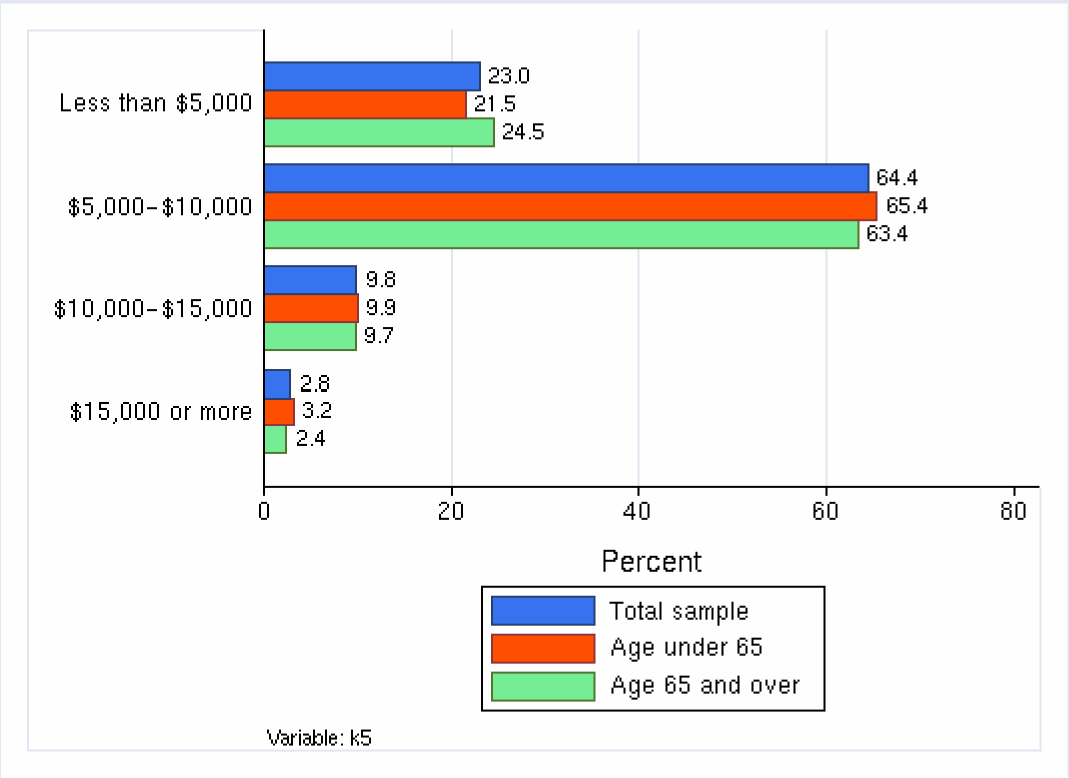


Figure 5. Respondent personal income before taxes



2.3 Health and Functional Status

Figures 6 through 11 present health and functional status characteristics of the sample To qualify for personal care assistance, either though Medicaid home and community-based services waivers or state plan services, a person needs to have substantial health problems and functional limitations. The survey found high levels of poor or fair health status, substantial functional impairment and significant amounts of pain. Pressure sores were also relatively common. Judging by a high proportion of proxy responses, a significant portion of participants experienced cognitive impairment. Given these significant health issues, the relatively low level of unmet need for ADL/IADL assistance reported in the survey was surprising.

Figure 6. Self-reported health status (compared to other people of the same age)

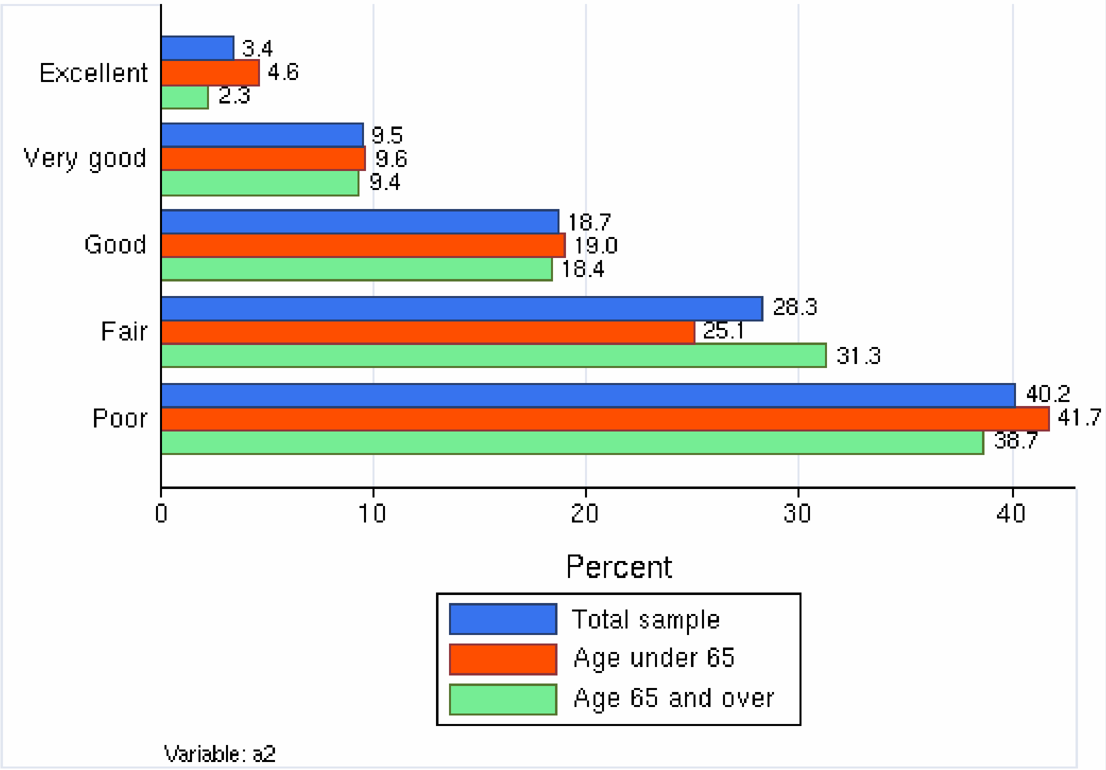
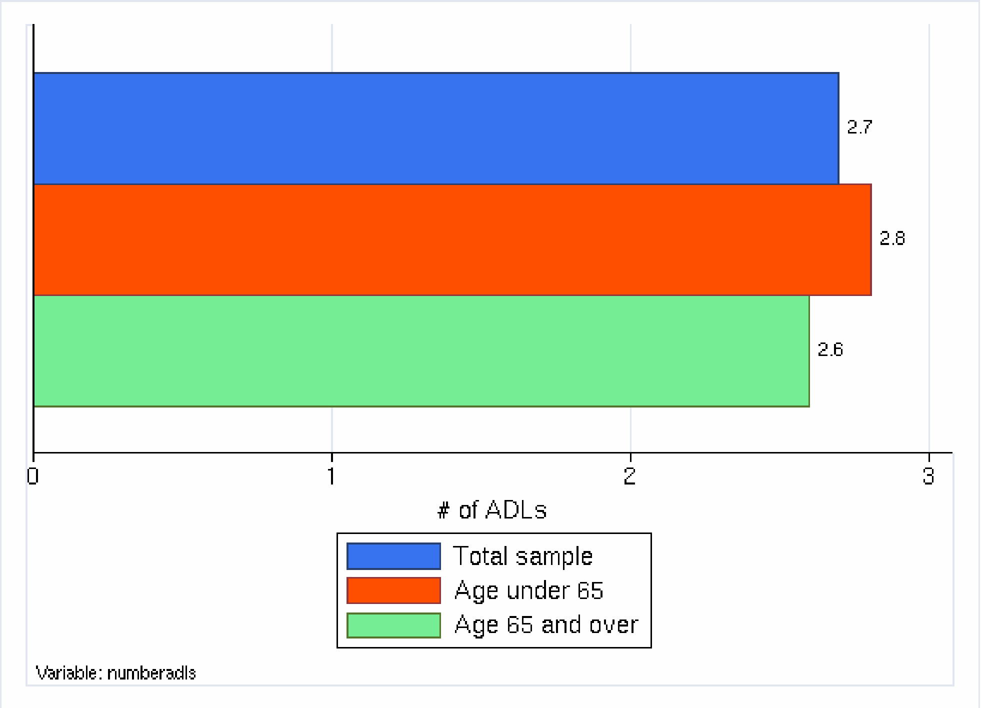
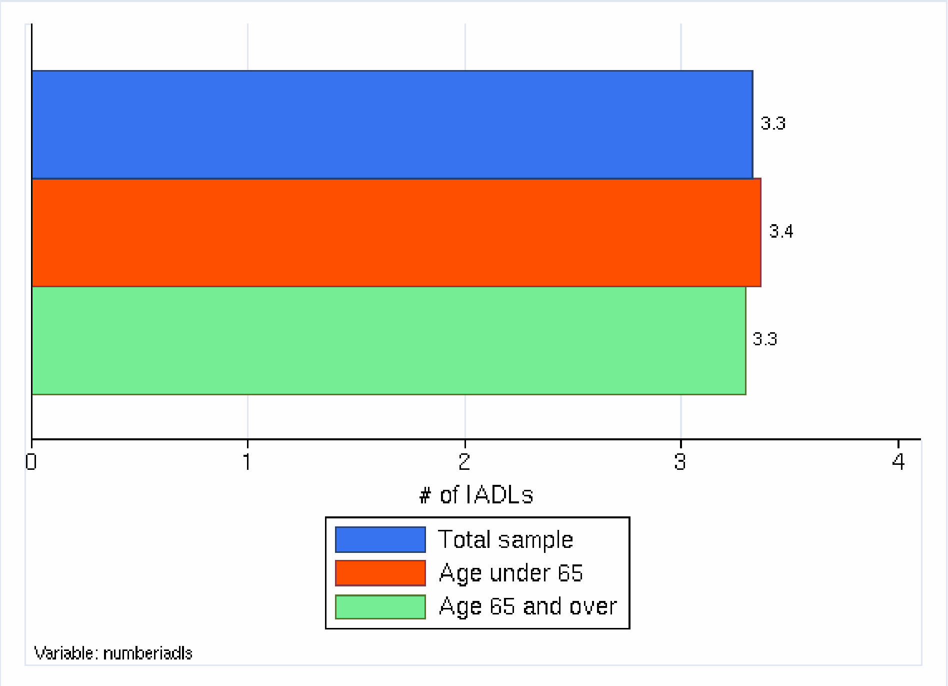


Figure 7. Mean number of limitations in activities of daily living (ADLs)[1]



[1] ADL scale ranges from 0 to 6 and includes bathing, dressing, eating, transferring, walking and toileting.

Figure 8. Mean number of limitations in instrumental activities of daily living (IADLs)[2]



[2] IADL scale ranges from 0 to 4 and includes cooking, managing medications, shopping, and doing light housework.

Figure 9. Mean number of unmet needs in the last month (ADLs and IADLs)

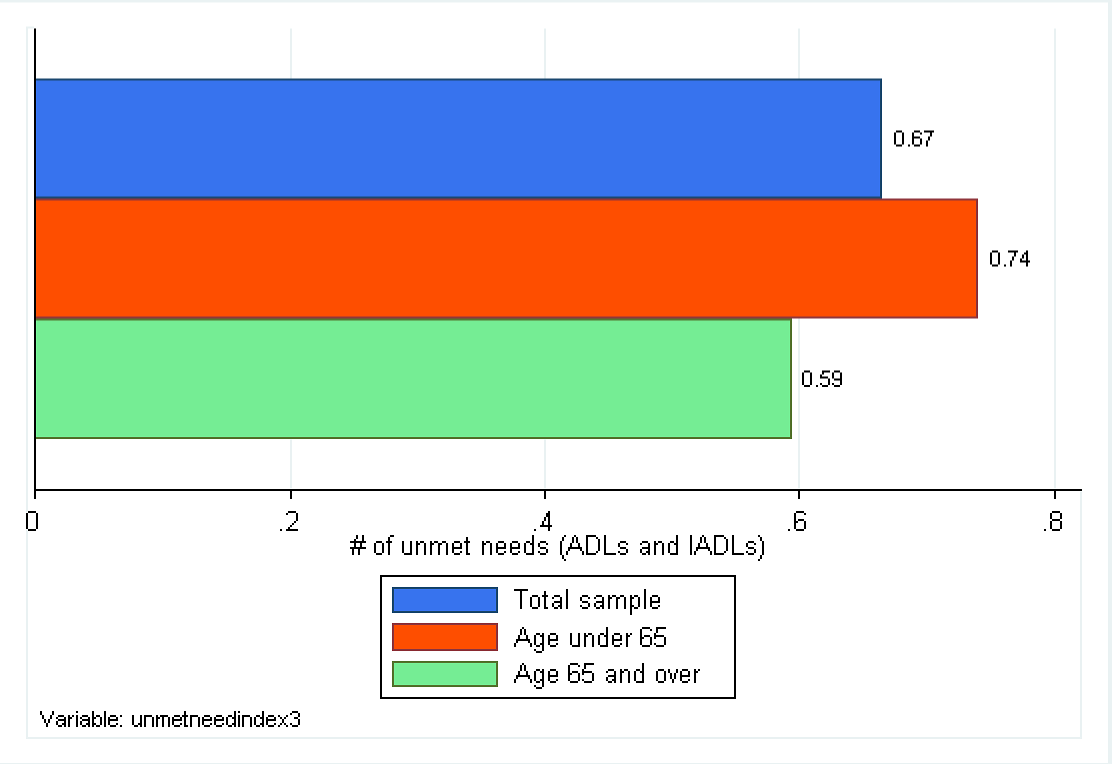


Figure 10. Pain in the past four weeks

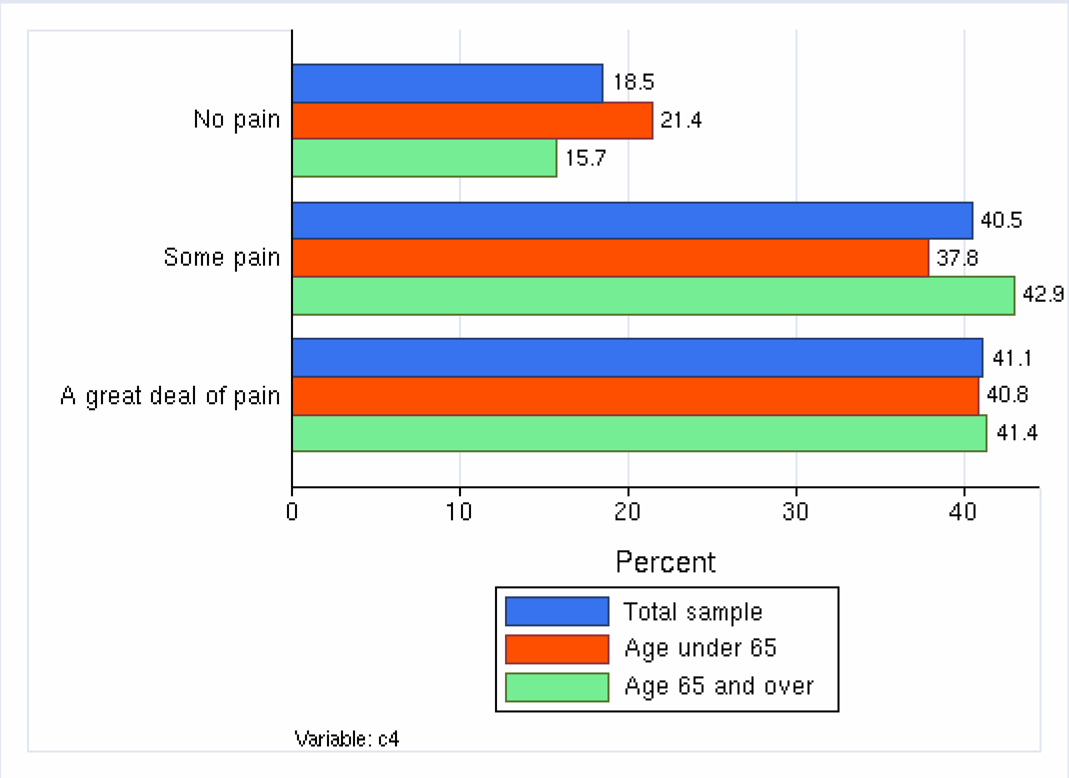
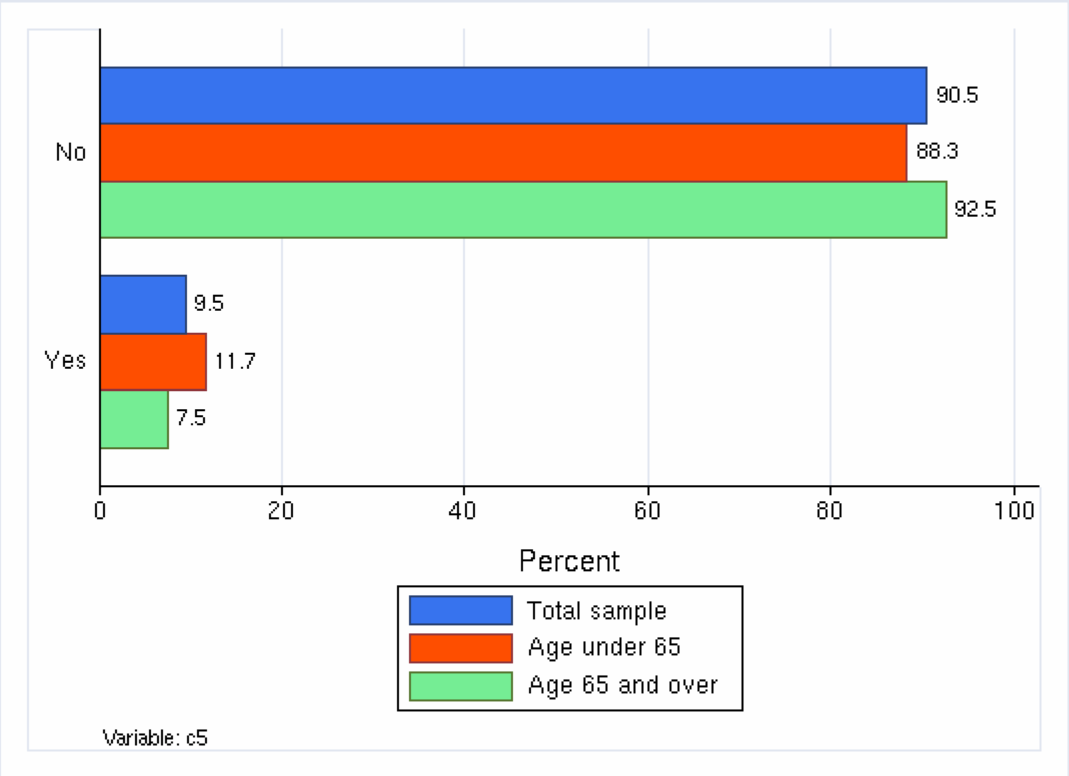


Figure 11. Pressure scores in the past six months



2.4 Paid Care

Figures 12 through 19 describe paid personal care received by the survey participants. The great majority of the Medicaid home and community-based services beneficiaries in the six surveyed states reported a high degree of overall satisfaction with paid personal care and positively rated their relationship with paid helpers. A majority of respondents were satisfied with the amount of choice and control over scheduling and tasks preformed, but a significant minority reported that they wanted more hours of personal care.

In arranging and receiving personal care, beneficiaries reported several challenges. Sometimes they reported having difficulty finding a replacement worker and experienced lack of paid help on weekends. They also reported that some of the paid personal care workers were showing up late, not showing up on scheduled days, or not working hard enough.

Figure 12. Overall satisfaction with paid care/help

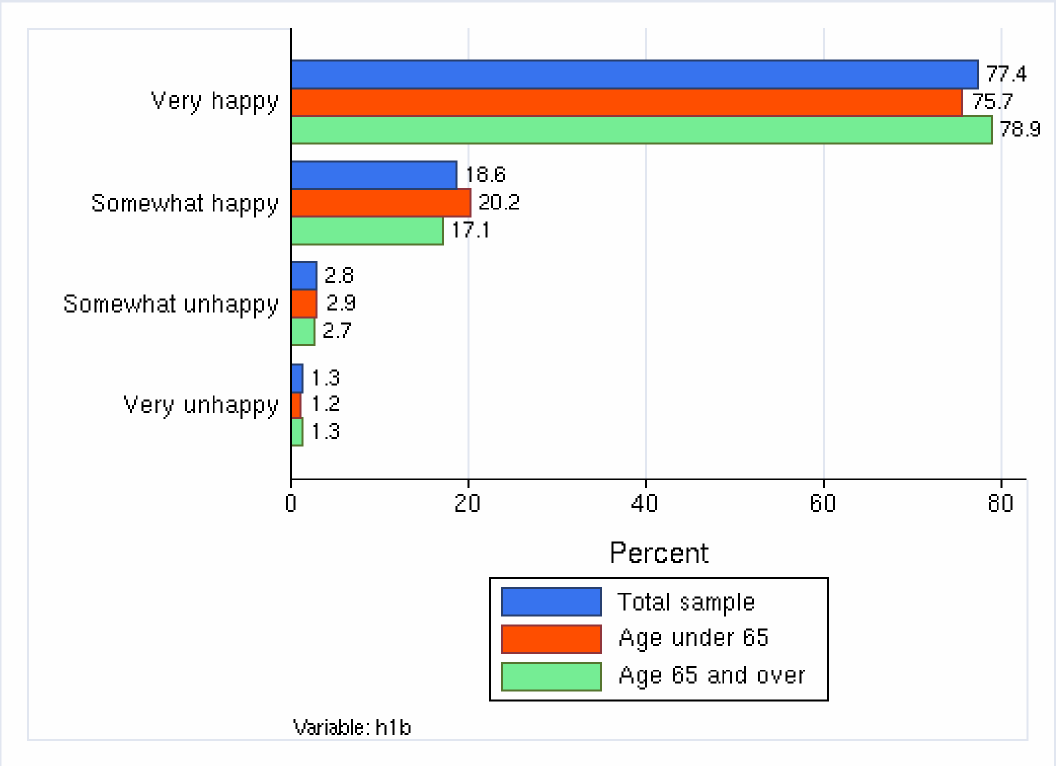


Figure 13. Total number of paid helpers last week

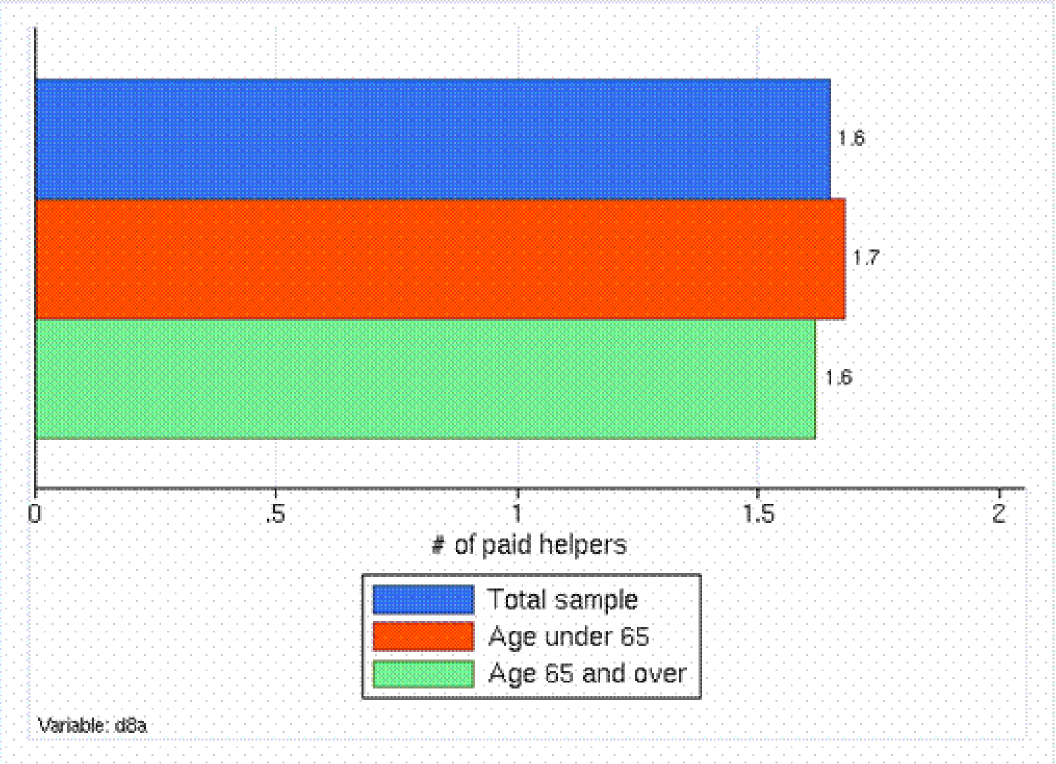


Figure 14. Problem or difficulty finding a replacement

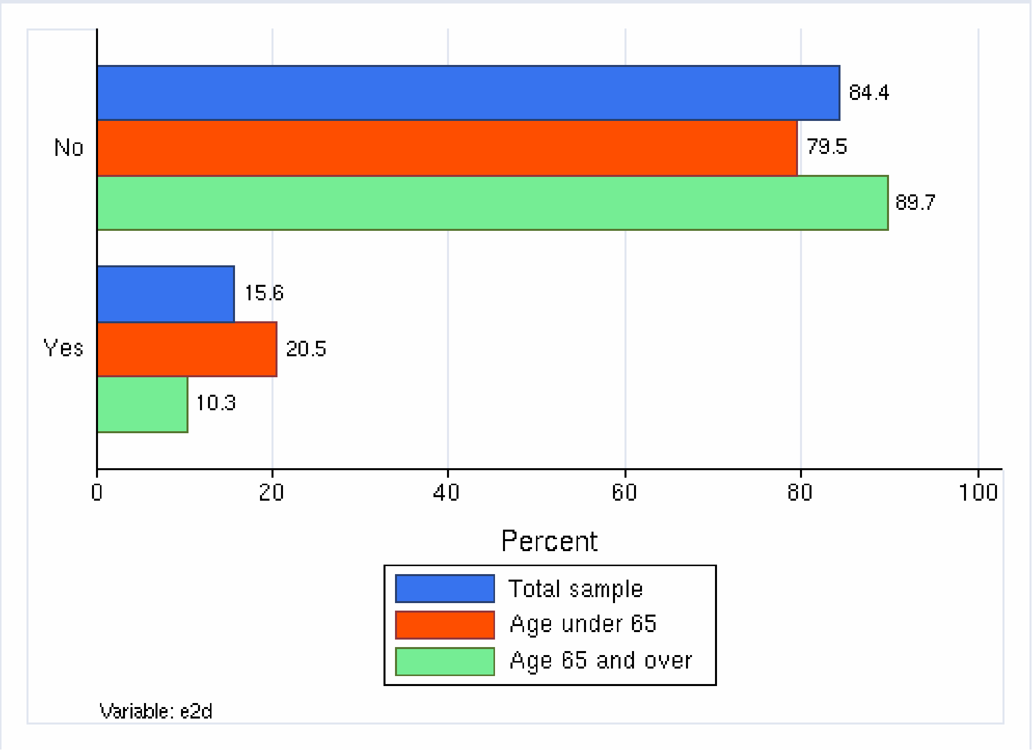


Figure 15. Paid help availability on Saturday/Sunday last week

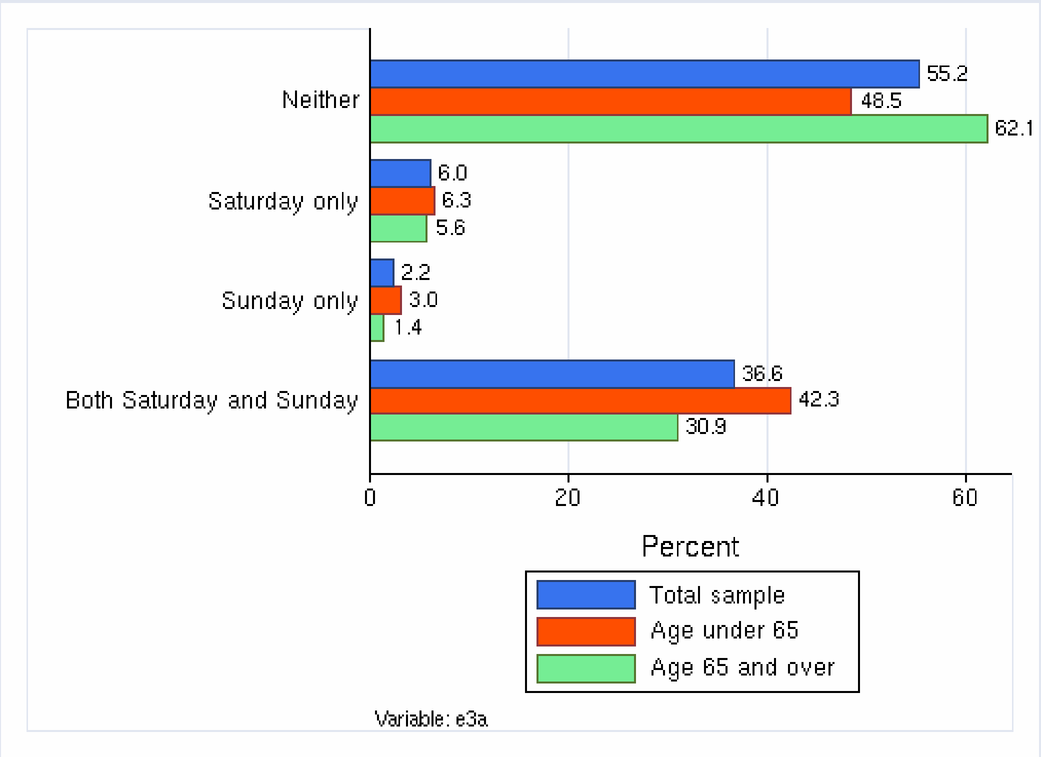


Figure 16. Adequacy of hours of paid help provided

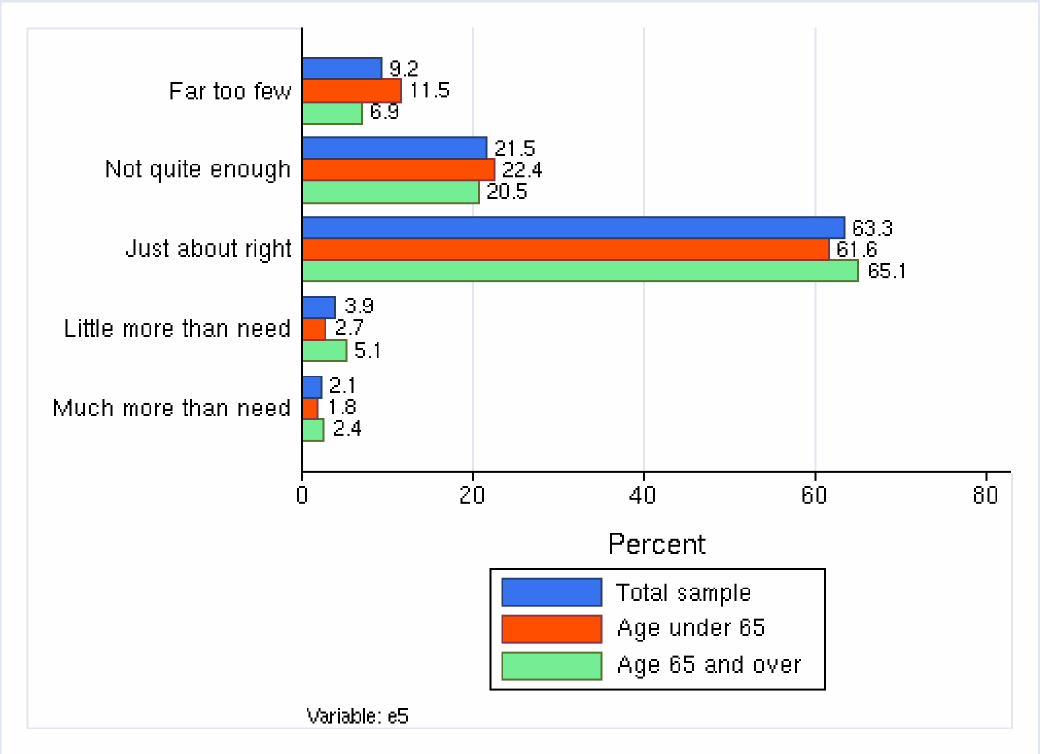


Figure 17. Respondent difficulty in resolving problems with paid helpers

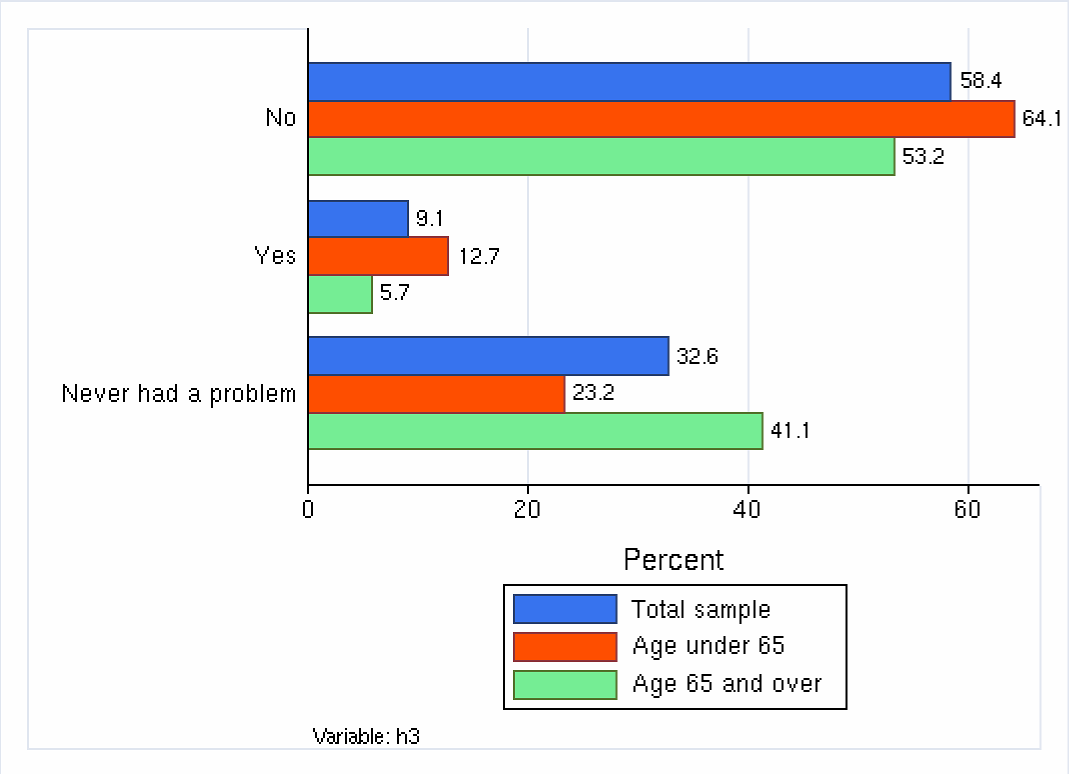


Figure 18. Respondent difficulty in communicating with paid helper

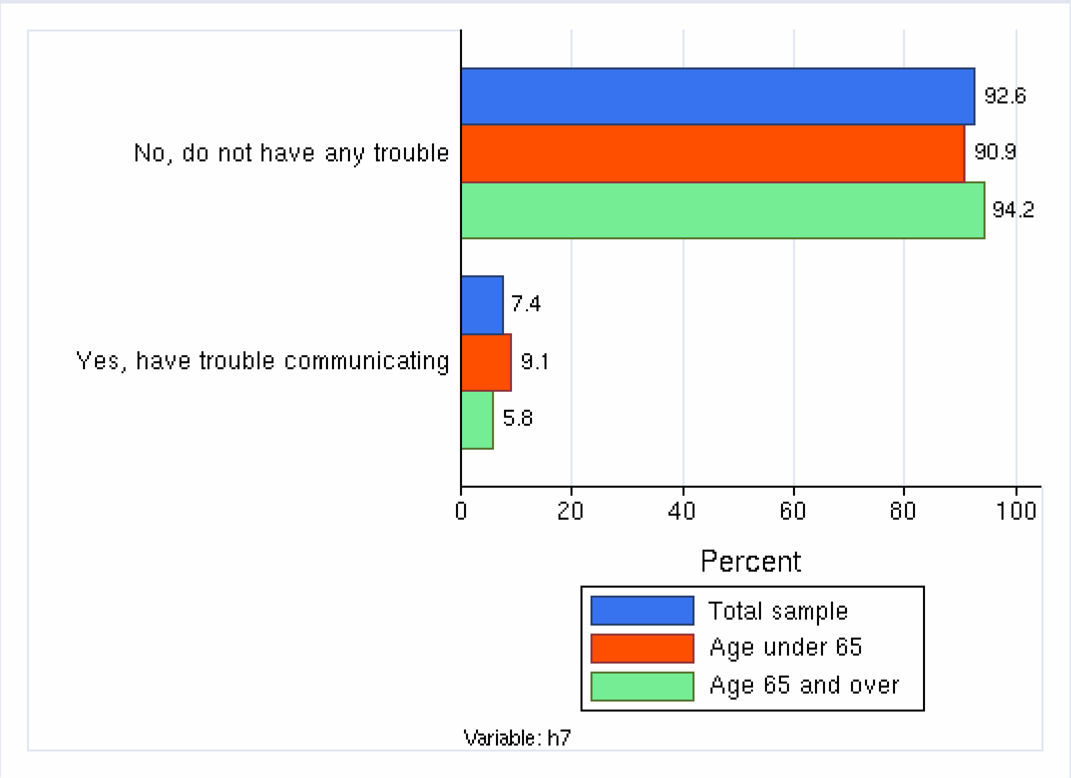


Figure 19. Frequency of selected problems with paid helpers

2.5 Consumer Control

Figures 20 through 24 present data on consumer control over Medicaid home and community services as described by the survey respondents. The majority of respondents were satisfied with the amount of choice and control over scheduling and tasks preformed, but a significant minority wants more hours of care. Most often, family members, friends, and case managers are in charge of the overall care received by survey respondents.

Figure 20. Respondent satisfaction with level of choice over tasks paid helpers should perform

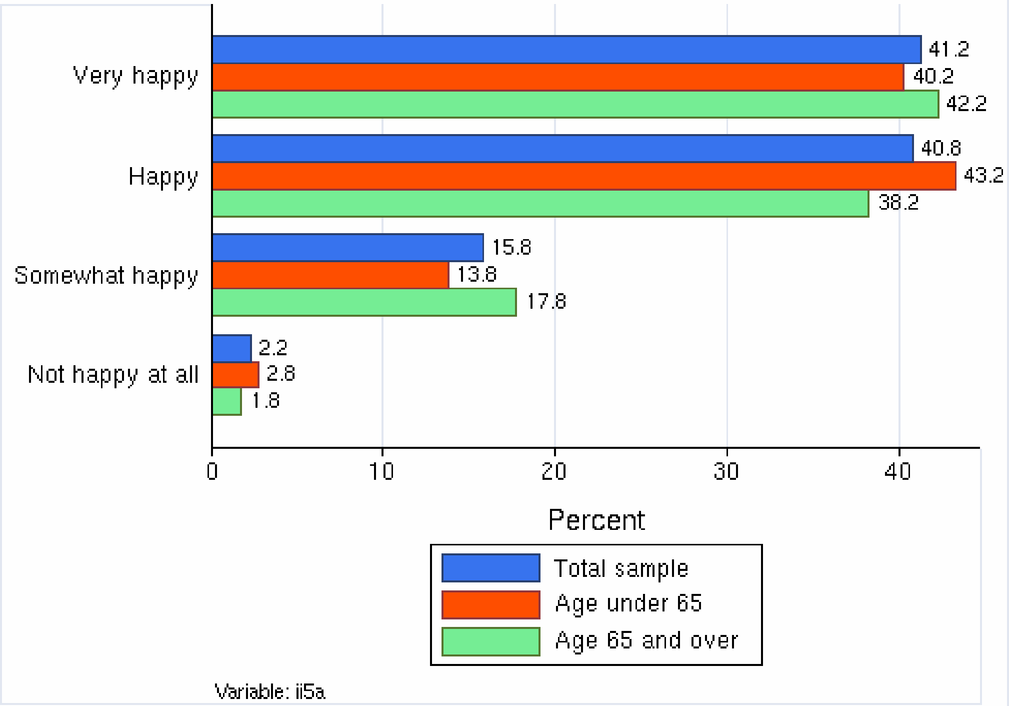


Figure 21. Responsibility for choosing paid helper

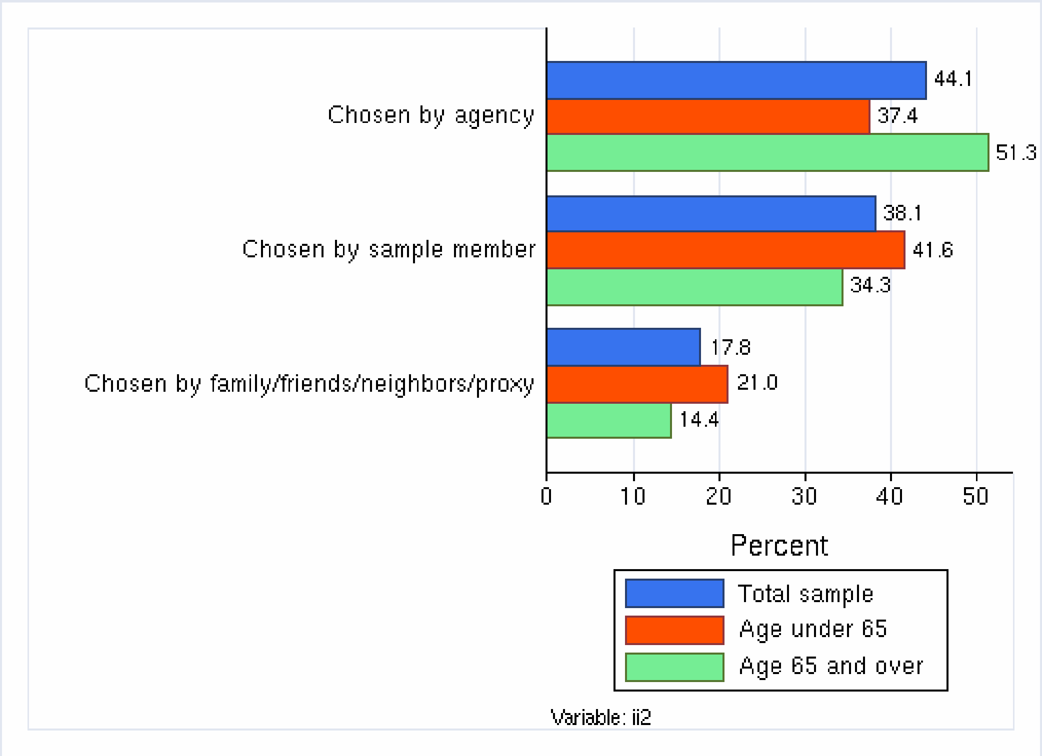


Figure 22. Respondent controls when and how things are done

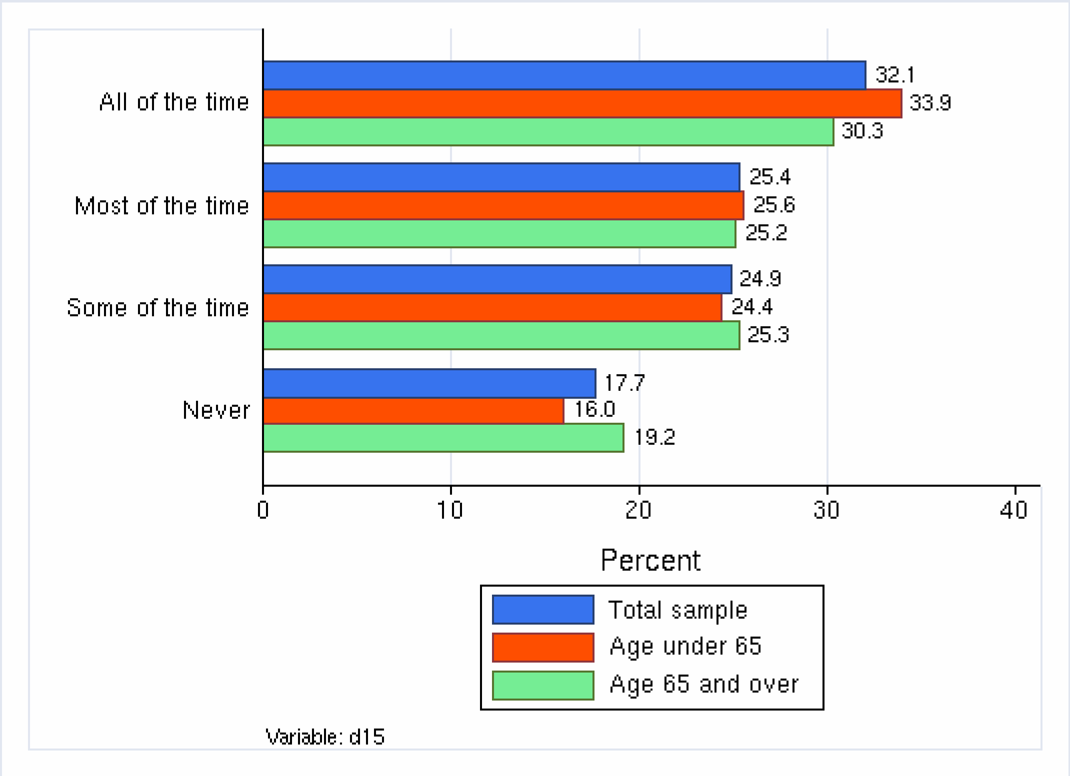


Figure 23. Level of respondent choice of tasks paid helpers should perform

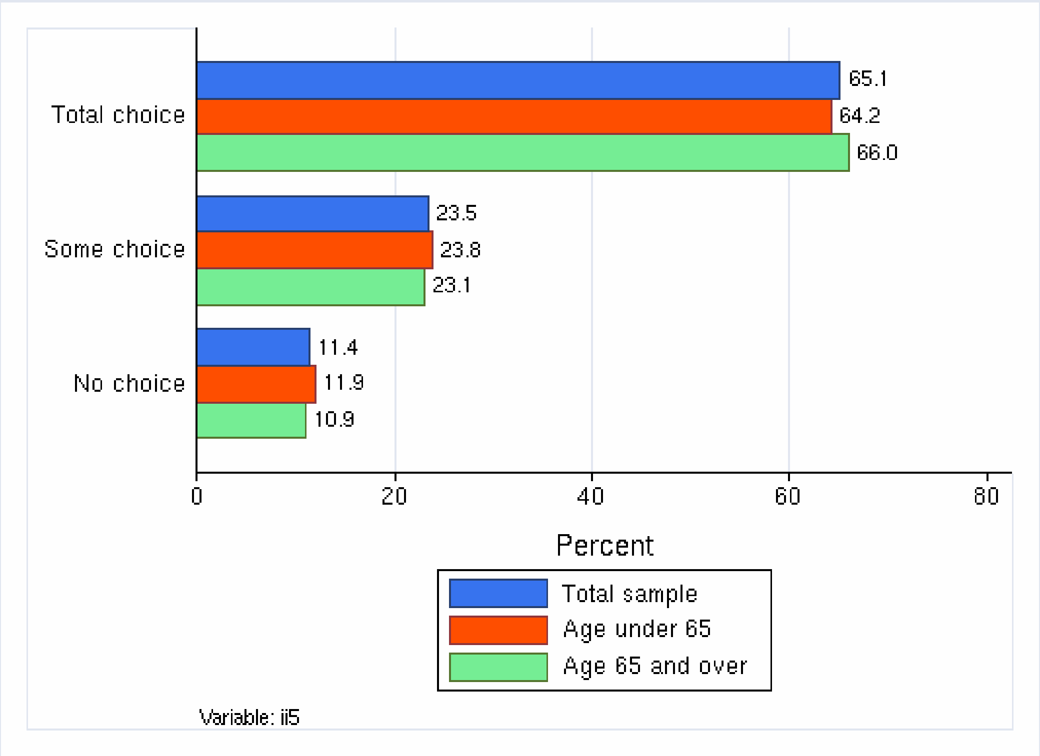
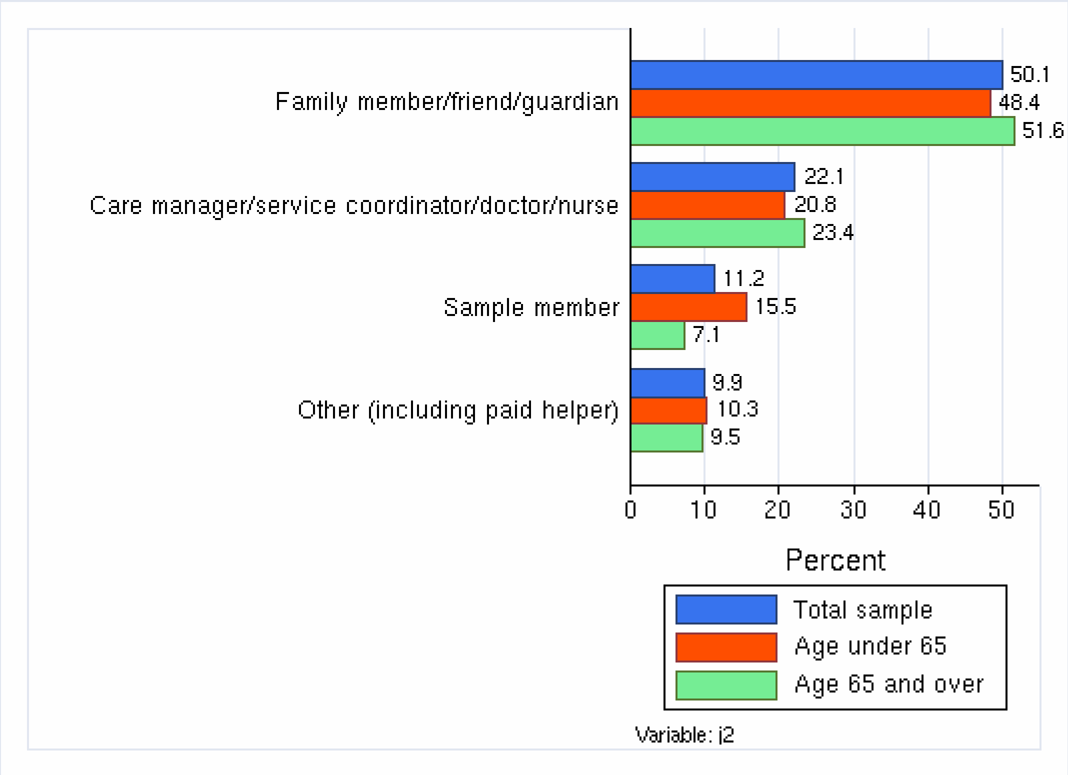


Figure 24. Individual in charge of overall care of respondent



CHAPTER 3
PERSONAL CARE SATISFACTION AMONG AGED AND PHYSICALLY DISABLED MEDICAID BENEFICAIRIES

3.1 Introduction

One of the key rationales for expanding HCBS is the assumption that satisfaction with non-institutional long-term care (LTC) services is higher than with nursing home care. However, measuring and ensuring quality of care in the home and community setting is at an early level of development compared to nursing home care (Geron, 1996; Kane and Huck, 2000; Montgomery and Kosloski, 1995; Weissert et al., 1983). Much less is known about the quality of HCBS than nursing home care, even though increasing numbers of people are receiving paid care at home (Wiener and Brown, 2005). Reliable measures and data on quality of care for nonskilled HCBS, such as personal care, homemaker services, and adult day health care, are not readily available. In contrast, CMS gathers a great deal of data on nursing homes and home health agencies, although no quantitative data on the views of beneficiaries are routinely collected.

Developing measures of quality for HCBS is difficult partly because of the special characteristics of the service (Wiener and Tilly, 2003). HCBS cover a variety of disparate services, which are provided in large numbers of physically-dispersed locations, making data collection difficult and expensive. Moreover, the measures are not well-developed, and collecting data from persons with cognitive impairments or high levels of disability is difficult (Kane, 1999). In addition, States are reluctant to establish detailed standards for HCBS because they fear replicating the rigidity of nursing homes. However, as expenditures for HCBS increase (U.S. Congressional Budget Office, 2004), policymakers are focusing more on quality of care for these services. For example, CMS has launched a major initiative to improve the quality assurance systems for Medicaid-funded home care (Stanton, 2003).

In addition to health outcomes and costs, one important component of quality of care is satisfaction with services. Satisfaction relates to how beneficiaries experience the care received compared to their standards or expectations (Linder-Peltz, 1982). Satisfaction measures can provide important information about inter-personal aspects of care, such as interactions and communication between providers and clients, clients' perceptions on how much providers respect, understand and listen to them, and whether clients are treated with dignity (Aharony and Strasser, 1993; Keepnews, 2003).

Although satisfaction with care received at home is now recognized as an important outcome (Geron et al., 2000); little is known about what factors affect satisfaction with a range of home care services, including personal assistance with activities of daily living (ADLs) and instrumental ADLs. People who use home care and home health services typically report high levels of satisfaction (Office of Inspector General, 1995; Geron et al., 2000), but previous research found that the social desirability effect—the tendency of respondents to provide an answer they think interviewer wants to hear—leads to reporting of high levels of satisfaction. High satisfaction ratings may also be related to clients' fears that negative ratings may result in an interruption of needed services.

Several studies examined Medicaid personal care services under 1915 (c) waiver program and found that client satisfaction is positively associated with having more choice and control (Doty, Kasper and Litvak, 1996), and that Medicaid beneficiaries receiving personal care under consumer directed programs were more satisfied than those getting their services via traditional agency-based programs (Foster et al, 2003, Benjamin, Matthias, and Franke, 2000, Beatty et al, 1996). A study by McCall et al. (2004) found that satisfaction with Medicare home health services is also associated with interpersonal aspects of client-staff interaction.

In reviewing research on patient satisfaction, Aragon and Gesell (2003) acknowledged that no generally accepted theory of patient satisfaction has emerged in the published health care research. Geron and colleagues (2000) provide a detailed overview of the factors affecting overall satisfaction with health care and note that few prior studies specifically analyze satisfaction with HCBS. In studying correlates of satisfaction with health care services, researchers usually examine demographic characteristics and health status.

It often is assumed that the LTC needs and goals of older people are different from those of younger people with physical disabilities, which may affect satisfaction with personal assistance services (Wiener and Sullivan, 1995). Younger people with physical disabilities often are thought to be more interested in independence, self-sufficiency, and participating in the normal activities of people without disabilities (Batavia, 2003). In contrast, older people with disabilities are often assumed to be too sick, frail, disabled or cognitively impaired to take an active role in managing their care (Cohen, 1990; Simon-Rusinowitz and Hofland, 1993; Wiener and Sullivan, 1995; and, Kane, 1999). Little empirical research exists to assess these assumptions and their affect on satisfaction with HCBS. The literature on satisfaction with acute care generally shows a positive association between patient satisfaction and age, although not all studies have found this relationship (Aharony and Strasser, 1993; Davies and Ware, 1988; Greenley, Young and Schoenherr, 1982).

Earlier research points to (1) a strong negative relationship between self-reported health and functional status and satisfaction with care; (2) poorer health and higher impairment levels resulting in less satisfaction; and (3) mixed findings on the effects of race, ethnicity, and age (Haviland, Morales, Reise, and Hays, 2003; Coughlin, Long, and Kendall, 2002; Pascoe and Attkisson, 1983). For example, one study found that Asians and Pacific Islanders are less satisfied with their health care than other groups, with the exception of African American respondents, who have comparable or higher satisfaction ratings than Caucasian respondents (Haviland et al., 2003). Other studies found that Caucasian respondents report higher satisfaction with services than other racial groups (Pascoe and Attkisson, 1983). Geron et al. (2000) found no association between satisfaction with home care services and age or race, but a negative relationship between physical disability and satisfaction. It is also important to note that dissatisfaction with health care services may also negatively affect physical and emotional health.

While not focusing on LTC and HCBS specifically, prior research indicates that race, language, and cultural concordance between patients and health care providers is another salient variable that affects satisfaction with care. Most studies find that patient-physician race concordance positively affects the perceived quality of care and increases satisfaction with health care services (Saha et al., 1999; LaVeist and Nuru-Jeter, 2002; LaVeist and Carroll, 2002; Shin and Moon, 2005). There is some evidence that these matches are also important in the HCBS setting. When home care agencies and adult day care centers hire providers from ethnic minority groups, it substantially increases participation from the respective ethnic communities (Gage et al., 2004).

Although less studied, social characteristics and living arrangements are also important factors that may affect satisfaction with services, especially for the younger physically disabled population. While we found no studies examining this relationship among people with physical disabilities, several studies of living arrangements among people with intellectual and developmental disabilities suggest there is a preference for independent living with supports in one's own home rather than for supervised living in a facility or other staffed community residence (Lakin, 2005; Kishi et al., 1988; Stancliffe and Abery, 1997). Group residence for people with intellectual and developmental disabilities was associated with low levels of individual choice and personal control because paid staff made many of the decisions (Emerson and Hatton, 1996; Kishi et al., 1988; Stancliffe, 1995; Stancliffe and Wehmeyer, 1995; Wehmeyer and Metzler, 1995). Consistently, in a study of board and care homes, Hawes (2005) found that elderly and nonelderly residents of mixed-age facilities were less satisfied with services than those who lived independently.

The goals of this study were to develop a measure of satisfaction with paid personal assistance provided through Medicaid and to identify demographic, health/functional status, and social/residential predictors of satisfaction with these services. Because it is often argued that younger people with physical disabilities have different expectations concerning home care than older people, we examined the study sample in total and separately for persons under and over age 65.

3.2 Methods

3.2.1 Survey

The study used survey data gathered from 2,597 community-residing Medicaid beneficiaries receiving HCBS in six states—Alabama, Kentucky, Maryland, Wisconsin, Washington, and Michigan (Snell et al., 2005).[6] The States were chosen to represent a range of developed and developing HCBS systems. The survey was conducted by Mathematica Policy Research, Inc., as part of a larger CMS-funded study of Medicaid HCBS (Wiener, Tilly, and Alecxih, 2002). The survey was fielded between May 2003 and June 2004, with the sample allocated proportionally among States based on the number of HCBS beneficiaries. The sample frame included older persons and younger people with physical disabilities. The intent of the sample design was to exclude people with developmental disabilities, although there may be a few respondents with intellectual disabilities that were included.[7] Because of the major policy interest in differences between older and younger persons with physical disabilities, the survey sample was stratified by age (under age 65 versus age 65 or over).

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[6] Wisconsin home care beneficiaries residing in counties participating in the Family Care demonstration were excluded from the sampling frame.

[7] Data on Medicaid HCBS beneficiaries with developmental disabilities analyzed for this project will be presented elsewhere by other authors.

This survey provides a rare opportunity for highly frail individuals to voice their concerns and describe their satisfaction with personal assistance services. Surveying such impaired populations is known to be difficult, and to ensure that data collected were of high quality, special modifications to survey design and procedures, including proxies and frequent fatigue probes were used.

Respondents participated in the survey directly or via proxy (paid and unpaid caregivers) and included participants living in their own homes and residents of assisted living facilities and other group settings. The survey, which took about 36 minutes to complete, was conducted primarily through telephone interviews using a computer-assisted telephone interviewing (CATI) system (N = 2,458) with some in-person interviews (N = 143).[8] The overall survey response rate was 72 percent, with 28 percent of respondents using a proxy. Most of the proxy responses were provided by unpaid caregivers.

Although there was no question on the survey about why a proxy respondent was needed, having a proxy often signifies mental health or cognitive problems or substantial physical disability or frailty. In our study sample, self-respondents had 3.2 instrumental ADL and 2.2 ADL limitations on average compared to 3.8 instrumental ADL and 3.8 ADL limitations among respondents with proxies. While unmet need was generally low in this population, respondents with proxies had slightly lower unmet need than self-respondents (0.4 ADLs/IADLs versus 0.7 ADLs/IADLs). Unpaid caregivers' relationships varied by age: among younger persons with physical disabilities, parents and other relatives provided most of the unpaid care (23 percent and 23 percent, respectively) followed by non-relatives (20 percent) and spouses (13 percent); for aged Medicaid recipients, most of the unpaid care was given by adult children and daughters/sons in law (61.9 percent) followed by other relatives (17 percent) and spouses (14 percent).

3.2.2 Statistical Analysis

In predicting satisfaction with personal care services, we developed an eight-item scale ranging from 0 to 100. We estimated an Ordinary Least Squares model that was right-censored at a scale value of 100 to account for the approximately one-half of all observations with the maximum value (55 percent for the overall sample, 52 percent for the sample younger than age 65, and 58 percent of the sample age 65 or over). The shape of the distribution of the remaining part of the satisfaction scale allowed us to assume the properties of a normal distribution.

We estimated State-level fixed effects to capture unobserved heterogeneity across States such as differences in HCBS programs. We estimated summary statistics using probability weights adjusted for nonresponse and post-stratification and stratified estimates by State, but did not do so with the regression models because we estimated fully specified models incorporating State effects.

We estimated three regressions on the dependent variable that was created to measure satisfaction: one regression for the overall analytic sample, one for the subgroup of respondents younger than age 65, and one for the respondent subgroup age 65 years or over. The two populations are likely to differ in their expectations and in the services or public programs

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[8] Four observations were later determined to be duplicates and were removed from the sample.

utilized. First, younger physically disabled adults may have higher expectations for participating in the workforce and community life, and subsequently might be more demanding (less satisfied) than elderly respondents. Second, these persons may differ in their eligibility for and participation in government programs (e.g., Older Americans Act and Medicaid services). Estimating satisfaction for these subgroups allowed us, in part, to account for these differences and determine whether satisfaction level differed between the two age groups.

Dependent Variable

To examine satisfaction with paid personal assistance, a subsample of 2,325 self-respondents and unpaid caregiver proxies who provided responses to eight survey items was selected to construct the Satisfaction with Paid Personal Assistance Scale (SPPAS).[9] Paid caregivers were not asked satisfaction questions. These items measure overall satisfaction, as well as interpersonal aspects of care provided by paid caregivers, such as communication with paid caregivers, how problems get resolved, how often paid caregivers get impatient or angry, and how well paid caregivers are trained (***Table 1***). Paid caregivers providing personal care to Medicaid HCBS beneficiaries can be hired through an agency or organization, or employed directly by respondents' families, if the State has a consumer-directed program. In consumer directed programs, personal care recipients are allowed to hire family members or friends to provide services. While one-half of sample respondents in the State of Washington hired a paid caregiver who was a family member, friend, or neighbor, only very small proportions of sample members in Michigan and Wisconsin did so. Sample respondents from Kentucky, Alabama, and Maryland do not have a consumer-directed option.

Prior to the scale construction, we performed several analytic steps to address issues of response grouping, survey item construction, and dummy variables. Two items required rescaling: for the question "Has it ever been difficult to get problems resolved or fixed?," we combined "no" responses with "never had a problem;" for the item "Is paid caregiver competent and well trained?," we combined the "sometimes/depends" with the "some helpers are, and some are not" categories As the SPPAS was constructed, several items were reversed so that higher scores would indicate more positive outcomes. The scale was set to a missing value if more than four items had missing responses. Dummy variables were scaled 0 or 100, three-response items were scaled 0, 50, and 100; four-response items were scaled 0, 33, 67, and 100; and five-response items were scaled 0, 25, 50, 75, and 100.

The scale ranged from 0 to 100 with a mean of 93.9 (standard error = 11.2) and Cronbach's (1951) alpha of 0.7. We evaluated the eight-item scale using factor analysis, which showed one dominant factor (eigenvalue 2.9). This factor loaded uniformly on all the variables, predicting a high correlation with the SPPAS scale, which was constructed as a mean of all items. The correlation between the scale and the factor was 0.97.

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[9] Paid caregivers acting as proxy respondents were not asked service satisfaction questions, and were not included in the study sample.

Independent Variables

Independent variables were grouped into three basic domains (details on variable construction are presented in ***Table 2***).

- Demographic characteristics of beneficiaries, including age, sex, and race. Under this domain, we also included a variable to indicate when care recipients and primary paid caregivers were of the same race or both reported Hispanic origin.[10] Income was not included as a variable because all survey respondents were very low-income Medicaid beneficiaries; 87 percent of respondents had annual incomes of $10,000 or less, so there was little variation across the study sample.
- Self-reported health and functional status of personal assistance recipients, including self-reported health status, number of limitations in six ADLs (bathing, dressing, eating, transferring, walking across the room, and toileting), and number of limitations in four instrumental ADLs (cooking, managing medications, shopping, and doing light housework). We also created a composite of ten items that asked about unmet needs for ADL and instrumental ADL assistance, a count variable ranging from 0 to 10. Additional health status indicators included prior nursing home use, recent pain or pressure sores, and bladder/bowel incontinence. A variable for proxy survey respondent was used to control for cognitive impairment in the sample population.
- Social Characteristics and Residence, including social involvement and participation; living in a group setting such as assisted living, group or adult foster home; and state of residence.
- Moreover, among the independent variables used in the regressions, health status (excellent, very good/good and fair/poor) was imputed based on survey respondents' ADL impairment for about 1 percent of the total sample for which a response was missing.

3.3 Results

3.3.1 Descriptive Findings

Table 1 presents the distribution of variable components comprising the SPPAS for the total sample and separately for younger people with physical disabilities and age 65 or over.

HCBS beneficiaries reported high levels of general satisfaction and with various aspects of their personal care. Overall, about 77 percent of respondents were "very happy" with paid care received, and about 19 percent were "somewhat happy." About 10 percent of respondents reported ever having difficulties resolving or fixing problems they encountered with their paid caregiver, and only 7 percent reported trouble communicating with the paid caregiver. Almost all (99 percent) got along "well" or "very well" with their paid caregiver, and 85 percent never experienced a problem of a paid caregiver ignoring them. Less then 5 percent complained about

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[10] Data limitations preclude further investigations of whether there is ethnic/racial match because clients and providers are related.

Table 1
Distribution of variables comprising the Satisfaction with Paid Personal Assistance Scale: 2004

Variable	All Survey Respondents	Respondents Under Age 65	Respondents Age 65 and Over
N	2,325	1,108	1,217
How Happy Overall With the Paid Care Received			
Very Happy	0.776	0.766	0.787
Somewhat Happy	0.186	0.200	0.172
Somewhat Unhappy	0.026	0.025	0.027
Very Unhappy	0.012	0.011	0.013
Has It Ever Been Difficult To Get Problems Resolved Or Fixed			
No	0.899	0.863	0.938
Yes	0.101	0.137	0.062 ***
How Well Get Along With Paid Caregiver			
Very Well	0.799	0.803	0.795
Well	0.189	0.184	0.195
Not Very Well	0.009	0.009	0.008
Not at all well	0.003	0.004	0.002
Any Trouble Communicating With Paid Caregiver			
No	0.929	0.920	0.939
Yes	0.071	0.080	0.061
Problems of Paid Caregiver Ignoring Survey Participant			
Never	0.852	0.822	0.883 ***
Seldom	0.084	0.110	0.057 ***
Sometimes	0.054	0.052	0.057
Often	0.006	0.010	0.002 **
Very often	0.003	0.005	0.001
Problems With Paid Caregiver Treating Survey Participant Badly			
Never	0.951	0.938	0.964 **
Seldom	0.029	0.037	0.02 *
Sometimes	0.012	0.017	0.008
Often	0.004	0.007	0.001 *
Very Often	0.003	0.002	0.005
Is Paid Caregiver Competent and Well Trained			
Yes	0.933	0.932	0.935
Sometimes	0.035	0.037	0.032
No	0.032	0.031	0.032
Is Paid Caregiver Respectful			
Yes	0.966	0.960	0.971
Sometimes	0.018	0.018	0.018
No	0.017	0.022	0.011 *

* Statistically significant at $p<0.10$.

** Statistically significant at $p<0.05$.

*** Statistically significant at $p<0.01$.

Significance testing is between respondents under age 65 and respondents aged 65 and over for each category.

NOTES: Results are weighted by wgt_pltnr.

SOURCE: RTI analysis of the Mathematica Policy Research's Home and Community-based Survey, 2004.

ever being treated badly by the paid caregiver. Slightly over 93 percent considered their paid caregiver competent and well trained, and about 97 percent found them respectful.

Although most of the satisfaction ratings appeared similar between the two age groups of interest, some differences were observed. More than twice the proportion of young physically disabled survey respondents reported difficulties in resolving or fixing problems with their paid caregiver compared to older people (14 versus 6 percent).

Table 2 presents summary statistics for the independent and dependent variables for the total sample, for younger persons with physical disabilities, and for older respondents. On the scale from 0 to 100, survey respondents rated their satisfaction with personal care at about 94 (93 for young adults with physical disabilities and 95 for elderly). By design, the sample was almost evenly split between those age 65 or over (52 percent) and those under age 65 years (48 percent). Among young adults with physical disabilities, about 37 percent were under age 44 and 63 percent were ages 45-64. For the older sample, about 20 percent were age 85 or over, and the rest were split evenly under and over age 75.

Overall, 26 percent of respondents were male but only 18 percent of older respondents were male, compared to 34 percent of younger adults with physical disabilities. In terms of race, 73 percent were Caucasian respondents, 16 percent were African American respondents, and slightly over 8 percent were Asian, without much difference in racial distribution between young adults with physical disabilities and age 65 or over. For about 74 percent of respondents in the total sample and in both age groups, primary paid caregivers were of the same race as respondents.

In all States, to qualify for personal care assistance, either though Medicaid HCBS waivers or State plan services, a person needs to have substantial health problems and functional limitations; this is reflected in the low levels of self-reported health and functional status. Overall, about 68 percent of the total sample reported poor or fair health, and only 3 percent reported excellent health (5 percent among young adults with physical disabilities and 2 percent among older adults).

The survey sample was characterized by fairly high levels of frailty, which are somewhat similar among elderly and nonelderly subgroups; on average, survey respondents reported 2.4 limitations in ADLs and slightly more than three limitations in instrumental ADLs. About 17 percent of our study sample received proxy help to fill out the survey (14 percent for young adults with physical disabilities and 20 percent for older adults), further indicating the presence of physical or mental health limitations requiring assistance. Slightly over one-half of the sample reported some kind of incontinence problem (bladder or bowel).

Additionally, more than 18 percent of beneficiaries had been in a nursing facility at some previous point in time (16 percent for young adults with physical disabilities, and 21 percent for older adults). Disturbingly, the great majority (about 82 percent for both subgroups) reported some or a great deal of pain in the month prior to the survey, and approximately 9 percent of the sample (12 percent for young adults with physical disabilities and 7 percent for the older group) reported having pressure sores within the 6 months prior to participating in the survey.

Table 2
Variable construction and descriptive characteristics of the sample: 2004

Characteristic	Variable Construction	All Survey Respondents	Respondents Under Age 65	Respondents Age 65 and Over
N (Unweighted)		2,325	1,108	1,217
Satisfaction with Paid Personal Assistance Scale	Eight-item scale ranging from 0 to 100	93.9	93.0	94.8 ***
Demographics			Percent	
Under 44 Years	Dummy variable for respondent's age group	0.189	0.369	---
45-64 Years	Dummy variable for respondent's age group	0.323	0.631	---
65-74 Years	Dummy variable for respondent's age group	0.196	---	0.400
75-84 Years	Dummy variable for respondent's age group	0.194	---	0.397
85 Years or Over	Dummy variable for respondent's age group	0.099	---	0.202
Male	Dummy variable for respondent's gender	0.260	0.337	0.180 ***
White	Dummy variable for respondent's race	0.727	0.722	0.733
Black	Dummy variable for respondent's race	0.164	0.172	0.156
Asian	Dummy variable for respondent's race	0.083	0.087	0.079
Other Race	Dummy variable for respondent's race	0.025	0.019	0.032
Matching Race	origin	0.738	0.742	0.734
Health and Functional Status				
Fair/Poor Health	Dummy variable for self-reported health status	0.679	0.677	0.682
Good/Very Good Health	Dummy variable for self-reported health status	0.287	0.278	0.295
Excellent Health	Dummy variable for self-reported health status	0.034	0.045	0.023 **
Number of Instrumental ADL limitations	Four-item count scale ranging from 0 to 4; 1 for client needs help with each IADL	3.262	3.272	3.252
Number of ADL Limitations	Six-item count scale ranging from 0 to 6; 1 for client needs help with each ADL	2.430	2.475	2.382
Proxy Responding	Dummy variable=1 if proxy responded	0.171	0.142	0.201 ***
Ever Institutionalized	Dummy variable=1 if ever been a resident or patient in a nursing home	0.185	0.159	0.211 ***
Some or Great Deal of Pain	Dummy variable=1 if experienced pain 4 weeks prior to the survey	0.823	0.816	0.830
Having Pressure Sores	Dummy variable=1 if had sores 6 months prior to the survey	0.093	0.116	0.069 ***
Bladder/Bowel Difficulties	Dummy variable=1 if had incontinence problems 6 months prior to the survey	0.570	0.563	0.576
Unmet Needs for ADLs and IADLs	10 item count scale ranging from 0 to 10; 1 for each unmet need in the month prior to the survey	0.638	0.763	0.508 ***
Social Characteristics and Residence				
Social Participation	Dummy variable=1 if went out for social/recreational activities at least once a week prior to the survey	0.789	0.847	0.729 ***
Live in a Group Setting	Dummy variable= 1 if respondent lives in adult foster care, group home or assisted living	0.129	0.091	0.169 ***
State 1	Dummy variable for the state of residence	0.070	0.054	0.087 ***
State 2	Dummy variable for the state of residence	0.111	0.097	0.126 ***
State 3	Dummy variable for the state of residence	0.042	0.027	0.057 ***
State 4	Dummy variable for the state of residence	0.331	0.455	0.202 ***
State 5	Dummy variable for the state of residence	0.104	0.088	0.122 **
State 6	Dummy variable for the state of residence	0.341	0.279	0.407 ***

** Statistically significant at $p<0.05$.
*** Statistically significant at $p<0.01$.
Significance testing is between respondents under age 65 and respondents aged 65 and over for each category.
NOTES: Results are weighted. SPPAS - Satisfaction with paid personal scale.
SOURCE: RTI analysis of the Mathematica Policy Research’s Home and Community-based Survey, 2004.

The number of unmet needs is an indicator of whether beneficiaries think they are getting all the services they require. It is rather surprising that survey respondents reported less than one unmet ADL/IADL need on average. Younger physically disabled beneficiaries reported slightly higher unmet ADL/IADL needs than the elderly.

Social participation is another important measure of whether HCBS improve the life of their recipients by allowing them to maintain normal social activities despite their impairments. Overall, 79 percent of survey respondents reported getting out of the house for some kind of social or recreational activity at least once during the week prior to the survey. In terms of social participation, younger respondents got out of the house more often than the elderly.

Although most respondents lived at home, a significant minority lived in group settings. About 13 percent of respondents reported living in a group setting (9 percent for younger adults with physical disabilities and 17 percent for older respondents). ***Table 2*** also presents the distribution of survey respondents by their State of residence. Four percent of the sample lived in Maryland, 7 percent in Alabama, 10 percent in Wisconsin, 11 percent in Kentucky, 33 percent in Michigan, and 34 percent in Washington State.

Table 3 presents a zero-order correlation matrix for all the variables that comprise the SPPAS. All components are significantly (p <0.05 or higher) and moderately correlated. The range of the correlation coefficients between 0.2 and 0.4 confirms that the items are similar enough to belong in an index, but dissimilar enough that the index as a whole is better than their individual measures.

3.3.2 Multivariate Findings

Three censored regression models predicting satisfaction with home and community-based personal care assistance were estimated, one for all survey respondents (Model I), a second for respondents younger than age 65 (Model II), and one for those age 65 or over (Model III). For Model I (all survey respondents) the sample size was 2,301, and 1,267 observations were right-censored; for Model II (under age 65) the sample size was 1,101, and 585 observations were right-censored; and Model III (age 65 or over) had 1,200 observations, of which 682 were right-censored. Censoring is a technique used to account for a large number of observations at the minimum or maximum value of the dependent variable. Given that a large proportion of the sample had a value of 100 on the satisfaction scale, we needed to transform the dependent variable through censoring to eliminate bias in our estimates.

Table 4 presents the results for all three models. Few of the demographic characteristics appeared to be associated with satisfaction with personal care services. Compared to beneficiaries age 65-74, being very young (under age 44) is significantly and negatively related to satisfaction in the total sample (Model I), and when the sample was restricted to young persons with physical disabilities (reference group age 44-65 in Model II); however no age effect was detected in the sample of those age 65 or over. Minority racial status was not associated with satisfaction with personal assistance for total survey respondents, but younger Asians with disabilities were significantly more satisfied than Caucasian respondents; among older persons, minority racial status, and being a African American respondent in particular, was related to significant decreases in satisfaction with these services compared to Caucasian respondents.

Table 3
Correlation of variables comprising the Satisfaction with Paid Personal Assistance Scale: 2004

	(1)	(2)	(3)	(4)	(5)	(6)	(7)
How happy overall with the paid care received (1)							
Has it ever been difficult to get problems resolved or fixed (2)	0.2745**						
How well get along with paid caregiver (3)	0.3556**	0.1701**					
Any trouble communicating with paid caregiver (4)	0.2077**	0.1709**	0.2010**				
Problems of paid caregiver ignoring survey participant (5)	0.3623**	0.2968**	0.2637**	0.2665**			
Problems with paid caregiver treating survey participant badly (6)	0.2954**	0.2204**	0.2773**	0.1632**	0.4131**		
How competent and well trained is paid caregiver (7)	0.3446**	0.3251**	0.2113**	0.1604**	0.3289**	0.2515**	
How respectful is paid caregiver (8)	0.3648**	0.2091**	0.3084**	0.2001**	0.3237**	0.3541**	0.3430**

** Statistically significant at $p < 0.05$.

SOURCE: RTI analysis of the Mathematica Policy Research's Home and Community-based Survey, 2004.

Table 4
Predicting Satisfaction with Paid Personal Assistance Scale (SPPAS) censored normal regression results

	Model I		Model II		Model III	
	All survey respondents		Respondents Under Age 65		Respondents Age 65 and Over	
Unweighted N	2,301		1,101		1,200	
Variable	Coefficient	Standard Error	Coefficient	Standard Error	Coefficient	Standard Error
Demographics						
Under 44 years	-5.81	1.50 ***	-4.80	1.483 ***	---	
45-64 Years	-0.87	1.29	---		---	
75-84 Years	0.79	1.42	---		0.82	1.374
85 Years or Over	1.98	1.74	---		1.39	1.723
Male	-1.23	1.06	-0.61	1.430	-1.74	1.591
Black	-1.62	1.22	0.98	1.826	-4.35	1.630 ***
Asian	2.27	1.83	6.07	2.722 **	-1.85	2.421
Other Race	2.50	3.26	0.47	5.234	2.73	4.043
Race Match	5.15	1.01 ***	5.06	1.486 ***	5.84	1.364 ***
Health and Functional Status						
Fair/Poor Health	2.13	2.64	4.14	3.361	-1.43	4.370
Good/Very Good Health	-0.70	2.66	-1.89	3.382	-1.95	4.425
Number of Instrumental ADLs	0.60	0.52	0.82	0.724	0.37	0.742
Number of ADLs	0.67	0.27 **	0.61	0.377	0.77	0.391 **
Proxy Responding	-4.39	1.24 ***	-6.37	1.895 ***	-2.69	1.625
Ever Institutionalized	-2.94	1.19 **	-5.27	1.850 ***	-1.04	1.529
Some or Great Deal of Pain	-3.97	1.32 ***	-6.25	1.947 ***	-2.25	1.761
Pressure Sores	-1.44	1.54	-1.39	2.060	-1.95	2.344
Incontinence	-1.91	0.97 **	0.00	1.434	-3.65	1.281 ***
Unmeet ADL/IADL Needs	-3.09	0.28 ***	-3.55	0.373 ***	-2.50	0.410 ***
Social Characteristics and Residence						
Social Participation	2.25	1.07 **	2.75	1.717	2.64	1.336 **
Live in a Group Setting	-2.74	1.50	-6.01	2.444 **	-0.33	1.868
State 1	3.50	1.64 **	4.77	2.552	3.19	2.121
State 2	5.86	1.34 ***	6.67	2.061 ***	5.64	1.745 ***
State 3	0.49	1.85	8.71	3.289 ***	-3.21	2.199
State 4	3.83	1.47 ***	5.31	1.995 ***	2.75	2.266
State 5	2.05	1.95	6.21	3.049	-1.44	2.481
Constant	99.85	3.58	97.04	4.772	101.96	5.301

** Statistically significant at $p<0.05$.

*** Statistically significant at $p<.01$.

SOURCE: RTI analysis of the Mathematica Policy Research’s Home and Community-based Survey, 2004.

Matching race between survey participant and paid caregiver was associated with a five- to six-unit increase in satisfaction with personal assistance services in all three models; this suggests that when providers and caregivers have a common cultural background, it substantially increases satisfaction with HCBS.

As a group, health and functional status variables were stronger predictors of satisfaction with personal assistance than demographics. Overall, having specific physical and mental health limitations was associated with a decrease in satisfaction with services in all three models. In particular, having a proxy responding to the survey (possibly an indication of mental health or cognitive problems), having been institutionalized in the past, having some or a great deal of pain in the month preceding the survey, or having bowel/bladder incontinence were all related to significant decreases in satisfaction with services.

Surprisingly, persons with greater ADL impairments had slightly higher satisfaction with services, and greater IADL impairments had no effect within the total sample. However, unmet need for ADL and IADL assistance was associated with a substantial reduction in satisfaction with personal assistance. For each additional unmet need with one ADL or IADL, there is about three-unit decrease in the SPPAS rating for all three samples.

With the exception of a positive influence of ADL impairments and a negative effect of incontinence, other variables produced a similar effect when the sample was restricted to young respondents with physical disabilities. Physical and mental health problems seemed to have a lesser impact on satisfaction with services in the older cohort: only bladder/bowel incontinence and unmet ADL/IADL needs were negative and significant predictors of satisfaction among the older survey respondents. The number of ADL impairments produced a very small but statistically significant positive effect.

Among social and residential characteristics, social participation was associated with a significant increase in satisfaction with personal assistance in the total sample and among the survey participants age 65 or over, but not among the younger population. Living in a group setting such as an adult foster, assisted living, or group home was associated with significant reduction in satisfaction for younger people with physical disabilities, but not among older respondents, although the variable approached significance and had a negative sign. Younger persons with physical disabilities who resided in a group setting rated their satisfaction with personal assistance about six points lower than those who lived with family or by themselves.

3.4 Discussion

This study examined satisfaction with paid personal assistance services among Medicaid beneficiaries, both younger people with physical disabilities and persons age 65 or over. While not synonymous with quality, satisfaction is an important component of quality of care. Although satisfaction is difficult to measure, doing so is important because it addresses how the client experiences HCBS and, therefore, is key to empowering persons with disabilities. A major assumption of advocates for a more balanced LTC system is that consumers are more satisfied with HCBS than with institutional care. Moreover, as policymakers establish systems of HCBS that include both older clients and younger persons with physical disabilities, it is important to know whether the factors that produce a satisfied older consumer are the same that produce a satisfied younger person with physical disabilities, and vice versa.

In general, HCBS beneficiaries were very satisfied with the services they receive, which is consistent with the policy preference for noninstitutional services. Not only were overall ratings of service high, but relatively few persons experienced some of the negative aspects of care, such as not being able to resolve problems, not getting along with the paid caregiver, being ignored or badly treated by the paid caregiver, or being unable to communicate with the paid caregiver. Very high percentages of respondents rated their paid caregivers as helpful, well-trained, and respectful.

Because of different life expectations, older people and younger persons with physical disabilities may have different determinants of satisfaction. Indeed, this study of Medicaid HCBS beneficiaries found that certain factors predict satisfaction for both younger and older persons with disabilities, whereas other factors are age-group specific. Overall, young persons with physical disabilities are less satisfied with paid care than persons age 65 or over. All three blocks of variables, demographic, health/functional status, and social/residential characteristics appeared to be important in predicting satisfaction with paid assistance. While several variables were significant in our explanatory models of satisfaction, three key variables are of particular policy importance: race concordance between clients and paid caregivers, unmet need for ADL/instrumental ADL assistance, and group residential setting for young persons with physical disabilities.

First, the consistent positive coefficient and high significance of the race concordance variable for all age groups in our study confirms that factors beyond technical competence contribute to satisfaction with paid personal assistance, variables that policymakers have generally ignored. However, LTC is highly personal, and client-provider interactions have an impact on satisfaction with care. Although racial intolerance may be a factor, race is likely a proxy for sharing a common cultural and linguistic background, which is critical in something as intensely intimate and private as giving and receiving personal care services. To our knowledge, no studies to date have examined how matching race between clients and care providers affects satisfaction with personal care services, but a growing body of research finds that patient-physician race concordance positively affects the perceived quality of care and increases satisfaction with health care services (Saha et al., 1999; LaVeist and Nuru-Jeter, 2002; LaVeist and Carroll, 2002; and, Shin and Moon, 2005). In providing services to persons with disabilities, policymakers should pay greater attention to cultural competence of the providers, especially when race concordance is not possible.

Second, unmet need for personal assistance with ADLs and IADLs has a strong negative impact on satisfaction with care. Unmet need for ADL and IADL assistance is known to be associated with low income, multiple ADL impairments, minority status, and living alone (LaPlante, Kang, Kaye, and Harrington, 2004; Kennedy, 2001). Unmet needs affect quality of life and lead to negative consequences (Kennedy, 2001; Desai, Lentzner, and Weeks, 2001; LaPlante et al., 2004; Komisar, Feder, and Kasper, 2005). For example, Komisar et al. (2005) found that unmet needs lead to Medicaid beneficiaries not being able to bathe or transfer back to bed and having to suffer wetting and soiling themselves. Analyzing data from the national health interview survey, LaPlante and colleagues (2004) reported that unmet need for assistance results in a higher incidence of adverse events, such as discomfort, weight loss, dehydration, falls, and burns and leads to dissatisfaction with the help received. In particular, in this study, persons with unmet needs were dissatisfied with their primary caregiver's availability, amount of assistance, and the lack of backup care arrangements. As States face budget constraints in their provision of HCBS, policymakers should recognize that leaving ADL and instrumental ADL needs unmet will reduce consumer satisfaction as well as increase the risk of adverse events.

Finally, the finding that younger people with physical disabilities in group living arrangements are less satisfied with their personal assistance services should be a caution to policymakers and others who are promoting these services. This result parallels the findings of others regarding the younger population with developmental disabilities. However, it appears that persons age 65 or over in group home/assisted living settings are not less satisfied with personal assistance services compared with those receiving them in independent living settings. Speculatively, younger people with physical disabilities may find the organized setting of a residential care facility constraining and too limiting of their freedom of activity. This finding suggests that some of the enthusiasm of policymakers for assisted living and other group residential settings needs to be viewed with caution for the younger population with physical disabilities.

Other multivariate findings are also noteworthy. Prior history of being institutionalized and having some or a great deal of pain in the month preceding the survey greatly diminished satisfaction for young persons with physical disabilities, but did not affect satisfaction with services for persons age 65 or over. Older people, who commonly suffer from arthritis and other chronic disabling conditions, may be more accepting of pain and consider it as a part of the aging process.

Although this study adds to the limited literature on Medicaid HCBS, it does have some limitations. First, the study is limited to Medicaid beneficiaries in six States, and its results cannot necessarily be generalized to the national population of Medicaid beneficiaries receiving these services. However, the study includes States with a range of HCBS systems and a substantial sample of respondents. Second, satisfaction is an important indicator of quality of HCBS; however, because it is subjective, it is susceptible to cultural norms and expectations, making it difficult to measure reliably. Measuring satisfaction with home-based care is prone to response bias, as well as cohort effect. As unpaid caregivers serving as proxies constitute a large part of the survey respondent pool, we assumed that unpaid caregiver proxies are unbiased when responding to satisfaction questions on behalf of the survey respondents.

Finally, while the literature indicates that Medicaid beneficiaries receiving their services via consumer directed programs where they can also hire family members or friends tend to be more satisfied than those receiving them through traditional agency-based care, we were unable to test the effect of consumer direction across all six States as the survey indicator for consumer direction turned out to be unreliable. The problems with identifying consumer direction also affected our ability to analyze the family affiliation of paid caregivers. For example, significant percentages of respondents in states without consumer-direction programs reported family members (spouses, children and parents) as paid caregivers, even though respondents in those states cannot hire relatives to provide Medicaid-funded personal assistance. As a result, we decided against using paid caregiver family affiliation in the analysis even though we recognize that hiring relatives can affect satisfaction with personal care services and may account for some of our findings on racial congruence. Additionally, it is worth noting that the scope of this study is limited in that we do not examine other aspects of the quality of paid personal assistance beyond satisfaction.

Despite these limitations, our study provides important insights on the determinants of consumer satisfaction with paid personal assistance services, many of which are under the control of Medicaid policymakers. These results underscore the importance of cultural competency, meeting the ADL and IADL needs of people with disabilities, and finding the right living arrangement for people with disabilities to maximize satisfaction with services. The study also extends our understanding of the age-specific factors affecting satisfaction with paid assistance for young people with physical disabilities and age 65 or over. While many determinants of satisfaction operate for both older people and physically disabled persons under age 65, not all of the determinants are the same across the two age groups, factors that should be taken into account in designing services for the two populations. These findings emphasize the importance of availability and adequacy of the HCBS to frail and impaired populations and provide information that can improve services to people with disabilities.

CHAPTER 4
WORKFORCE ISSUES AND CONSUMER SATISFACTION IN MEDICAID PERSONAL ASSISTANCE SERVICES

4.1 Introduction

Many community-dwelling Americans with disabilities of all ages need daily help with personal assistance needs. These needs include help with such tasks as shopping and paying bills and less frequently with activities of daily living such as bathing and eating. While a majority of these persons receive assistance with these activities from unpaid family members, friends, and neighbors, a sizeable minority receives assistance from paid paraprofessional helpers (Stone and Wiener, 2001).

Little is known about the quality of paid home and community-based services, even though increasing numbers of people are receiving paid care at home (Wiener and Brown, 2005). Developing measures of quality for home and community-based services is difficult, partly because many types of services are covered across large geographical areas (Wiener and Tilly, 2003). Reliable measures and data on quality of care for non-skilled home and community-based services such as personal care are not readily available.

One component of the quality of care is satisfaction with services (Donabedian, 1966). Satisfaction relates to how beneficiaries experience care received compared to their standards or expectations (Linder-Peltz, 1982). Satisfaction measures can provide important information about interpersonal aspects of care, such as interactions and communication between providers and consumers, consumers' perceptions on how much providers respect, understand and listen to them, and whether consumers are treated with dignity (Aharony and Strasser, 1993; Keepnews, 2003). They also can provide information about whether consumers think they are receiving enough of the right types of care.

Geron and colleagues (2000) provide an overview of the factors affecting satisfaction with health care and found that few prior studies analyze satisfaction with home and community-based services. Researchers usually examine demographic characteristics and health status when studying correlates of satisfaction with health care (Geron et. al. 2000), but these characteristics may not provide needed information to inform policies affecting the organization, delivery, and financing of home and community-based services. For example, few researchers have examined the effects of workforce-related factors such as recruitment and retention of workers on consumer satisfaction with personal care services (Larson, Hewitt, and Lakin, 2004). In particular, examining the independent effects of such workforce factors on consumer satisfaction would address an important gap in the literature on satisfaction with home and community-based services.

At least four major workforce factors may affect consumer satisfaction with personal assistance services: 1) difficulty recruiting and retaining workers, 2) inadequate worker training, 3) potential mistreatment of consumers, and 4) lack of communication and inappropriate care caused by differences in the cultural preferences of workers and consumers (Stone and Wiener, 2001). First, providers and consumers report problems in recruiting and retaining direct service workers. In 2002, 37 states reported that direct care shortages were a "serious workforce issue"

(Harmuth and Dyson, 2002). While prior work (American Health Care Association, 2002) shows that turnover and vacancy rates for certified nursing assistants in nursing homes is very high, home care turnover and vacancy rates are believed to be lower, but still substantial (Stone and Wiener, 2001).

Satisfaction with personal assistance services is likely compromised by the vacancies and high turnover of these workers. The vacancies mean that consumers may not have enough workers to meet their needs. High turnover means that continuity of care is reduced, with staff not having time to get to know the needs and preferences of individual consumers. Workers who are providing care in understaffed environments may experience high levels of stress and frustration, which may contribute to high turnover and poor quality of care. Quality of care is also affected when workers do not show up for work or show up late and agencies and consumers are required to find backup workers on short notice.

The second major problem that may affect consumer satisfaction with personal assistance services is inadequate worker training. Consumers who perceive that their workers are not well trained and who experience substandard care may be less satisfied than consumers who perceive their workers have been properly trained. Low levels of education and training may make it difficult for workers to provide the standard of care that consumers' desire. Paid certified nursing assistants and home health aides are required under federal law to receive 75 hours of initial training, but state training requirements for personal care workers vary greatly and generally are not extensive. Consumers usually orient workers as to how they would like personal care tasks performed, but in addition, may end up providing ad hoc training for workers new to the field to address shortcomings in prior training.

The third major problem potentially affecting satisfaction concerns how workers treat and respect consumers. Consumers may be less satisfied with care if they are not treated well and respected by their workers. Mistreatment by paid and unpaid caregivers has been reported in a few limited studies, and some researchers believe that the problem is underreported (Bonnie and Wallace, 2003). Estimates of the occurrence of abuse and neglect of older people in the general population (regardless of source) have varied from about 2 to 10 percent annual incidence, although the basis of these estimates is uncertain (Branch, 2001).

The fourth major problem that may affect satisfaction is the issue of cultural competency such as how well workers and consumers communicate and get along with each other (Saha, Komaromy, Koepsell, and Bindman, 1999; LaVeist and Nuru-Jeter, 2002; LaVeist and Carroll, 2002; Shin and Moon, 2005). Given the very personal nature of these services, workers who can understand and accommodate cultural differences in privacy and custom can help ensure higher consumer satisfaction with care. This mutual understanding can help ameliorate situations where disagreements or problems arise.

4.2 Study Design and Data

The goal of this study is to assess the impact of workforce issues on two measures of consumer satisfaction with Medicaid personal assistance services among older people and physically disabled persons under age 65 using primary data analysis. First, we examine the independent effects of problems with recruitment and retention on a consumer satisfaction scale.

Second, we analyze the independent effects of worker training, treatment, and respect on a single consumer satisfaction measure.

This effort is part of a larger research project (Wiener, Tilly, and Alecxih, 2002) funded by the Centers for Medicare & Medicaid Services, The Lewin Group and its subcontractors, RTI International, the University of Minnesota Research and Training Center on Community Living, Mathematica Policy Research and The Medstat Group studying Medicaid financing and delivery of home and community-based services to older people and younger adults with physical disabilities, as well as to individuals with mental retardation and developmental disabilities. The overall goal of the larger project is to study selected programs to assess their effects on consumer quality of care and Medicaid utilization and expenditures. States chosen for inclusion in the study include ones with well-developed community-based systems and states that are in the process of developing their non-institutional services systems. States included in the study for the part of the project focusing on older people and younger persons with physical disabilities are Alabama, Kentucky, Maryland, Michigan, Washington, and Wisconsin.

4.2.1 Survey Methodology.

Mathematica Policy Research, Inc. conducted a survey of Medicaid home and community-based services beneficiaries in the six selected states (Snell et al., 2005). The target population for the HCBS study consisted of all adult Medicaid home and community-based services waiver and personal care option recipients. The sample was allocated proportionally among states based on the number of home and community-based services beneficiaries in each state. The sample was selected using simple random sampling and weights were computed from the inverse of the selection probability, which varied by state. Respondent data was adjusted for non-response, first for the ability to locate a person, and then for whether or not the located person responded. Because of the interest in differences between older and physically disabled persons under age 65, the survey sample was stratified by age (under age 65 and age 65 and over).

The survey was fielded between May 2003 and June 2004. The survey respondents participated in the survey directly or via proxy (paid and unpaid caregivers) and included participants living in their own homes and residents of assisted living facilities and other group settings. The survey, which took about half an hour to complete, was conducted primarily through telephone interviews using a computer-assisted telephone interviewing (CATI) system (N = 2,458) with some in-person interviews (N = 143)[11]. The overall survey response rate was 72 percent, with 28 percent of respondents using a proxy respondent, though the percentage of proxy respondents in the analyses reported was only 16 percent. Survey data were obtained from 2,597 community-residing Medicaid beneficiaries.

4.2.2 Dependent Variables

We developed two measures of consumer satisfaction for use as dependent variables in six regression analyses. We analyzed the first measure of consumer satisfaction using three regressions—one on the overall sample, one on persons under age 65, and one on persons age 65

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[11] Four observations were later determined to be duplicates and were removed from the sample.

and over. The dependent variable in these three regressions is the Satisfaction with Paid Personal Assistance Scale, a 100-point, 8-item scale designed to measure the satisfaction of respondents with paid care received and various aspects of their relationship with their workers (Khatutsky, Anderson and Wiener, 2006). The scale comprised 8 questions (***Table 5***). These items measure overall satisfaction, as well as specific interpersonal aspects of care provided by paid helpers, such as communication with paid helpers, how problems get resolved, how often paid helpers get impatient or angry, and how well they are trained. Consequently, the scale had complete responses for 2,325 of the 2,597 self-respondents and unpaid caregiver proxies in the sample. Paid caregivers who were proxies were not asked questions about satisfaction to eliminate potential bias.

We constructed the scale by collapsing response categories of individual survey questions as needed to increase variability across response categories, and by assigning a scale value to all response categories within each underlying variable created for use in the scale. Dummy variables included in the scale were scaled 0-100, variables with three response categories were scaled 0-50-100, variables with four response categories were scaled 0-33-67-100, and variables with five response items were scaled 0-25-50-75-100. We did not adjust the scale for the fact that this method allowed binary variables to have more weight than categorical variables. The scale was set to a missing value if more than 4 of the 8 potential items had missing responses. We designed the scale to range from 0 to 100 so that coefficients associated with independent variables could be interpreted as percentage point differences in satisfaction across the categories of each variable. The scale had a mean of 93.9 (standard deviation of 11.2) and a Cronbach's alpha of 0.7.

We evaluated the 8-item scale using factor analysis, which showed one dominant factor (eigenvalue 2.9). This factor loaded uniformly on all the variables, predicting a high correlation with the SPASS scale, which was constructed as a mean of all items. The correlation between the scale and the factor was 0.97.

We analyzed the second measure of consumer satisfaction also using three regressions—one on the overall sample, one on persons under age 65, and one on persons age 65 and over. The dependent variable in these three regressions is one item from the 8-item scale, the 4-level Overall Satisfaction with Paid Care measure, designed to assess the independent effects of worker training, treatment and respect for a client on satisfaction with paid services. While measures of worker training, treatment, and respect were part of the 8-item scale used previously, we use them as independent variables with the other controls in this second part of our analyses to test whether they had a separate relationship on the Overall Satisfaction with Paid Care variable apart from their contribution to the 8-item scale. The Overall Satisfaction with Paid Care variable had values for 2,303 of the 2,597 respondents in the sample.

4.2.3 Independent Variables

Primary independent variables of interest for workforce policy included 1) whether one had ever had a problem or difficulty finding a replacement worker, 2) whether a worker had either not shown up when scheduled or had shown up late, 3) how many paid workers one had retained in the last six months, 4) how well workers were trained, 5) how well they treated the

Table 5
Proportions for responses to variables comprising the Satisfaction with Paid Personal Assistance Scale

	All survey respondents	Survey respondents under age 65	Survey respondents Age 65 and older
N (unweighted)	1,340	728	612
How happy overall with paid care received			
Very happy	0.755	0.752	0.758
Somewhat happy	0.205	0.212	0.194
Somewhat unhappy	0.027	0.023	0.033
Very unhappy	0.013	0.012	0.014
Has it ever been difficult to get problems resolved or fixed			
Yes	0.132	0.170	0.078
No	0.868	0.830	0.922
How well get along with paid helper			
Very well	0.810	0.795	0.830
Well	0.183	0.197	0.163
Not very well	0.005	0.006	0.004
Not at all well	0.002	0.002	0.002
Any trouble communicating with paid helper			
Yes	0.073	0.088	0.052
No	0.927	0.912	0.948
Problems of paid helper ignoring survey participant			
Never	0.845	0.816	0.887
Seldom	0.089	0.118	0.047
Sometimes	0.054	0.049	0.063
Often	0.007	0.012	0.000
Very often	0.004	0.005	0.003
Problems with paid helper treating survey participant badly			
Never	0.948	0.938	0.963
Seldom	0.031	0.037	0.023
Sometimes	0.016	0.020	0.009
Often	0.001	0.002	0.001
Very often	0.003	0.003	0.005
Is paid helper competent and well trained			
Yes	0.917	0.915	0.921
Sometimes	0.044	0.051	0.034
No	0.039	0.035	0.045
Is paid helper respectful			
Yes	0.961	0.955	0.969
Sometimes	0.021	0.021	0.022
No	0.018	0.024	0.010

NOTE: Results are weighted and stratified by state.

SOURCE: RTI analysis of the MPR HCBS survey, 2004.

Computer Output: wava_wf07

consumer, and 6) whether they respected the consumer. While we used all six variables in the three regressions on the Overall Satisfaction with Paid Care measure, the last three of these variables were part of the Satisfaction with Paid Personal Assistance Scale and were not used as independent variables in the three regressions on that dependent variable. Our ability to control for these workforce characteristics separately is a strength of the study.

We grouped the remaining independent variables into three domains—demographic characteristics, health and functional characteristics, and social and residential characteristics—for use as controls. We present details of variable construction in ***Table 6*** along with the means for the overall sample analyzed as well as for those respondents over and under age 65. For demographics characteristics, we included variables representing age groups as dummy variables with the group aged 65 to 74 years as the omitted group. Approximately 59.1 percent of the sample used in regressions was under age 65. Other demographic characteristics modeled included categorical measures for gender (men were 26.0 percent) and race (Caucasians were 71.3 percent, African Americans were 17.2 percent, and Asians were 8.7 percent). We also included a variable to indicate when care recipients and paid caregivers have a matching race or Hispanic origin (mean of 73.4 percent) in an attempt to control for any effects of cultural competency of workers. We did not include income given the lack of variability in this Medicaid eligible population.

We included a broad range of health and functional status characteristics. For self-reported health status, 69.1 percent of the sample reported fair or poor health, 27.5 percent reported good or very good health, and 3.4 percent reported excellent health. We included a measure of the number of limitations in six activities of daily living (ADLs), including bathing, dressing, eating, transferring, walking across the room, and toileting (mean of 2.56). We also created a measure for the number of limitations in four instrumental activities of daily living (IADLs), including cooking, managing medications, shopping, and doing light housework (mean of 3.24). Approximately 15.8 percent of sample respondents were proxies who were used in the survey to address limited cognitive status in the sample population. We also included a composite of ten items that asked about unmet needs for ADL and IADL assistance, a count variable ranging from 0 to 10 (mean of 0.81). Additional health status indicators included any prior nursing home use (mean of 18.9 percent), incidence of recent pain (mean of 86.9 percent) or pressure sores (mean of 12.0 percent), and problems with bladder /bowel incontinence (mean of 60.4 percent). We imputed self-reported health status based on survey respondents' ADL impairment for about 1 percent of the total sample for which a response was missing on the original categorical variable.

We created a measure of social participation to identify respondents who took part in social or recreational activity at least once a week (mean of 79.7 percent). We also included the respondent's state of residence to control for state-level differences such as the design and operation of state home and community-based services programs and other factors.

The sample size for regressions was reduced to 1,340 observations for the regression on the eight-item scale and to 1,307 observations for the regression on the Overall Satisfaction with Paid Care measure almost entirely because not all respondents were asked whether they had had a problem replacing a worker. This question was not asked of the 874 persons who either lived in group settings or who had never had to replace a worker. Those who did and did not respond to

Table 6
Variable construction and descriptive characteristics of the sample

Characteristics	Variable construction	All survey respondents	Survey respondents under 65 years old	Survey respondents age 65 and over
N (unweighted)		1,340	728	612
Satisfaction with Paid Personal Assistance Scale (SPPAS)	8-item scale ranging from 0 to 100	93.20	92.27	94.55
Workforce Issues				
Problem replacing a paid worker	Dummy variable =1 if consumer reports problems replacing a paid worker	0.184	0.232	0.114
Not show up as scheduled or show up late	Dummy variable =1 if consumer reports problem with paid worker not showing up or showing up late	0.144	0.142	0.147
Number of paid helpers in last 6 months	Count variable for number of paid helpers reported in the last 6 months	2.788	2.871	2.667
Demographics				
Age 18 to 44	Dummy variable for respondent’s age group	0.230	0.390	—
Age 45 to 64	Dummy variable for respondent’s age group	0.361	0.610	—
Age 65 to 74	Dummy variable for respondent’s age group	0.173	—	0.424
Age 75 to 84	Dummy variable for respondent’s age group	0.159	—	0.389
Age 85 and over	Dummy variable for respondent’s age group	0.077	—	0.187
Male	Dummy variable for respondent’s gender	0.260	0.328	0.161
Caucasian	Dummy variable for respondent’s race	0.713	0.727	0.693
African American	Dummy variable for respondent’s race	0.172	0.161	0.188
Asian	Dummy variable for respondent’s race	0.087	0.090	0.081
Other race	Dummy variable for respondent’s race	0.029	0.022	0.038
Matching race	Dummy variable = 1 if survey participant and paid caregiver report the same race or Hispanic origin	0.734	0.720	0.755

(continued)

Table 6 (continued)
Variable construction and descriptive characteristics of the sample

Characteristics	Variable construction	All survey respondents	Survey respondents under 65 years old	Survey respondents age 65 and over
Health and functional status				
Fair / poor health	Dummy variable for self-reported health status	0.691	0.698	0.680
Good / very good health	Dummy variable for self-reported health status	0.275	0.260	0.297
Excellent health	Dummy variable for self-reported health status	0.034	0.042	0.023
Number of IADL limitations	4-item scale ranging from 0 to 4	3.238	3.261	3.204
Number of ADL limitations	6-item scale ranging from 0 to 6	2.564	2.625	2.476
Proxy responding	Dummy variable=1 if proxy responded	0.158	0.131	0.196
Ever institutionalized	Dummy variable=1 if ever been a resident or patient in a nursing home	0.189	0.185	0.194
Some or great deal of pain	Dummy variable=1 if experienced pain 4 weeks prior to the survey	0.869	0.865	0.875
Having pressure sores	Dummy variable=1 if had sores 6 months prior to the survey	0.120	0.142	0.088
Bladder /bowel difficulties	Dummy variable=1 if had incontinence problems 6 months prior to the survey	0.604	0.598	0.612
Unmet needs for ADLs and IADLs	10-item scale ranging from 0 to 10	0.814	0.936	0.637

(continued)

Table 6 (continued)
Variable construction and descriptive characteristics of the sample

Characteristics	Variable construction	All survey respondents	Survey respondents under age 65	Survey respondents age 65 and over
Social characteristics and residence				
Social participation (%)	Dummy variable=1 if went out for social/recreation at least once a week prior to the survey	0.797	0.833	0.744
State 1	Dummy variable for the state of residence	0.086	0.065	0.116
State 2	Dummy variable for the state of residence	0.163	0.136	0.202
State 3	Dummy variable for the state of residence	0.034	0.026	0.045
State 4	Dummy variable for the state of residence	0.302	0.385	0.181
State 5	Dummy variable for the state of residence	0.100	0.087	0.118
State 6	Dummy variable for the state of residence	0.315	0.300	0.337

NOTES: Results are weighted and stratified by state.

SOURCE RTI analysis of the MPR HCBS survey, 2004.

Computer Output: wava_wf06

this question did not differ on important demographic, health and functional status measures used in the analysis. Only a very small number of observations were randomly missing across the independent variables to be used in regressions.

4.3 Methodology

In predicting satisfaction with personal care services using the SPPAS, we estimated an ordinary least squares (OLS) model that was right-censored at a scale value of 100 to account for the approximately half of all observations with that value (54.7 percent for the overall sample, 51.8 percent for the sample under age 65, and 58.2 percent of the sample age 65 and older). The shape of the distribution of the remaining part of the satisfaction scale allowed us to assume the properties of a normal distribution. For the 4-level categorical measure for Overall Satisfaction with Paid Care, we estimated an ordered logistic regression model. We estimated summary statistics using probability weights adjusted for non-response and post-stratification and stratified estimates by state, but did not do so with the regression models because we estimated fully specified models incorporating state effects to capture unobserved heterogeneity across states. As part of our data collection arrangement with the six states, we agreed not to identify any individual state. Thus, the states are identified only by number.

We report results from our models at conventional levels of significance, first in the overall sample, and then for each age subgroup separately. We had reason to believe that the two populations would differ in their expectations. For example, we anticipated that younger disabled adults would have higher expectations for participating in the workforce and community life, and subsequently might be more demanding (less satisfied) than elderly respondents. Estimating satisfaction for these subgroups allowed us in part to account for these differences and determine whether levels of satisfaction differed between them.

4.4 Results

In the overall sample, as well as in the age-related subgroup analyses, the workforce policy variables often were significant indicators of satisfaction, while demographic and health and functional status variables were seldom significant. We found a 10-plus percentage point difference in satisfaction for problems in replacing workers and for when workers never show up or show up late. We found lesser, but still significant effects for most of the remaining workforce related variables.

4.4.1 Regression on the Satisfaction with Paid Personal Assistance Scale

Two of the three workforce characteristics analyzed in this set of regressions were statistically significant determinants of consumer satisfaction (***Table 7***). In the regression on this scale in the overall sample, respondents having problems or difficulty in replacing workers were 10.2 percentage points less satisfied than those without a problem. Younger persons with disabilities with this problem were 8.6 percentage points less satisfied than persons without this problem while older persons with this problem were 13.5 percentage points less satisfied. Respondents in the overall sample who had a worker who did not show up or showed up late were 14.9 percentage points less satisfied than those respondents whose workers showed up when scheduled or on time. Younger persons with disabilities were 14.7 percentage points less satisfied if a worker was late or did not show up for work, which was similar to older persons,

Table 7
Ordinary least squares (OLS) regression on Satisfaction with Paid Personal Assistance Scale (SPPAS)

	All survey respondents			Survey respondents under age 65			Survey respondents age 65 and over		
N (unweighted)	1340			728			612		
Variable	Coefficient	Std err		Coefficient	Std err		Coefficient	Std err	
Workforce Problems									
Problem replacing a paid worker	-10.23	1.55	*	-8.56	1.89	*	-13.53	2.62	*
Not show up as scheduled or show up late	-14.92	1.50	*	-14.71	2.04	*	-15.27	2.18	*
Number of paid helpers in last 6 months	-.19	0.18		-0.39	0.23		0.29	0.31	
Demographics									
Age 18 to 44	-4.07	1.89	*	-3.15	1.69		—	—	
Age 45 to 64	-0.98	1.68		—	—		—	—	
Age 75 to 84	-0.06	1.93		—	—		0.39	1.92	
Age 85 and over	2.34	2.38		—	—		2.23	2.41	
Male	-0.54	1.36		-0.13	1.67		0.13	2.33	
African American	-2.85	1.55		-0.08	2.16		-5.55	2.20	*
Asian	1.53	2.33		3.72	3.13		-2.19	3.42	
Other race	1.93	3.89		-6.23	5.34		9.00	5.86	
Race match	3.39	1.31	*	2.48	1.72		5.35	1.99	*

(continued)

Table 7 (continued)
Ordinary least squares (OLS) regression on satisfaction with paid personal assistance scale (SPPAS)

	All survey respondents			Survey respondents under age 65			Survey respondents age 65 and over		
Health and functional status									
Fair/poor health	0.51	1.33		3.34	1.79		-1.74	1.94	
Number of IADLs	0.47	0.64		0.58	0.80		0.24	1.06	
Number of ADLs	0.56	0.35		0.66	0.45		0.32	0.57	
Proxy responding	-5.21	1.61	*	-7.20	2.23	*	-2.94	2.30	
Ever institutionalized	-1.62	1.52		-3.45	2.07		1.13	2.20	
Some or great deal of pain	-1.44	1.77		-5.38	2.38	*	2.48	2.61	
Pressure sores	0.59	1.80		0.28	2.22		0.75	3.03	
Incontinence	-0.85	1.27		2.14	1.72		-3.34	1.85	
Unmeet ADL / IADL needs	-2.08	0.33	*	-2.26	0.41	*	-1.76	0.53	*
Social characteristics and residence									
Social participation	1.47	1.36		0.93	1.95		2.95	1.87	
State 1	4.95	2.03	*	5.44	2.82		3.64	2.91	
State 2	7.56	1.78	*	9.12	2.42	*	4.91	2.60	
State 3	1.28	2.60		11.49	3.97	*	-5.28	3.50	
State 4	5.20	1.94	*	6.92	2.37	*	3.38	3.45	
State 5	3.39	2.58		5.02	3.55		1.07	3.714	
Constant	102.26	3.57	*	100.20	4.43	*	100.88	5.21	*

NOTES:

* Statistically significant at $p<0.05$

SOURCE: RTI analysis of the MPR HCBS survey, 2004.

Computer Output: wava_wf06

who were 15.3 percentage points less satisfied. We did not find that the number of paid workers consumers had hired over the last six months was a statistically significant predictor in any of the three regressions.

Only a few demographic characteristics had statistically significant effects on satisfaction. In the main regression, respondents age 0 to 44 were 4.0 percentage points less satisfied than persons age 65 to 74, the omitted age category. There were no statistically significant effects of age in the subgroup analyses. Race was a significant determinant of satisfaction for older persons with disabilities, with African American respondents 5.5 percentage points less satisfied than Caucasian respondents, with no significant effect in the regressions on the overall sample and younger persons. Our indicator of matching race between respondent and worker was a significant determinant of satisfaction in the main regression (3.4 percentage points more satisfied) and in the regression on older persons (5.3 percentage points), but not in the regression for younger persons. There were no significant gender effects.

Among health and functional characteristics, proxy status and our index of unmet need were statistically significant in the regressions. Proxy respondents in the main regression were 5.2 percentage points less satisfied than self-respondents, and 7.2 percentage points less satisfied in the younger group with disabilities. For every unmet need reported by respondents, satisfaction ratings were only slightly lower, with reductions of 2.1 percentage points in the main regression, 2.3 percentage points for younger respondents, and 1.8 percentage points for older persons. Younger persons with disabilities who had some or a great deal of pain in the last four weeks reported 5.4 percentage points lower satisfaction. Measures of self-reported health status, ADLs and IADLs were not statistically significant in any regression.

4.4.2 Regression on Overall Satisfaction with Paid Care

We found that workforce characteristics analyzed in the three regressions using this dependent variable were almost always statistically significant (***Table 8***). Consumers who had problems or difficulty with replacing workers were somewhat less satisfied in both the overall sample and among physically disabled persons under age 65, but there was no significant effect among older persons. Respondents in the overall sample and in both age subgroups who reported problems with workers not showing up or arriving late were much less satisfied than those persons who had not encountered any problems and the findings were all significant. Consumers in the overall sample and in the younger population were only slightly less satisfied for every additional paid helper they had hired over the last six months, with no significant effect in the older population.

The workforce variables included in this regression but not included in the Satisfaction with Paid Personal Assistance Scale were almost always significant with large effects. Respondents who sometimes or always perceived their workers to be well trained were much more satisfied in the overall sample and both age subgroups, and the findings were all significant. Respondents with workers who treated them badly very often or often were significantly and greatly dissatisfied in all three regressions. In the overall sample and in the younger population, workers who sometimes or seldom treated consumers badly caused these consumers to also be significantly and greatly dissatisfied, but not to the extent as when the worker treated respondents badly often or very often. Finally, consumers in the overall sample

Table 8
Ordered logistic regression of the probability of overall satisfaction with paid care

	All survey respondents		Survey respondents under age 65		Survey respondents age 65 and over	
N (unweighted)	1,307		711		596	
Variable	Coefficient	Std err	Coefficient	Std err	Coefficient	Std err
Workforce Problems						
Problem replacing a paid worker	-0.45	0.19 *	-0.52	0.23 *	0.37	0.35
Not show up as scheduled or show up late	-0.83	0.23 *	-0.67	0.32 *	-1.06	0.36 *
Number of paid helpers in last 6 months	-0.05	0.02 *	-0.06	0.03 *	-0.04	0.03
Paid workers some or all well trained	1.56	0.35 *	1.21	0.50 *	2.07	0.52 *
Paid worker treats badly often/very often	-3.61	0.82 *	-4.20	1.24 *	-3.01	1.19 *
Paid worker treats badly some/seldom	-1.30	0.29 *	-1.57	0.35 *	-0.90	0.53
Paid worker is respectful of needs/wants	1.05	0.51 *	0.70	0.65	2.29	1.02 *
Demographics						
Age 18 to 44	-0.08	0.24	—	—	—	—
Age 45 to 64	-0.05	0.21	0.03	0.21	—	—
Age 75 to 84	-0.34	0.23	—	—	-0.32	0.25
Age 85 and over	0.06	0.30	—	—	0.06	0.31
Male	-0.23	0.17	-0.44	0.21 *	0.25	0.31
African American	-0.60	0.19 *	-0.85	0.26 *	-0.38	0.29
Asian	0.02	0.28	0.24	0.40	-0.33	0.41
Other race	-0.52	0.43	-0.78	0.64	-0.35	0.60
Race match	0.19	0.16	0.29	0.21	0.08	0.26

(continued)

Table 8 (continued)
Ordered logistic regression of the probability of overall satisfaction with paid care

	All survey respondents			Survey respondents under age 65			Survey respondents age 65 and over		
Variable	Coefficient	Std err		Coefficient	Std err		Coefficient	Std err	
Health and functional status									
Fair/poor health	-0.11	0.16		0.01	0.23		-0.12	0.25	
Number of IADLs	0.14	0.08		0.19	0.11		0.05	0.14	
Number of ADLs	-0.00	0.04		0.02	0.06		-0.05	0.07	
Proxy responding	-0.17	0.20		-0.30	0.29		-0.01	0.30	
Ever institutionalized	0.09	0.19		-0.28	0.26		0.45	0.31	
Some or great deal of pain	-0.00	0.22		-0.26	0.30		0.13	0.34	
Pressure sores	0.18	0.22		0.24	0.28		0.17	0.37	
Incontinence	-0.24	0.16		-0.01	0.21		-0.52	0.25	*
Unmeet ADL / IADL needs	-0.09	0.04	*	-0.12	0.05	*	-0.09	0.07	
Social characteristics and residence									
Social participation	0.14	0.17		0.04	0.25		0.28	0.24	
State 1	0.27	0.25		-0.09	0.35		0.45	0.39	
State 2	0.39	0.22		0.36	0.30		0.29	0.33	
State 3	-0.09	0.30		0.59	0.49		-0.47	0.42	
State 4	0.53	0.25	*	0.52	0.31		0.31	0.45	
State 5	-0.26	0.29		-0.36	0.40		-0.26	0.46	
Constant 1	-2.18	0.67	*	-3.65	0.88	*	-1.28	1.20	
Constant 2	-1.24	0.66		-2.14	0.84	*	0.29	1.23	
Constant 3	1.29	0.66		0.61	0.84		2.68	1.25	*

NOTES:

* Statistically significant at $p<0.05$

SOURCE: RTI analysis of the MPR HCBS survey, 2004.

Computer Output: wava_wf05

and in the older population who reported that their workers treated them with respect were much more satisfied than when they were not treated with respect, but there was no significant effect in the younger population.

As in the prior regressions using the 8-item satisfaction scale, few demographic characteristics were significant predictors of satisfaction with care. Males in the younger group with disabilities were somewhat less likely to be satisfied with paid care, but there were no significant gender effects in the overall sample or among older persons. When considering race, African American beneficiaries in both the overall sample and among physically disabled persons under age 65 were somewhat less likely to be satisfied with paid care and the findings were significant. The indicator for matching race between the consumer and the worker was not significant in any regression. There were no significant age effects in any of the regressions performed.

Few health and functional characteristics were significant predictors of satisfaction with paid care. Older consumers with incontinence problems were somewhat less satisfied than those older persons without this problem. The unmet need index was a significant predictor of satisfaction with paid care for respondents in the overall sample and the younger population with disabilities, who were only slightly less likely to be satisfied for every unmet need experienced. There was no significant effect of unmet need in the older population. Self-reported health status, measures of ADLs and IADLs, and other health related factors were not significant in any regression.

4.5 Discussion

This study highlights the importance of workforce issues to consumers who use Medicaid personal assistance services. While other studies (Anderson, et. al. 2004) focus on the lack of available and trained workers to meet the demand for services, this study demonstrates the importance that consumers place on services that are reliable and that satisfy their preferences. Efforts to recruit and retain workers need to consider the desires of consumers for reliable and caring workers if the care is to be valued.

This study’s findings add to prior work on consumer satisfaction with personal assistance services by measuring the independent effects of workforce-related characteristics on consumer opinions. Two related papers examined the effects of demographic, health, functional status, and social variables (Khatutsky, Anderson, and Wiener, 2006) and consumer-direction (Wiener, Khatutsky, and Anderson, 2006) on the same satisfaction scale we used in this study. We found that workforce-related issues are powerful predictors of client satisfaction with services, taking precedence over other domains. While this study specifically sought to measure client satisfaction with paid personal assistance, there are other areas of life for frail and disabled Medicaid beneficiaries that are important to study. Other satisfaction scales could be constructed to measure a consumer’s sense of their overall condition or satisfaction with quality of life. Especially since satisfaction is likely to be a key outcome variable in assessing the quality of home and community-based services, more research is needed on scales for measuring satisfaction with these services.

Consumer problems with worker recruitment in this study (e.g., replacing a worker and dealing with their unscheduled absences) were always more important indicators of consumer dissatisfaction than problems with retention (e.g., having many different workers over time). This finding implies that when you count on someone else to meet your personal assistance needs, having services performed by any number of different workers is better than having no services at all.

Whether consumers perceived that their workers were well trained and competent also strongly and consistently affected consumer satisfaction. In this study, having well-trained workers was valued as much as having no recruitment problems. Consumers expect paid workers to have sufficient training to perform required tasks well.

Worker mistreatment of consumers was a very strong and consistent indicator of dissatisfaction. One would expect to find great dissatisfaction among consumers who were being mistreated by workers, and the magnitude of the coefficient for being treated badly often or very often was the highest of all measures included in our analyses. While a statistically significant predictor, problems with mistreatment were reported by only 5 percent of consumers in this sample, and only 2 percent of consumers reported mistreatment occurring more than very infrequently. While this problem is not large in our sample, the fact that it exists is troubling. Our findings differed across the two age groups regarding the effect of worker respect for consumers, with significant impacts only for older persons. Older persons in this sample may have been disproportionately served by family members, from whom the consumer had higher expectations for respect than for workers with whom there was no prior relationship.

The only two non-workforce related characteristics that routinely rose to statistical significance were whether the respondent was African American and the degree to which a respondent had unmet needs. The measure of racial concordance may be indicative of the preferences of respondents for persons who share the same cultural, ethnic and linguistic background, but may also reflect racial bias. A similar measure for race or cultural match may be informative for future research to better understand how these issues affect worker performance and consumer receipt of services.

Two limitations affect these analyses. First, the study is limited to Medicaid beneficiaries in six states, and its results cannot necessarily be generalized to the national population of Medicaid beneficiaries receiving these services. However, the study includes states with a range of home and community-based systems and a substantial sample of respondents. For context, another paper (Wiener, Tilly, and Alecxih, 2002) conducted as part of this larger CMS study fully describes the features of the Medicaid home and community-based systems in each of these states. Second, satisfaction is an important indicator of quality of home and community-based services; however, because it is subjective, it is susceptible to cultural norms and expectations and social desirability, making it difficult to measure reliably (Geron et al., 2000).

This study suggests that workforce factors have a major effect on consumer satisfaction with their personal assistance services. Making it easier to find replacement workers, having workers show up on time, reducing worker turnover, increasing worker training, and insisting that workers treat consumers with respect and not mistreat them would all likely improve consumer satisfaction with paid home and community-based services. Improving consumer satisfaction is a key element to empowering consumers and ensuring that the services they receive meet their needs.

CHAPTER 5
ARE CONSUMER-DIRECTED HOME CARE BENEFICIARIES SATISFIED? EVIDENCE FROM WASHINGTON STATE

A key issue in the design of home and community services programs is the extent to which clients control their services. Traditional public home care programs rely on public or private agencies to hire and fire home care workers, schedule and direct services, monitor quality of care, discipline workers if necessary, and pay workers and applicable payroll taxes. In the agency-directed model, clients can express preferences for services or workers, but have no formal control over them. This approach to care operates from the assumption that professional expertise and accountability is critical to the provision of good quality care at reasonable cost. At its extreme, a "medical model" is imposed and individuals with disabilities are considered to be "sick," as opposed to needing compensatory services, such as help with bathing (Parsons, 1951).

A major innovation in long-term care in the United States and Europe is the development of consumer-directed home care. These programs represent the opposite end of the management continuum from agency-directed services. These programs give consumers control over who provides services, when they are provided and how these services are delivered. Typically, consumer-directed programs allow the consumer to hire, train, supervise, and fire the home care worker. In some programs, beneficiaries receive cash payments enabling them to purchase the services they want. The goal of this article is to assess whether Medicaid beneficiaries receiving consumer-directed care in Washington State are more or less satisfied than those receiving agency-directed care.

Consumer-directed home care has slowly become an international policy trend. A number of other countries, including France, the Netherlands, the United Kingdom, Austria, and Germany, have implemented programs to give beneficiaries more control over their home care services (Tilly, Wiener, and Cuellar, 2000; Cuellar and Wiener, 2000; Wiener, Tilly, and Cuellar, 2003). In addition, a growing number of American states are incorporating consumer–direction into their home care programs, including California, Michigan, Oregon, Washington, and Wisconsin (Wiener, Tilly, and Alecxih, 2002; Tilly and Wiener, 2001).

The Centers for Medicare and Medicaid Services is promoting consumer-directed services through the Real Choice Systems Change Grants and the Independence Plus Initiative (O'Keeffe, Wiener, and Greene, 2005; Smith, 2002). In addition, the Office of the Assistant Secretary for Planning and Evaluation, the Centers for Medicare and Medicaid Services and the Robert Wood Johnson Foundation are sponsoring "cash and counseling" demonstrations in Florida, Arkansas, and New Jersey, and other states where Medicaid beneficiaries of all ages are being given the opportunity to receive cash rather than service benefits (Doty, 1998; Dale, Brown, Phillips, Schore, and Carlson, 2003; Foster, Brown, Phillips, Schore, and Carlson, 2003).

Advocacy for consumer-direction in the United States began during the 1970s with the Independent Living Movement. Younger adults with disabilities demanded the right to receive and manage their own services in home and community settings to become part of mainstream society (Batavia, 1998, 2001, 2003; DeJong, Batavia, and McKnew, 1992). The movement rejects societal perceptions that persons with disabilities are "vulnerable" and "need protection"

(Simon-Rusinowitz and Hofland, 1993; Wiener and Sullivan, 1995). The Independent Living Movement contends that people with disabilities have the ability and right to make the decisions about the services that affect their lives.

While granting that consumer direction may work for some highly motivated, cognitively intact younger people, skeptics argue that older people with disabilities are too sick, too frail, too disabled and too often cognitively impaired to take on the tasks of directing their own care, even with the help of surrogate decision makers (Kane, 1999; Benjamin, 2001; Tilly and Wiener, 2001). Although reporting less interest than younger people, opinion surveys suggest that a significant minority of older people with disabilities are interested in consumer direction (Glickman, Stocker, and Caro, 1997; Simon-Rusinowitz et al., 1997). In fact, older people with disabilities participate extensively in consumer-directed programs, especially in state programs that have a long history, such as Oregon, Washington, Michigan and Wisconsin. In a recent survey of state units on aging and Medicaid directors, 58 consumer-directed home care programs were identified, of which 38 percent started in the last five years (Infield, 2005).

Probably the most contentious issue surrounding consumer-directed home care services relates to whether quality of care is adequate (Tilly and Wiener, 2001; Benjamin, 2001). Compared with agency-directed care, consumer-directed services lack the standard quality assurance structures of training of paraprofessionals, supervision by professionals and provision of technical services by professionals. As a result, critics contend that consumer-directed providers will be more likely to neglect and abuse beneficiaries of services (Benjamin, 2001). In addition, it is argued that consumers will be unable to arrange for backup assistance or manage emergencies.

A limited number of research studies find that satisfaction with consumer-directed services, a major component of quality, is at least comparable to that for agency-directed services and may be higher. In a study of elderly Medicaid personal care beneficiaries in Maryland, Michigan and Texas, respondents who reported that they had a great deal of choice consistently reported more satisfaction with their services than those without choice (Taylor, Leitman, and Barnett, 1991). Of the three states, however, only Michigan had a full consumer-directed home care program. A small study of younger clients of consumer-directed services in Virginia found that they reported higher satisfaction and greater work productivity than those receiving agency or informal services (Beatty, Richman, Tepper, and DeJong, 1998).

In a study of California's In-Home Supportive Services beneficiaries in the mid-1990s, consumer-directed respondents reported more satisfaction than agency-directed clients with their services and the freedom to select them, a stronger preference for managing services, higher perceived quality of care and higher emotional, social and physical well-being (Benjamin, Matthias, and Franke, 1998). Consumer-directed respondents also reported greater satisfaction with the providers' ability to assist them then did agency-directed services. Other differences in outcomes between the two groups were not significant. A limitation of the study was that agency-directed services were available in only 12 of the 58 counties in California, while consumer-directed services were available in all 58 counties. Within counties where there is a choice, there was a tendency for case managers to assign less disabled clients and clients believed to have difficulty recruiting a worker to the agency-directed services; clients needing the paid worker to provide paramedical tasks or to drive a car were more likely to be assigned to consumer-directed services (Doty, Benjamin, Matthias, and Franke, 1999). The net effect of these decision factors was systematic differences in the characteristics of clients participating in the two service models.

Finally, in a study of the cash and counseling demonstration program in Arkansas, Medicaid consumer-directed beneficiaries reported much higher levels of satisfaction and much lower levels of dissatisfaction than beneficiaries receiving agency-directed services (Foster et al., 2003). Consumer-directed beneficiaries also reported that workers were more likely to complete tasks, arrive on time and were less likely to neglect the client or be rude or disrespectful. This finding was true for both younger adults with physical disabilities and older persons. The Arkansas Independent Choices program was a voluntary demonstration for people age 18 or older who were eligible for Medicaid personal care services. Volunteers who were randomly assigned to the treatment group received a monthly allowance that they could use to hire workers (except spouses) and to purchase other services or goods related to their needs, such as assistance devices and home modifications. Persons assigned to the control group received regular agency-directed services. A limitation of the study was that it was a demonstration project and not an ongoing program fully integrated into the operations of the Arkansas Medicaid program. In addition, participants in the program were persons who, by definition, volunteered for the program and were interested in directing their own care, so may not be representative of average Medicaid beneficiaries.

The purpose of this study is to add to the knowledge and debate about consumer-directed home care services by analyzing satisfaction with paid care in Washington State. Washington State has offered consumer-directed home care services as part of its Medicaid program for over a decade and has integrated it into the mainstream of its service delivery system. Conducted as part of a large project on home and community-based services funded by the Centers for Medicare and Medicaid Services, this study uses a survey of Medicaid home and community-based services beneficiaries in Washington and Medicaid administrative data. The analyses provides a profile of persons receiving agency-directed and consumer-directed services and assesses whether, controlling for other factors through multivariate methods, persons using consumer-directed services have higher or lower levels of satisfaction compared to persons receiving agency-directed services. Because it is commonly believed that older people and physically disabled persons under age 65 have different expectations, interest and capabilities to manage their own care, the data were analyzed for the sample as a whole and for older people and younger persons with physical disabilities separately.

As part of its long-standing commitment to a social model of long-term care, consumer-directed home care is not only a mainstream component of community-based services in Washington, it is the dominant model (Wiener et al., 2004; Wiener and Lutzky, 2001a,b). Over half of Medicaid home care beneficiaries use consumer-directed home care rather than agencies.

Clients in both the Medicaid personal care program and the home and community-based services waiver, known as Community Options Program Entry System (COPES), have a choice of using licensed home care agencies or independent providers. Under the Independent Provider option, the worker is a direct employee of the client, with the state assuming responsibility for paying workers and taxes. With assistance from the Area Agencies on Aging’s case manager, the client is responsible for hiring, orienting, supervising, and finding replacements for the caregiver.

Although recently abandoned, a major factor shaping home care in Washington was a long-standing state policy that required clients who needed more than 112 hours of service per month to use independent providers. Devised principally as a cost containment mechanism, the rule was intended to keep in-home per person expenditures below 90 percent of the average cost of nursing facility care.

5.1 Design and Methods

As part of a research project funded by the Centers for Medicare & Medicaid Services, The Lewin Group and its subcontractors, RTI International, the University of Minnesota Research and Training Center on Community Living, Mathematica Policy Research and The Medstat Group are studying Medicaid financing and delivery of home and community-based services to older people and younger adults with physical disabilities, as well as to individuals with mental retardation and developmental disabilities.

The larger study seeks to examine a broad range of state systems of home and community-based services, concentrating on the role of Medicaid. States chosen for inclusion in the study include ones with well-developed systems and states that are in the process of developing their noninstitutional services systems. Alabama, Kentucky, Maryland, Michigan, Washington, and Wisconsin were selected for the portion of the project focusing on older people and younger persons with physical disabilities. The overall goal of the project is to study selected programs to assess their effects on quality of care, utilization of services and cost. The first component of the project involved case studies of the range of the services, coverage, financing, administration, and quality assurance systems in the six states (Wiener et al., 2002; Wiener and Goldenson, 2001; Wiener and Lutzky, 2001a,b; Tilly and Goldenson, 2001; Tilly, 2001; Tilly and Kasten, 2001a,b).

The second component of the study was a survey of Medicaid home and community-based services beneficiaries in the six selected states conducted by Mathematica Policy Research, Inc. (Snell, Zhao, Lu, Potter, and Ciemnecki, 2005). The survey was fielded between May 2003 and June 2004, with the sample allocated proportionally among states based on the number of home and community-based services beneficiaries in each state. Because of the major policy interest in differences between older and physically disabled persons under age 65, the survey sample was stratified by age (under age 65 and age 65 and over). For this study, we used the Washington State sample from the survey because it represented a state with a long history of use of consumer-directed care and state administrative information could accurately identify Medicaid beneficiaries participating in the consumer-directed option.

In Washington, the state required consent by the Medicaid beneficiary in advance of being contacted by Mathematica Policy Research (Snell et al., 2005). The state mailed letters explaining the study to all persons in the initial sample. Beneficiaries were asked to return an enclosed postcard within two weeks if they did not want to participate in the study. Of the 2,962 advance letters mailed, 510 were returned as nondeliverable and 738 clients returned postcards indicating that they did not want to participate in the study. The state did not allow the researchers to conduct follow-up on the “nondeliverable” letters. Washington then provided contact data for the remaining 1,714 cases to Mathematica Policy Research, which then selected the survey sample of 1,246 beneficiaries from the eligible cases. The state drew the initial sample in November 2001 and provided Mathematica Policy Research with the sample willing to participate in March 2003. Data collection began in Washington in September 2003, and ended in June 2004. The survey was primarily conducted through telephone interviews using the Computer Assisted Telephone Interviewing (CATI) system, with a few in-person interviews. Of the 1,246 Medicaid beneficiaries in the sample, 424 were ineligible, primarily because of death or admission to a nursing home. Of the 821 persons found to be eligible, 601 or 73.2 percent completed the survey.

Surveying impaired populations is known to be difficult, and to ensure that data collected were of high quality, special modifications to survey design and procedures, including use of proxies, interviewer checkpoints, and fatigue and reinforcement probes were used. The survey respondents participated in the survey directly or via proxy (paid and unpaid caregivers) and included residents living in their own homes as well as in assisted living facilities and other group settings. Information on 14 percent of the sample was provided by proxy respondents.

The State of Washington's Department of Social and Health Services used administrative data to determine whether sample persons in the survey used the Independent Provider during the sample period. The State found matching data for 599 of the 601 respondents (99.7 percent). A total of 292 of the 599 persons (48.7 percent) were identified as participants in the Independent Provider option. For this study which examined consumer satisfaction with paid home care, respondents were excluded if they had a proxy respondent who was also a paid caregiver as were a few respondents who had missing responses to underlying questions used to develop the satisfaction rating. These exclusions reduced the final sample to 513 respondents, 232 persons (45.3 percent) used the Independent Provider option.

5.2 Statistical Methodology

We used both descriptive statistics and multivariate regression to analyze the data. In predicting satisfaction with personal care services, we estimated an ordinary least squares (OLS) model that was right-censored at a scale value of 100 to account for the approximately half of all observations with that value (52.8% for the overall Washington sample, 46.5% for the sample under age 65, and 57.9% of the sample age 65 and older). The shape of the distribution of the remaining part of the satisfaction scale allowed us to assume the properties of a normal distribution. We also estimated a survey-adjusted version of our model with probability weights and stratification that did not account for censoring, but found that fewer demographic and health and functional status variables for which we anticipated significant results were significant. The regression coefficients in this version of the model are smaller in absolute value because so many observations are clustered at 100. We estimated summary statistics using probability weights adjusted for non-response and post-stratification, but did not do so with the regression models because we estimated fully specified models.

Three regressions were estimated on the dependent variable created to measure satisfaction: one regression was estimated for the overall analytic sample, one for the subgroup of respondents under age 65, and one for the subgroup of respondents that was age 65 and older. The two populations are likely to differ in their outlook and in the services provided. Younger disabled adults may have higher expectations for participating in the workforce and community life, and subsequently might be more demanding (less satisfied) than elderly respondents.

Estimating satisfaction for these subgroups allows us to account for these differences and determine whether levels of satisfaction differed between the two age groups.

5.2.1 Dependent Variable

To examine satisfaction with paid care as part of the larger study, data on a subsample of 2,325 self-respondents and unpaid caregiver proxies who provided responses to 8 survey items was selected to construct the Satisfaction with Paid Personal Assistance Scale (SPPAS) (Khatutsky, Anderson, and Wiener, 2005). Sample members with paid caregivers who were proxy respondents were not asked these questions and were not included in these analyses. These eight items, presented for Washington in ***Table 9***, measure overall satisfaction, as well as interpersonal aspects of care provided by paid helpers, such as communication with paid helper, how problems get resolved, how often paid caregivers get impatient or angry, and how well paid caregivers are trained.

We constructed the scale by collapsing response categories of variables as needed to increase variability across response categories, and by assigning a scale value to all response categories within each underlying variable of the scale. Dummy variables were scaled 0-100, variables with three response categories were scaled 0-50-100, variables with four response categories were scaled 0-33-67-100, and variables with five response items were scaled 0-25-50-75-100. The scale was set to a missing value if more than 4 items had missing responses. The scale ranged from 0 to 100 with a mean of 93.9 (standard deviation of 11.2). The scale's Cronbach's alpha was 0.7 for the six-state sample. We evaluated the 8-item scale using factor analysis, which showed one dominant factor (eigenvalue 2.9). This factor was uniformly loaded on all the variables, predicting a high correlation with the SPASS scale, which was constructed as a mean of all items. The correlation between the scale and the factor was 0.97.

5.2.2 Independent Variables

Independent variables were grouped into four domains (details on variable construction are presented in ***Table 10***):

- *Home and Community-based Services Options*, including variables for whether or not the respondent participated in the Independent Provider option in Washington, in which a respondent directs his or her own services, the state plan personal care option, or neither. Agency-directed services include persons in residential care facilities, such as assisted living facilities.

- *Demographics Characteristics* of beneficiaries, including age, gender, and race. Under this domain, we also included a variable to indicate when care recipients and paid caregivers have a matching race. Income was not included as a variable because all survey respondents were very low-income Medicaid beneficiaries, resulting in little variation.

- *Self-reported Health and Functional Status* of personal assistance beneficiaries, including self-reported health status, number of limitations in six activities of daily living (ADLs) (bathing, dressing, eating, transferring, walking across the room and toileting), number of limitations in four instrumental activities of daily living (IADLs) (cooking, managing medications, shopping, and doing light housework). A composite was created of ten items that asked about unmet needs for ADL and IADL assistance, a count variable ranging from 0 to 10. Additional health status indicators included prior nursing home use, recent pain or pressure sores, and bladder /bowel incontinence. A variable for proxy survey respondent is used to control for cognitive impairment in the sample population.

- *Social Characteristics and Residence,* including a variable for social involvement and participation, and a variable for living in a group setting such as assisted living facilities or adult foster home.

Of the independent variables used in regressions, self-reported health status (excellent, very good/good and fair/poor) was imputed based on survey respondents' ADL impairment for about 1% of the total sample for which data was missing.

5.3 Results

Table 9 presents the descriptive statistics on the components comprising the Satisfaction with Paid Personal Assistance Scale for the total sample and separately for those persons with consumer-direction vs. agency-directed care. Home and community-based services beneficiaries generally report high levels of general satisfaction and with various aspects of their personal care. Overall, about 76% of respondents are "very happy" with paid care received in Washington. About 14% of respondents report ever having difficulties resolving or fixing problems they encountered with their paid caregiver and 92% report never having trouble communicating with the paid caregiver. Most respondents (80%) get along "very well" with their paid helper and 83% never experienced the problem of a paid helper ignoring them. Less then 6% complained about ever being treated badly by the paid caregiver. Slightly less than 91% consider their paid caregiver competent and well-trained and about 96% find them respectful.

While most of the satisfaction ratings appear similar between those with consumer-directed vs. agency-directed care, there are also some differences. Persons with consumer-directed care were more likely than persons with agency-directed care to report being "very happy" with their care and to have workers who were well-trained, and were less likely to report having difficulty getting problems fixed.

Table 10 lists the variables used in the multivariate analyses and their means for all survey respondents in Washington and for survey respondents under age 65 and age 65 and over. A total of 45% percent of respondents used consumer-directed care, with 54% of physically disabled persons under age 65 and 38% of older clients using this service option.

Table 11 presents the means for the analytic variables for persons with and without consumer direction for the overall sample and for the populations under age 65 years old and age 65 and older. Overall, compared to persons using agency-directed services, persons using

Table 9
Distribution of variables comprising the Satisfaction with Paid Personal Assistance Scale (SPPAS)

	All survey respondents	Consumer-directed care	Agency-directed care	Statistical significance
N (unweighted)	513	228	285	
How happy overall with the paid care received				
Very happy	0.762	0.804	0.728	**
Somewhat happy	0.194	0.160	0.222	*
Somewhat unhappy	0.032	0.025	0.039	
Very unhappy	0.011	0.012	0.011	
Has it ever been difficult to get problems resolved or fixed				
Yes	0.138	0.107	0.162	*
No	0.862	0.893	0.838	
How well get along with paid helper				
Very well	0.799	0.809	0.792	
Well	0.190	0.182	0.197	
Not very well	0.008	0.004	0.012	
Not at all well	0.002	0.004	0.000	
Any trouble communicating with paid helper				
Yes	0.085	0.064	0.102	
No	0.915	0.936	0.898	
Problems of paid helper ignoring survey participant				
Never	0.827	0.834	0.822	
Seldom	0.095	0.111	0.082	
Sometimes	0.067	0.040	0.089	**
Often	0.009	0.015	0.004	
Very often	0.002	0.000	0.003	
Problems with paid helper treating survey participant badly				
Never	0.943	0.942	0.943	
Seldom	0.032	0.033	0.032	
Sometimes	0.015	0.012	0.018	
Often	0.004	0.004	0.003	
Very often	0.006	0.009	0.004	
Is paid helper competent and well trained				
Yes	0.905	0.952	0.867	***
Sometimes	0.059	0.040	0.075	
No	0.036	0.008	0.058	***
Is paid helper respectful				
Yes	0.957	0.969	0.948	
Sometimes	0.024	0.016	0.031	
No	0.019	0.015	0.021	

NOTES: Results are weighted.
* Statistically significant at p<0.05.
SOURCE: RTI analysis of the MPR HCBS survey, 2004.
Computer Output: wava_cd12a.

Table 10
Variable construction and descriptive characteristics (means) of the sample, by age

Characteristics	Variable construction	All survey respondents	Survey respondents under age 65	Survey respondents age 65 and over	Difference between age groups significant
N (unweighted)		513	228	285	
Satisfaction with Paid Personal Assistance Scale (SPPAS)	8-item scale ranging from 0 to 100	92.58	90.26	94.46	*
Home and community-based services options					
Consumer direction	Dummy variable=1 if respondent uses consumer-direction	0.453	0.541	0.382	*
State plan personal care	Dummy variable=1 if respondent uses Medicaid state plan personal care	0.370	0.405	0.341	
Demographics					
Age under 44 (%)	Dummy variable for respondent's age group	0.125	0.280	—	
Age 45 to 64 (%)	Dummy variable for respondent's age group	0.322	0.720	—	
Age 65 to 74 (%)	Dummy variable for respondent's age group	0.211	—	0.383	
Age 75 to 84 (%)	Dummy variable for respondent's age group	0.217	—	0.394	
Age 85 and over (%)	Dummy variable for respondent's age group	0.122	—	0.222	
Male (%)	Dummy variable for respondent's gender	0.271	0.371	0.190	*
African American (%)	Dummy variable for respondent's race	0.075	0.088	0.064	
Asian (%)	Dummy variable for respondent's race	0.138	0.150	0.128	
Other race (%)	Dummy variable for respondent's race	0.031	0.018	0.042	
Matching race (%)	Dummy variable =1 if survey participant and paid helper report the same race	0.746	0.731	0.758	

(continued)

Table 10 (continued)
Variable construction and descriptive characteristics (means) of the sample, by age

Characteristics	Variable construction	All survey respondents	Survey respondents under age 65	Survey respondents age 65 and over	Difference between age groups significant
Health and functional status					
Fair / poor health (%)	Dummy variable for self-reported health status	0.684	0.709	0.663	
Good / very good health (%)	Dummy variable for self-reported health status	0.284	0.250	0.312	
Number of IADL limitations (#)	4-item scale ranging from 0 to 4; 1=needing help with each IADL	3.402	3.379	3.421	
Number of ADL limitations (#)	6-item scale ranging from 0 to 6; 1=needing help with each ADL	2.703	2.638	2.756	
Proxy responding (%)	Dummy variable=1 if proxy responded	0.135	0.053	0.202	*
Ever institutionalized (%)	Dummy variable=1 if ever been a resident or patient in a nursing home	0.275	0.325	0.234	*
Some or great deal of pain (%)	Dummy variable=1 if experienced pain 4 weeks prior to the survey	0.864	0.895	0.839	
Having pressure sores (%)	Dummy variable=1 if had sores 6 months prior to the survey	0.101	0.132	0.075	*
Bladder /bowel difficulties (%)	Dummy variable=1 if had incontinence problems 6 months prior to the survey	0.630	0.651	0.614	
Unmet needs for ADLs and IADLs (#)	13 item scale ranging from 0 to 13; 1=unmet need in the month prior to the survey	0.709	0.988	0.482	*
Social characteristics and residence					
Social participation (%)	Dummy variable=1 if went out for social activities/recreation at least once a week prior to the survey	0.804	0.873	0.749	*
Live in a group setting (%)	Dummy variable= 1 if respondent lives in adult foster care, group home or assisted living facility	0.178	0.106	0.236	*

NOTES: Results are weighted.

* Statistically significant at p<0.05.

SOURCE RTI analysis of the MPR HCBS survey, 2004.

Computer Output: wava_cd09a and wava_cd09c

Table 11
Means of analytic variables for respondents in consumer directed and agency-directed options

	Overall sample			Survey respondents under age 65			Survey respondents age 65 and over		
	Consumer Directed	Agency Directed		Consumer Directed	Agency Directed		Consumer Directed	Agency Directed	
N (unweighted)	233	284	—	124	105	—	109	179	—
Satisfaction with Paid Personal Assistance									
Scale (SPPAS)	94.05	91.28	*	91.65	88.68		96.84	92.82	*
State Programs									
State plan personal care	0.434	0.318	*	0.397	0.420		0.477	0.258	*
Demographics									
Age under 44 (%)	0.160	0.099		0.298	0.266		0.000	0.000	
Age 45 to 64 (%)	0.376	0.273	*	0.702	0.734		0.000	0.000	
Age 65 to 74 (%)	0.205	0.218		0.000	0.000		0.442	0.347	
Age 75 to 84 (%)	0.182	0.248		0.000	0.000		0.392	0.395	
Age 85 and over (%)	0.077	0.162	*	0.000	0.000		0.166	0.258	
Male (%)	0.317	0.229	*	0.372	0.366		0.254	0.148	*
Caucasian (%)	0.715	0.789		0.749	0.730		0.677	0.824	*
African American (%)	0.076	0.077		0.078	0.109		0.072	0.058	
Asian (%)	0.186	0.097	*	0.160	0.138		0.216	0.073	*
Other race (%)	0.023	0.037		0.013	0.023		0.035	0.045	
Matching race (%)	0.876	0.636	*	0.828	0.619	*	0.931	0.645	*

Table 11 (continued)
Means of analytic variables for respondents in consumer directed and agency-directed options

	Overall sample			Survey respondents under age 65			Survey respondents age 65 and over		
	Consumer Directed	Agency Directed	Test result	Consumer Directed	Agency Directed	Test result	Consumer Directed	Agency Directed	Test result
<u>Health and functional status</u>									
Fair / poor health (%)	0.776	0.612	*	0.743	0.672		0.815	0.576	*
Good / very good health (%)	0.200	0.350	*	0.226	0.274		0.168	0.394	*
Excellent health (%)	0.024	0.039		0.031	0.054		0.017	0.030	
Number of IADL limitations (#)	3.620	3.224	*	3.594	3.130	*	3.651	3.280	*
Number of ADL limitations (#)	3.413	2.122	*	3.377	1.762	*	3.456	2.335	*
Proxy responding (%)	0.143	0.135		0.091	0.018	*	0.204	0.204	
Ever institutionalized (%)	0.231	0.306	*	0.267	0.390		0.190	0.257	
Some or great deal of pain (%)	0.912	0.818	*	0.903	0.875		0.922	0.785	*
Having pressure sores (%)	0.129	0.076		0.164	0.093		0.089	0.065	
Bladder /bowel difficulties (%)	0.639	0.618		0.667	0.624		0.606	0.614	
Unmet needs for ADLs and IADLs (#)	0.612	0.787		0.796	1.229		0.399	0.525	
<u>Social characteristics and residence</u>									
Social participation (%)	0.850	0.767	*	0.878	0.868		0.819	0.707	*
Live in a group setting (%)	0.036	0.300	*	0.033	0.192	*	0.038	0.364	*

NOTES: Results are weighted . Statistically significant at p≤0.05.

SOURCE: RTI analysis of the MPR HCBS survey, 2004. Computer Output: wava_cd10a.

consumer direction were more likely to be younger, male, Asian, have a paid caregiver of the same race, be in fair or poor health, have more ADL and IADL problems, have some or great deal of pain, have had pressure sores, and have higher levels of social participation. They are less likely to live in a group setting or to have ever been institutionalized, and have fewer unmet ADL or IADL needs. Average ratings for the Satisfaction with Paid Personal Assistance Scale were higher for persons with consumer direction than for persons with agency-directed care. With few exceptions, the means were the same for the different age groups.

Table 12 presents the results of the multivariate regressions predicting satisfaction with paid personal assistance for the total sample and for the two age groups separately. In Model 1, which includes all survey respondents, consumer direction was not a statistically significant predictor of satisfaction with paid personal assistance. Among the other variables, under age 44 (compared to age 65-74), male, fair/poor and good/very good self-reported health (compared to excellent health), incontinence, and unmet ADL/IADL needs were significant predictors of satisfaction. In Model II, which includes survey respondents under age 65 years of age, consumer direction was also not a significant predictor of satisfaction; among other variables, only unmet ADL/IADL was a significant predictor of satisfaction. In Model III, which includes survey respondents age 65 and older, consumer direction was a highly significant predictor of satisfaction with paid care; persons using consumer direction had satisfaction ratings that were 8.25 percentage points above older people using agency-directed care. Among other variables for this model, age 85 and older, number of ADLs, incontinence, and number of unmet ADL/IADL needs were significant predictors of satisfaction.

5.4 Discussion

One of the main policy directions in long-term care is the expansion of consumer-directed home care, where individual consumers have the authority to hire, train, supervise, schedule, and fire their workers. This study analyzed consumer-directed and agency-directed home care among Medicaid beneficiaries in Washington, with a particular focus on whether people using consumer-directed home care had higher satisfaction with their paid care. Washington is one of the leaders in consumer-directed care and has provided this option to beneficiaries for many years on a statewide basis. Thus, it offers the opportunity to examine a fully-implemented, mature, statewide program of consumer direction that is part of the mainstream of the home and community-based service system.

The descriptive analysis provides important new information on who does and does not choose consumer-directed home care. First, it is often argued that consumer-directed home care is primarily for physically disabled persons under age 65 and older persons are not interested. In Washington, while younger people with disabilities were more likely than older people to choose that option, 38 percent of older Medicaid home and community-based services beneficiaries in Washington (compared to 54 percent of the younger population) chose consumer direction, a very substantial minority.

Second, some observers contend that consumer direction is primarily for people with modest disabilities and that people with substantial disabilities are too sick, too functionally impaired or too weak to take on these responsibilities. Contrary to these expectations, among the

Table 12
Predicting Satisfaction with Paid Personal Assistance Scale (SPPAS): Censored normal regression

	Model I			Model II			Model III		
	All survey respondents			Survey respondents under age 65			Survey respondents age 65 and older		
Unweighted N	513			228			285		
Variable	Coefficient	Std err		Coefficient	Std err		Coefficient	Std err	
State Programs									
Consumer direction	2.60	2.26		-2.67	3.33		8.25	2.97	*
State plan personal care	-1.53	2.11		-0.32	3.12		-2.21	2.989	
Demographics									
Age under 44	-8.03	3.44	*	—	—				
Age 45 to 64	-3.56	2.63		4.66	3.36				
Age 75 to 84	1.56	3.07		—	—		1.43	2.82	
Age 85 and over	0.99	3.70		—	—		1.22	3.44	
Male	-4.49	2.25	*	-2.78	3.20		-6.90	3.11	*
African American	-0.52	3.66		-2.49	5.28		1.67	5.12	
Asian	-0.49	2.88		3.65	4.32		-5.34	3.71	
Other race	0.62	5.57		7.58	11.35		-2.97	5.85	
Race match	3.27	2.41		6.06	3.61		1.99	3.22	
Health and functional status									
Fair/poor health	0.16	5.47	*	6.20	7.13		-14.86	9.72	
Good /very good health	2.53	5.56	*	2.60	7.39		-15.94	9.73	
Number of IADLs	0.67	1.26		1.33	1.87		-0.28	1.66	
Number of ADLs	1.015	0.567		0.728	0.906		1.529	0.719	*
Proxy responding	-4.12	3.20		-0.98	6.99		-6.35	3.40	
Ever institutionalized	-0.55	2.17		-0.52	3.13		-2.38	2.88	
Some or great deal of pain	-5.92	3.12		-3.28	5.22		-6.61	3.64	
Pressure sores	-4.80	3.21		-2.66	4.49		-8.09	4.51	
Incontinence	5.01	2.10	*	-2.32	3.22		-6.91	2.60	*
Unmeet ADL / IADL needs	-4.748	0.578	*	-5.654	0.740	*	-2.986	0.944	*

(continued)

Table 12 (continued)
Predicting Satisfaction with Paid Personal Assistance Scale (SPPAS): Censored normal regression

	Model I		**Model II**		**Model III**	
	All survey respondents		Survey respondents under age 65		Survey respondents age 65 and over	
Variable	Coefficient	Std err	Coefficient	Std err	Coefficient	Std err
Social characteristics and residence						
Social participation	4.11	2.49	4.94	4.30	2.94	2.87
Live in a group setting	-5.54	2.98	-7.15	5.12	-2.26	3.66
Constant	107.78	7.72 *	87.900	11.04 *	125.00	11.44 *

NOTES:

* Statistically significant at p≤0.05.

SOURCE: RTI analysis of the MPR HCBS survey, 2004.

Computer Output: wava_cd11

total sample, as well as among physically disabled persons under age 65 and older beneficiaries, persons using consumer-directed services were, on average, substantially more disabled and much more likely to rate their health as fair or poor. Some of this differential may be a residual of the earlier state policy that required persons needing a high level of service to use consumer direction.

Third, within Washington, elderly Asians were much more likely to choose consumer-directed home care over agency-directed care. The ability to hire relatives or friends provided by the Independent Provider option may provide a mechanism for older Asians to ensure that they receive care from a person who understands their cultural traditions, language and preferences. Indeed, as an indicator of that motivation, overall, consumer-directed beneficiaries were more likely than agency-directed beneficiaries to have caregivers of the same race as the client.

The multivariate analyses addressed the question of whether people using consumer-directed home care were more satisfied with their care than people using agency-directed services, controlling for a number of factors. For the overall sample, there was no statistically significant difference in the level of satisfaction between people using the two types of care. Thus, contrary to the fears of some observers, the quality of consumer-directed home care was no worse than agency-directed home care, at least by one important measure. One speculative reason for the lack of difference is that home care agencies, faced with years of competition from consumer-directed care, have modified their practices to give consumers more control and choice.

The results of the subgroup analyses were surprising. Since consumer-direction is strongly identified with younger people with disabilities and their advocates and they are most vocal in their support for consumer-directed care, it was expected that they would be the group where the difference in satisfaction between the two types of care would be strongest. Similarly, it is often argued that older people are not interested in or capable of consumer-directed care and prefer to delegate those tasks to agencies. Contrary to expectations, for physically disabled persons under age 65, there was no statistically significant difference in satisfaction between consumer-directed home care and agency-directed care, but there was a large and statistically significant difference in consumer-direction's favor for older people. One possible hypothesis to explain this difference is that persons under the age of 65 who used non-family/friends as independent providers had lower satisfaction scores than did similar persons in the older population. While this might be the case, there are not enough physically disabled persons under age 65 using non-family/friends to substantially reduce the overall satisfaction scores (analysis not shown). Similarly, while there is greater use of proxy respondents by persons with consumer direction under age 65, their numbers are small (9.1% vs. 1.8%)—9.1% for those under 65 years of age, and 18% for those aged 65+; for the older population, the use of proxies was more frequent, but the proportion was exactly the same for consumer-directed and agency-directed care (20.4%).

This study adds to the growing, but still small, literature on consumer-directed home care and Medicaid home and community-based services. Like all studies, it has some limitations. First, the study is limited to Medicaid beneficiaries in Washington and its results cannot necessarily be generalized to the national population of Medicaid beneficiaries receiving home and community-based services or to the overall population of people with disabilities. The choice of Washington was made because it has a well-developed system of home and community-based services, a long history of offering home and community-based services, and we were able to match to state administrative data to obtain our measure of consumer-direction.

Second, satisfaction is an important indicator of quality of home and community-based services. Because it is subjective, however, it is susceptible to cultural norms and expectations, making it difficult to measure reliably. Measuring satisfaction with home-based care is also prone to response bias, as well as cultural and cohort differences (Geron et al., 2000). Nonetheless, it measures an important dimension of quality of care and is often used to assess services in a number of settings.

States, CMS, and consumer advocates are promoting the use of consumer-directed home and community-based services as a way to empower consumers and craft services that better meet their needs. Skeptics argue that the quality of care in consumer-directed programs is inadequate. This study supports the premise that consumer satisfaction in consumer-directed home care is not inferior to agency-directed care. The positive effect of consumer-direction for older people supports the idea that this service option should not be limited to physically disabled persons under age 65.

CHAPTER 6
MEDICATION USE AMONG MEDICAID USERS OF HOME AND COMMUNITY-BASED SERVICES

6.1 Introduction

Over the past decade the use of and expenditures on prescription drugs has grown dramatically. Prescription drug expenditures increased from $51.3 billion in 1993 to $179.2 billion in 2003 (Smith et al., 2005). This growth may be attributed to increased access through more insurance coverage, increased number of drug products in existing therapeutic categories, new products in diseases that previously lacked treatment, and the increase in price for these products.

Access to prescription drugs and over-the-counter medications depends on several factors, including (1) financial capability or access in terms of adequate insurance coverage or income sufficient to purchase the drug, (2) physical and mental capabilities to obtain the prescription either by walking or driving to or obtaining delivery from the pharmacy, and (3) necessary diligence to remain compliant with the therapy. For older people and younger persons with physical disabilities who are eligible for Medicaid, non-financial factors may play a large role in achieving adequate medication therapy. However, research on factors associated with access unrelated to insurance coverage is rare.

Medicare’s new prescription drug benefit uses private health plans which utilize financial methods and drug management techniques (such as formularies, prior authorizations, etc.) to control costs which may affect access to medications. As beneficiaries who are both eligible for Medicaid and Medicare transition to this new Medicare drug benefit, it is even more important to understand these access issues. This article attempts to fill this information void by examining factors associated with medication taking behavior in a Medicaid-covered elderly and disabled population receiving HCBS in Alabama, Kentucky, Maryland, Michigan, Washington and Wisconsin.

6.2 Background

Estimates of the number of the people unable to obtain medications appear at first glance to vary widely. A *USA Today*/Kaiser Family Foundation/Harvard School of Public Health (2005) survey of Americans on health care cost reports that among the 23 percent of people who had difficulty paying medical expenses, 56 percent said the problem bill included prescription drugs. This same survey found that among those with difficulty paying medical bills, 20 percent did not fill a prescription. Kennedy and colleagues (2004) found that the percent of the non-institutionalized population who failed to purchase a prescription due to cost was small, but grew from 4.7 percent in 1997 to 5.9 percent in 2002. The apparent discrepancy in estimates is the result of using different denominators (total non-institutionalized population versus the population with difficulty paying medical bills); once the same denominator is used, the estimates are roughly similar.

While these estimates appear low, the consequences of not obtaining needed prescription drugs could be dire (Tamblyn et al., 2001; Soumeri et al., 1994). Thus, it is important to understand the characteristics of those not receiving needed medications. Previous research on the general population found higher rates of unmet medication need in certain subpopulations including African American persons, working age adults (18-64), females, people with low incomes, persons without insurance, and Medicare and Medicaid beneficiaries (Kennedy, Coyne, and Sclar, 2004). People without insurance had the highest level of unmet medication need, 17.9 percent, followed by persons who were dually eligible for Medicare and Medicaid, 11.4 percent; and with Medicaid beneficiaries reporting 7.8 percent (Kennedy, Coyne, and Sclar, 2004). A 2003 study of persons with chronic conditions found that 39 percent of the publicly insured (Medicaid or disabled Medicare beneficiaries) and 17 percent of older people with Medicare did not fill a prescription due to cost (Reed, 2005).

Lack of access by Medicaid beneficiaries is especially troubling since all States have some prescription drug benefit with low or no co-payments. In 2003, 35 States had some form of cost sharing for their Medicaid prescription drug benefit, with the amounts charged ranging from $0.50 to $3.00 (Kaiser Commission on Medicaid and the Uninsured, 2003). While a co-payment of $3.00 may appear to be nominal, for a person with several prescriptions on a low, fixed income, this could represent a financial barrier. Nelson and colleagues (1984) found that the impact of an additional $0.50 co-payment on a Medicaid population results in a decrease in their prescription drug utilization. Using similar data, Reeder and Nelson (1985) examined the effect of this co-payment change (an addition of a $0.50 co-payment to Medicaid) within 10 specific drug categories. They found the effect of increased co-payment on monthly prescription drug expenditures varied among therapeutic groups. Little change in monthly expenditures occurred in the analgesic and hypnotic drug groups, while the cardiovascular, diuretic, and psychotherapeutic drug groups had significant declines in both the level and growth of monthly expenditures post co-payment increase. Thus, even nominal changes in cost sharing may affect the utilization of key medications.

The inability to fill prescriptions could also be a result of other restrictions that States place on use of prescription drugs (such as prior authorization, preferred lists of drugs or mandatory generic substitution). Another cause for inadequate access to prescription drugs may be lack of transportation or lack of authorization to use mail service pharmacies.

Prescription drugs are particularly important to older people and physically disabled persons under age 65 because many have substantial needs for acute care as well as long-term care (Komisar, Hunt-McCool, and Feder, 1997/1998). For persons with chronic illnesses, not filling a needed prescription for treatment of a chronic disease could have severe health consequences, including adverse events and emergency department use (Soumeri et al., 1994). There is a paucity of information regarding medication access in the chronically ill/disabled population.

6.3 Data/Methods

This section presents a description of the data used in this analysis, defines the dependent and independent variables used, and describes our analytical methodology.

6.3.1 Data

This research uses survey data from 2,597 older persons and younger adults with physical disabilities who were community-residing Medicaid beneficiaries receiving HCBS in six

States—Alabama, Kentucky, Maryland, Wisconsin, Washington, and Michigan (Snell et al., 2005).[12] The States were chosen to represent a range of developed and developing HCBS systems. The survey was conducted by Mathematica Policy Research, Inc., as part of a larger CMS-funded study of Medicaid HCBS (Wiener, Tilly, and Alecxih, 2002) and sampled Medicaid beneficiaries using home health, State plan personal care, and HCBS waiver services. The survey was fielded between May 2003 and June 2004, with the sample allocated proportionally among States based on the number of HCBS beneficiaries. The survey was conducted primarily through telephone interviews using a computer-assisted telephone interviewing system with some in-person interviews. Because of the major policy interest in differences between older and physically disabled persons under age 65, the survey sample was stratified by age (under 65 versus 65 or over). The overall survey response rate was 72 percent, with 28 percent of respondents using a proxy.

In our analysis of examining medication access issues, we examine the entire sample n=2,597. In the multivariate analysis, we included indicator variables for those missing responses to variables, and, thus our sample size is $n = 2,597$. The sample responding to the mental health scale is smaller, mostly because these questions were not asked of proxy respondents, and thus, for that bivariate analysis involving the mental health scale, our $n = 1,895$.

6.3.2 Dependent Variables

In this study we examined if the person takes medications and then conducted separate analyses regarding medication-taking behavior for persons taking medications. First, we examined variations in the probability of taking medication. This variable is defined as taking prescription or over-the-counter medications on a regular basis. Next, we examined factors associated with the following three questions: (1) Did the respondents have someone help them or remind them to take medications? (medication help); (2) Did the respondents have difficulty taking medications because no one was available to help them? (medication difficulty); (3) In the past month, did respondents not obtain medications they thought they needed? (unmet need). Indicator variables were created for these three questions with yes equaling one and no equaling zero.

6.3.3 Independent Variables

We examined several variables that could be associated with medication taking behavior including: (1) health and mental health status, (2) satisfaction and autonomy with HCBS, (3) facilitators and barriers to accessing drugs such as transportation issues, and (4) demographics.

The Satisfaction with Paid Personal Assistance Scale was used to examine whether satisfaction with paid personal assistance services was associated with medication use (Khatutsky, Anderson, and Wiener, 2006). Satisfaction with home-based personal care may indicate better connection and experience with the health and social service systems and may result in a positive predisposition toward the health care system. The items from this scale measure overall satisfaction, as well as interpersonal aspects of care provided by paid caregivers,

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[12] Wisconsin home care beneficiaries residing in counties participating in the Family Care demonstration were excluded from the sampling frame.

such as communication with paid caregiver, how problems get resolved, how often paid caregivers get impatient or angry, and how well paid caregivers are trained. The scale included an 8-item composite and ranges from 0 to 100 with a mean of 93.9 (standard error = 11.2) and Cronbach's (1951) alpha of 0.7. A further description of the scale and its development can be found in Khatutsky, Anderson, and Wiener (2006).

We also include a measure of consumer autonomy to examine the association between involvement in one's own home care services and access to medications. This could reflect several important personal characteristics, such as self-efficacy and self-directedness, that may influence medication taking behavior. This is measured by an indicator variable for those who decide when and how home care services are done most or all of the time equaling one, all else equaling zero.

Health status measures include self-reported health status, which has five levels including excellent, very good, good, fair, and poor. In the multivariate models we include two indicator variables—one for fair or poor health status, and one for good or very good health status, leaving excellent health status as the reference category. Functional status measures include the number of limitations in six activities of daily living (ADLs), which are the person needs help with bathing, dressing, eating, transferring, walking across the room, and toileting. While the survey also collected data on number of instrumental activities of daily living (IADLs), these measures include managing medications which is one of our dependent variable, and thus we exclude IADLs from our analysis. As mental health status is an important factor in health behavior and improved mental health may improve compliance while lower mental health status is sometimes associated with poor health and health behavior, we also include a mental health scale consisting of five questions from the SF-36® (Ware et al, 1993) to assess anxiety and depression. The scale varies from 0 to 100 with higher scores indicating better mental health status.

Impediments to medication access and use include lack of transportation to acquire new medications as well as poor eyesight to read and use drugs appropriately. We examine measures of unmet transportation need as an indicator variable that equals one if the person was unable to go where they wanted because of lack of transportation many times in the past month. We also created an indicator variable for the use of special transportation in the past month to signal increased access. Poor eyesight is measured through an indicator variable if the person reported a lot of trouble seeing.

Demographic variables include age, sex, and race. For the bivariate analysis we categorized age into five levels (under 45, 45 to 64, 65 to 74, 75 to 84, and 85 and over). In the multivariate models, we include age as a continuous variable and also include the square of age to capture non-linearities as we expect the increased probability of unmet need or need for assistance in medication taking to increase with age, but not in a direct one-to-one fashion.

As education is an important predictor of health behavior, we include whether a person had a high school education or less (compared to those with at least some college education). Being married or living with a partner may increase a person's ability to access medications, and thus we include a measure of marital/partner status in our analysis. People in rural areas may have more difficulty accessing prescription drug and thus we include an indicator for those residing in a metropolitan statistical area.

6.3.4 Methods

There is sparse previous research or theories to guide our models on factors associated with non-financial access to medication issues. Thus, we first present exploratory analyses using bivariate statistics to compare the independent variables by the dependent variables (all of which are indicator variables). To test for statistically significant differences, chi-squared test statistics are used for categorical independent variables and the Wald test (Rao and Scott, 1981) for continuous independent variables (such as age).

To gain an overall picture of the associated factors in each of the four medication access variables—taking medications on a regular basis, needing help in taking medications, difficulty in taking medications without assistance, and unmet medication needs, we also perform multivariate probit analysis, which is used when the dependent variable is dichotomous and a high percentage of cases are one response category. Probit analysis is similar to logistic regression models but allows the marginal effects to be interpreted as the effect on the probability of the outcome instead of an odds ratio. As the coefficients from non-linear modes are not easily interpretable, we present the marginal effects for each variable (indicator variables present the effect of changing from 0 to 1). The marginal effects were calculated at the means of the sample and allow ease in interpretation in that they represent the percentage point change or change in probability. All analyses use survey estimation procedures in Stata® (StataCorp LP, 2003) which incorporates the complex survey sampling design in the statistical procedures.

Finally, many of the health status, barrier, satisfaction, and choice variables are potentially correlated with unobserved variables (or themselves are choice variables) in our models which will bias the results, we also perform reduced form models that exclude these variables. In addition, endogeneity or feedback issues may bias our results. For example, a person who is unable to obtain a needed prescription drug could lead to the person's health deteriorating or a low self-reported health. On the other hand, someone with lower health status may have not been able to access a bus or call in a prescription refill, leading to being unable to obtain a needed prescription. Thus, we also present a reduced form (demographics only) model (Model 2) as comparators to the full models (Model 1). As these models are exploratory and not hypothesis testing, this provides a baseline for future research.

For all estimates we used probability weights adjusted for non-response and post-stratification. For the multivariate models we included State-level fixed effects to capture unobserved heterogeneity across States such as differences in Medicaid prescription drug programs as well as HCBS programs. All six States have prior authorization and preferred drug list programs. In addition, they all charge $1 for generic drugs and up to $3 for brand drugs. What is not known is often pharmacists collect these co-payments. While according to the Social Security Act a pharmacist may not refuse to dispense a medication to a Medicaid patient because they are unable to pay, the inability to pay may be a psychological barrier to certain beneficiaries. As we have no measure of stringency of these drug utilization management programs, the State fixed effects will attempt to capture this variation.

6.4 Results

In this population of Medicaid HCBS beneficiaries, nearly 95 percent of Medicaid beneficiaries receiving Medicaid HCBS took medications (***Table 13***) on regular basis. Of those

Table 13
Descriptive statistics by medication use and medication taking behaviors (column percents)

	Medication Use			Assistance needed in taking medications (Medication Help)			Difficulty in taking medications because no assistance available (Medication Difficulty)			Did not get needed medication(s) in past month (Unmet Need)			Overall
	Yes	No		Yes	No		Yes	No		Yes	No		
Overall	94.9	5.1		64.5	35.5		3.6	96.4		6.1	93.9		
Married or living with partner	16.3	10.1		17.9	13.3		15.23	16.3		16.9	16.5		15.9
Male	28.2	44.6	***	32.2	23.3	***	31.2	29.1		23.5	28.7		29.0
Age			***			***						***	
age <44	19.5	54.3		24.3	18.0		19.3	22.2		22.6	20.1		22.1
45 to 64	31.0	18.3		27.8	35.0		40.8	29.8		48.5	29.9		30.3
65 to 74	19.6	8.9		17.7	21.2		19.6	18.9		14.2	19.8		18.9
75 to 84	19.5	12.0		19.0	18.8		13.2	19.2		12.8	20.0		19.0
85 and over	9.9	6.6		11.2	7.1		7.4	9.8		1.74	10.2		9.7
High school education or less	77.7	87.7	*	80.2	73.2	***	63.0	78.2	***	57.8	78.9	***	77.7
Four years of college	19.2	11.9		17.0	23.2	**	34.3	18.7	**	34.6	16.1	***	19.2
More than 4 years of college	3.1	0.3	**	2.9	3.6		2.3	3.1		7.6	2.8	***	3.1
Income less than 20,000	98.9	97.6		99.1	98.5		97.0	99.0		96.8	99.0	*	98.9
African-American	16.1	15.9		17.4	13.8	*	13.2	16.6		17.1	16.0		16.1
Live in Metropolitan Statistical Area	66.5	74.5		69.1	63.2	**	71.2	66.9		65.2	66.7		67.0
At least one unmet transportation need	36.4	28.1		31.9	44.5	***	82.6	34.7	***	74.6	33.6	***	36.4
Use special transportation	24.7	25.1		22.8	28.2	**	45.6	23.9	***	35.7	24.0	**	24.7
A lot of trouble seeing	22.5	17.3		26.7	14.7	***	31.2	22.1		27.8	22.3		22.5

(continued)

Table 13 (continued)
Descriptive statistics by medication use and medication taking behaviors (column percents)

	Medication Use			Assistance needed in taking medications (Medication Help)			Difficulty in taking medications because no assistance available (Medication Difficulty)			Did not get needed medication(s) in past month (Unmet Need)			Overall
	Yes	No		Yes	No		Yes	No		Yes	No		
Any informal care last week	44.1	46.1		47.0	38.6	***	56.9	43.6	*	50.2	43.7		44.0
Consumer choice all of the time	24.0	33.3		27.2	26.5	***	43.7	23.3	***	21.0	24.2		24.0
Health Status			***									*	
Excellent	3.1	16.6		3.8	4.1		1.6	4.0		0.00	3.4		3.9
Very Good	9.3	16.6		10.2	9.1		6.5	9.9		5.0	9.6		9.8
Good	19.4	27.9		18.6	22.2		14.2	20.2		19.4	19.4		19.9
Fair	28.8	24.5		28.2	31.8		34.6	28.3		24.6	29.2		28.5
Poor	39.3	14.5		39.2	35.5		46.3	37.7		50.8	38.5		37.9
Number of ADLs	2.6	2.9		3.3	1.3	***	2.7	2.6		2.4	2.6		2.2
Satisfaction Scale	95.0	93.8		94.1	93.3		83.5	94.2	***	86.0	94.4	***	94.0
Mental Health Scale	53.5	69.5	***	52.8	54.4		41.3	54.0	**	38.2	54.8	***	54.2
n	2464	133		1675	922		2503	94		2438	159		21597

* Statistically significant at p<0.1;

** Statistically significant at p<0.05;

*** Statistically significant at p<0.01.

who took medications, 64.5 percent had assistance with taking their medications. Only 3.6 percent have difficulty taking medications because no one was available to help and only 6.1 percent did not obtain medications that they thought they needed in the past month.

Few differences exist between those who use medications and those who do not with the exception of health status and sex. The mental health scale is also significantly lower for those taking medications compared to those not taking medications. This lower mental health status with the self-reported health status indicates the overall lower health of those who take medications in this population.

Medicaid beneficiaries who had assistance with taking medications are more likely to be an African American males with a high school education or less living in a metropolitan statistical area (MSA). People with unmet transportation needs are more likely to need assistance in taking their medication while those who use special buses, vans, or other transportation are less likely to need assistance in taking their medications. The need for help in taking medications is associated with poor vision. On the other hand, those needing assistance may be finding the help they need from informal care and they have higher probability than those who do not need assistance of involvement in their personal care choices all of the time, although the difference is not great in absolute terms. Finally, while needing assistance with medications may not be associated with self-reported health status, persons who had assistance in medication taking have significantly more ADL problems than those who do not.

Very few demographic factors, with the exception of education, are associated with difficulty in taking medications. Transportation again plays a key role; respondents with difficulty taking medications are significantly more likely to have unmet transportation needs and are more likely to use special transportation. Autonomy appears to have an effect; people who are involved all the time in their personal care decisions and people who are less satisfied with their personal care are more likely to have medication difficulties. This finding about autonomy could be the result of confounding not controlled in the bivariate analysis as well as reverse causation described earlier in the methods section. People who receive informal care appear to have a higher likelihood of difficulty taking medications which could reflect endogeneity or confounding again not controlled in bivariate analysis. Finally, Medicaid home care beneficiaries with difficulty taking medications have a lower mental health status than those without difficulty taking medications.

Medicaid home care beneficiaries who report an unmet need for medications are more likely to be younger and have a higher education than those not reporting an unmet need. Again, transportation is a key factor in unmet need as a higher percentage of respondents with an unmet need for medications report an unmet transportation need and are more likely to use special transportation. The differential in health status between HCBS users with unmet medication needs and those without unmet needs is striking, with 50 percent of those with unmet medications needs reporting poor health status and a poorer mental health status as well. In addition, those with unmet medication needs are less satisfied with their paid home care help.

The primary reasons for not receiving a medication (or the reason for the unmet medication need) are presented in ***Table 14***. Despite their Medicaid coverage, the main cause for unmet need is problems of financial access, including that the medications cost too much or the

Table 14
Reason for unmet medication need

	Percentage	Lower CI	Upper CI
Too sick/frail /disabled/nobody to go for me	9.03%	4.83%	16.23%
Transportation problems	9.75%	5.55%	16.59%
Costs too much/couldn't afford	53.04%	44.07%	61.81%
Plan wouldn't pay for prescription	9.97%	5.71%	16.84%
Too busy to take time	1.11%	0.15%	7.63%
Hours inconvenient	4.54%	1.93%	10.3%
Thought I'd get better without it	1.31%	0.27%	6.15%
Other	1.35%	0.26%	6.72%
Pharmacy wouldn’t/couldn’t give appropriate dosage	2.07%	0.75%	5.61%
Ran out of prescription	3.69%	1.37%	9.56%
Forgot to get refill/prescription	0.86%	0.12%	6.02%
Didn’t want to take medicine	1.03%	0.14%	7.1%
Error in calling-in prescription	2.24%	0.64%	7.6%

NOTE: N= 161, weighted n= 3433

medications were not affordable (53 percent). Another financial barrier that causes unmet medication need is the plan not paying for the drug (nearly 10 percent). The secondary reasons for not receiving a needed medication are other non-financial access issues including the beneficiary being sick, frail, disabled, having no one to obtain the drugs or no delivery service available, and transportation problems.

The multivariate probit models are presented in ***Tables 15-18***. The probability of a person taking medications on a regular basis are shown in ***Table 15***. Age and measures of health status increase the probability of taking medications on a regular basis. The indicator for the mental health scale missing, which occurs when a proxy answers the survey, is also strongly positively associated with taking medications on a regular basis.

The next model (***Table 16***) examines the probability of needing help in taking medications. In these models, being male significantly increases (7 to 10 percentage points—refer to marginal effects) the probability of needing assistance in taking medications in both Models 1 and 2. In Model 1, African American persons have a slight, approximately 1 percentage point, increase in the probability of needing help in taking their medications compared to all other races. An increase in the number of ADLs by one raises the probability of needing help taking medications by 9 percentage points. The only other health status measure that is significant in this model is having a lot of trouble with eyesight, which increases the probability of needing help taking medications by 11 percentage points. The mental health status missing significantly increases the probability of needing help by almost 25 percentage points. Since this variable is missing when a proxy person is responding to the survey, this may indicate the severity of the disability. Consumer autonomy is associated with an increased probability of needing assistance by 10 percentage points. Using special transportation is associated with lower probability of needing assistance in taking medications. When health status measures are

Table 15
Probit models: Probability person takes medication on a regular basis

(n=2597)

	Model I			Model II		
Variables	Coefficient	p-value	Marginal Effect	Coefficient	p-value	Marginal Effect
Male	-0.126	0.238	-0.011	-0.189	0.062	-0.019
African American	0.093	0.476	0.007	0.137	0.281	0.012
Income < 20000	0.386	0.461	0.042	0.328	0.437	0.038
Missing income	0.222	0.680	0.016	0.127	0.778	0.011
Age	0.048	0.000	0.004	0.068	0.000	0.006
Age-squared	-0.0003	0.004	-0.00003	-0.0005	0.000	-0.00005
Highest grade is high school	-0.340	0.021	-0.024	-0.355	0.012	-0.029
Missing education	-0.458	0.124	-0.055	-0.629	0.041	-0.096
Married or living with partner	0.014	0.934	0.001	0.099	0.529	0.009
MSA	-0.179	0.127	-0.014	-0.115	0.329	-0.011
Number of ADLS	-0.025	0.338	-0.002			
Mental Health Scale	-0.007	0.011	-0.001			
Missing mental health scale	-0.578	0.008	-0.061			
Satisfaction Scale	-0.007	0.208	-0.001			
Missing satisfaction scale	-0.608	0.227	-0.075			
Consumer choice all of the time	-0.121	0.267	-0.011			
Any informal care last week	-0.068	0.534	-0.006			
Unmet Transportation need	-0.023	0.829	-0.002			
Use special transportation	0.068	0.540	0.005			
A lot of trouble with eyesight	-0.063	0.603	-0.005			
Fair/Poor Health status	0.800	0.000	0.087			
Good/Very Good Health status	0.578	0.003	0.040			
State 1	0.245	0.183	0.017	0.253	0.154	0.020
State 2	-0.271	0.205	-0.028	-0.243	0.243	-0.028
State 3	-0.266	0.125	-0.024	-0.271	0.089	-0.027
State 4	-0.177	0.313	-0.016	-0.169	0.309	-0.017
State 5	-0.019	0.936	-0.002	-0.100	0.664	-0.010
Constant	0.839	0.375		-0.231	0.687	

Table 16
Probit models: Probability a person needs help taking medications

(n=2597)

	Model I			Model II		
Variables	Coefficient	p-value	Marginal Effect	Coefficient	p-value	Marginal Effect
Male	0.231	0.005	0.071	0.297	0.000	0.104
African American	0.376	0.000	0.109	0.288	0.001	0.099
Income < 20000	0.378	0.290	0.131	0.488	0.132	0.187
Missing income	0.556	0.135	0.148	0.403	0.232	0.134
Age	-0.031	0.022	-0.010	-0.076	0.000	-0.028
Age-squared	0.0002	0.029	0.0001	0.001	0.000	0.0002
Highest grade is high school	0.125	0.150	0.041	0.287	0.000	0.107
Missing education	0.215	0.371	0.064	1.008	0.000	0.262
Married or living with partner	0.162	0.096	0.050	0.300	0.000	0.103
MSA	-0.002	0.976	-0.001	0.114	0.112	0.042
Number of ADLS	0.298	0.000	0.095			
Mental Health Scale	-0.001	0.698	-0.0002			
missing mental health scale	0.905	0.000	0.246			
Satisfaction Scale	0.003	0.279	0.001			
Missing satisfaction scale	0.789	0.021	0.199			
Consumer choice all of the time	0.341	0.000	0.102			
Any informal care last week	-0.054	0.459	-0.017			
Unmet Transportation need	-0.107	0.148	-0.034			
Use special transportation	-0.186	0.020	-0.061			
A lot of trouble with eyesight	0.382	0.000	0.112			
Fair/Poor Health status	0.025	0.913	0.008			
Good/Very Good Health status	0.065	0.781	0.021			
State 1	0.304	0.005	0.089	0.322	0.001	0.110
State 2	0.366	0.014	0.103	0.197	0.119	0.068
State 3	0.370	0.002	0.113	0.112	0.263	0.040
State 4	0.656	0.000	0.192	0.515	0.000	0.178
State 5	0.276	0.065	0.081	0.156	0.234	0.055
Constant	-1.012	0.105		1.311	0.004	

Table 17
Probit models: Probability person has difficulty taking medications

(n=2597)

	Model I			Model II		
Variables	Coefficient	p-value	Marginal Effect	Coefficient	p-value	Marginal Effect
Male	0.101	0.468	0.003	0.072	0.570	0.005
African American	-0.110	0.526	-0.003	-0.087	0.554	-0.006
Income < 20000	-0.592	0.172	-0.033	-0.531	0.218	-0.053
Missing income	-0.432	0.359	-0.010	-0.466	0.320	-0.022
Age	0.009	0.692	0.000	0.028	0.164	0.002
Age-squared	-0.00005	0.795	-0.000002	-0.0003	0.115	-0.00002
Highest grade is high school	-0.357	0.012	-0.015	-0.300	0.018	-0.024
Missing education	perfect predictor, dropped					
Married or living with partner	-0.094	0.560	-0.003	-0.118	0.444	-0.007
MSA	0.130	0.341	0.004	0.140	0.283	0.009
Number of ADLS	0.034	0.313	0.001			
Mental Health Scale	-0.004	0.125	0.000			
Missing mental health scale	-0.161	0.461	-0.005			
Satisfaction Scale	-0.015	0.000	-0.0005			
Missing satisfaction scale	-1.855	0.000	-0.024			
Consumer choice all of the time	0.549	0.000	0.025			
Any informal care last week	0.073	0.573	0.002			
Unmet Transportation need	0.845	0.000	0.039			
Use special transportation	0.336	0.008	0.013			
A lot of trouble with eyesight	0.092	0.478	0.003			
Fair/Poor Health status	0.042	0.927	0.001			
Good/Very Good Health status	-0.122	0.794	-0.004			
State 1	0.134	0.492	0.005	0.136	0.421	0.010
State 2	-0.374	0.197	-0.008	-0.342	0.161	-0.017
State 3	-0.147	0.473	-0.005	-0.326	0.078	-0.020
State 4	-0.079	0.692	-0.003	-0.131	0.467	-0.008
State 5	-0.235	0.413	-0.006	-0.341	0.197	-0.018
Constant	-0.682	0.527		-1.652	0.018	

Table 18
Probit models: Probability person has unmet medications needs

(n=2597)

	Model I			Model II		
Variables	Coefficient	p-value	Marginal Effect	Coefficient	p-value	Marginal Effect
Male	-0.126	0.310	-0.005	-0.202	0.080	-0.019
African American	0.109	0.453	0.005	0.096	0.492	0.010
Income < 20000	-0.422	0.293	-0.027	-0.638	0.103	-0.094
Missing income	-0.558	0.205	-0.016	-0.813	0.058	-0.047
Age	0.035	0.088	0.002	0.060	0.001	0.006
Age-squared	-0.0003	0.055	-0.00002	-0.001	0.000	-0.0001
Highest grade is high school	-0.462	0.000	-0.027	-0.501	0.000	-0.062
Missing education	-0.887	0.034	-0.018	-1.111	0.005	-0.047
Married or living with partner	0.066	0.653	0.003	-0.013	0.921	-0.001
MSA	-0.056	0.650	-0.003	-0.005	0.964	0.000
Number of ADLS	0.031	0.293	0.001			
Mental Health Scale	-0.009	0.000	-0.0004			
Missing mental health scale	-0.808	0.000	-0.028			
Satisfaction Scale	-0.017	0.000	-0.001			
Missing satisfaction scale	-1.784	0.000	-0.032			
Consumer choice all of the time	-0.036	0.769	-0.002			
Any informal care last week	0.006	0.960	0.000			
Unmet Transportation need	0.626	0.000	0.035			
Use special transportation	0.143	0.187	0.007			
A lot of trouble with eyesight	0.018	0.879	0.001			
Fair/Poor Health status	5.426	0.000	0.386			
Good/Very Good Health status	5.524	0.000	0.965			
State 1	0.468	0.006	0.031	0.408	0.011	0.052
State 2	-0.094	0.712	-0.004	-0.049	0.831	-0.005
State 3	0.249	0.191	0.012	0.088	0.611	0.009
State 4	0.096	0.622	0.004	0.052	0.773	0.005
State 5	-0.243	0.386	-0.009	-0.344	0.189	-0.027
Constant	-5.555	0.657		-1.896	0.003	

removed, age, education, and residence in an metropolitan statistical area (MSA) become significant. Age and education may be correlated with unmeasured health status and health behavior variables while residence in an MSA may be associated with transportation or other barriers to care.

Very few covariates are significantly associated with the probability a person has difficulty in taking medications (***Table 17***). Increased satisfaction lowers the probability of having difficulty in taking medications while unmet transportation needs increase the probability of having difficulty. Note that the satisfaction result is opposite of the bivariate results suggesting confounding could exist in the bivariate analysis. Using special transportation services is also associated with increased difficulty in taking medications which may be due to correlation with unobserved severity of disability.

In examining the probability of unmet medication needs, we find health status is an important factor (***Table 18***). In Model 1, fair/poor self-reported health status and lower mental health scale have large significant positive association with unmet medications needs. This model finds that unmet transportation needs increases the probability of unmet medication needs by nearly 4 percentage points. Model 1 also finds that increasing the satisfaction with paid help by 10 points lowers the probability of unmet medications needs by 1 percentage point. With State-fixed effects being significant, some indirect evidence exists that State policies may be associated with unmet medication needs.

An unexpected result was that high school education or lower is associated with a decrease in the probability of unmet prescription drug need (lowering the probability by nearly 3 percentage points). Generally, increasing education increases the probability of positive health behavior, but in this context in may also increase awareness of lack of appropriate or needed care. Again, when health status measures are dropped from the model, age, which previously was not significant in Model 1, becomes a significant factor. Education results become stronger in Model 2 (after dropping potential endogenous measures) indicating some correlation with the health status, satisfaction, or autonomy measures.

6.5 Conclusion

Our results find that the unmet medication need in the Medicaid home and community-based care population is about the same as the overall Medicaid population in 2002 (6.3 versus 7.8 percent) (Kennedy et al., 2004). Most respondents with unmet need listed financial access as the primary reason. This is surprising because Medicaid coverage requires little or nominal out-of-pocket payments for prescription drugs and includes over-the-counter drugs if included on a prescription. More research is needed regarding the effects of Medicaid drug policy on access to care. Previous research has shown that prior authorization and mandatory generic substitutions has significant effect on beneficiaries' access to drugs (Cunningham, 2005). These results may indicate that nominal cost sharing (such as those used in Medicaid) could have an impact on this elderly and disabled population. In addition, the lack of coverage of over-the-counter medications may also affect the unmet medication need. As many important therapies are available over-the- counter (such as aspirin, non-steroidal anti-inflammatory, etc.), more research should examine access to these products. Future research should also examine the interaction of various State health policies affects the community and home-based population.

Persons with unmet medication need are more likely to be more severely disabled, the younger population, and persons with higher education. This high-need population should be examined more closely about possible consequences of this unmet medication need. Are they not obtaining needed chronic medications, are they declining to fill marginal medications that may not affect their health, or are they not purchasing over-the-counter drugs? Persons who lack access to medications already have lower health status and the lack of necessary therapies may have caused this lower health status or may contribute to further declines, but it is important to tease out the directionality of this effect.

The consistent effect of lack of adequate transportation on medication access in this study suggests that the importance of social services, such as those provided by Older Americans Act programs (42 *USC* 35). If other studies confirm the importance of transportation and access to special transportation, it will be important for policymakers to understand the interaction between these two programs.

Finally, increasing satisfaction with home care may have spillover effects on access to other health care services. As one increases satisfaction with home care services through better connecting them with the health and social service system, consumers may have less difficulty in accessing needed medications.

Although this study presents important issues regarding unmet medication needs in the aged and disabled population, several limitations exist. First, the survey was conducted in six States and may not be representative of the entire Medicaid population receiving HCBS. Second, as this is a point-in-time observational study, we cannot infer causality, but only describe associations. Finally, our measure of medication-taking behavior does not allow us to differentiate between not filling a prescription, not receiving a prescription, or not purchasing a needed over-the-counter medication.

This study highlights that the vast majority of older persons and younger adults with physical disabilities who are users of Medicaid HCBS report that they receive the medications they need and the help they need taking the medications. However, there is a small percentage of Medicaid home care beneficiaries that lack access to medication therapy. This group is quite fragile, with poor physical and mental health. As State governments address budget shortfalls through cost containment measures in Medicaid, it is important to understand how this may affect access to medications for the elderly and persons with disabilities. Moreover, with the implementation of the new Medicare prescription drug benefit, it is important to monitor the impact of the program on older people and physically disabled persons under age 65 who face special problems beyond financial issues in accessing prescription drugs (Huskamp and Keating, 2005).

CHAPTER 7
UNDERSTANDING THE RELATIONSHIP BETWEEN MEDICAID HOME AND COMMUNITY BASED SERVICES AND MEDICAID INPATIENT, OUTPATIENT, PRESCRIPTION DRUGS AND DME USE

Federal and state policymakers are concerned about the health care use of older people and physically disabled persons under age 65 from at least two different perspectives. First, while there is variation across individuals, people with disabilities, on average, have higher use of health care services than persons without disabilities (Alecxih, Corea, and Kennell, 1995). In addition to higher inpatient and institutional use, persons with disabilities also have higher use of outpatient services, prescription drugs, and durable medical equipment. Using a definition of disability based mainly on functional limitations drawn from the 1996 Medical Expenditure Panel Survey, DeJong et al., (2002) found that the 16 percent of persons meeting that definition accounted for about 34 percent of all adult visits to a physician and 41 percent of all adult prescriptions (including refills). In addition, older persons have higher utilization of health care services than younger persons.

As a result of their high use of services, older people and persons with disabilities account for a disproportionate share of Medicaid spending. Although they only represented 25 percent of Medicaid enrollees in 2003, they accounted for 70 percent of Medicaid expenditures (Kaiser Commission on Medicaid and the Uninsured, 2006). In 2003, estimated Medicaid spending per child was $1,410, compared to $11,659 per disabled enrollee and $10,147 per elderly enrollee.

Second, despite their high use of health care services, persons with disabilities face greater barriers to access than does the rest of the population (DeJong et al., 2002). Persons with disabilities often complain that physician offices and other health care facilities are not easily accessible (Gans, Mann, and Becker, 1993). In addition, primary care settings often have physical, social, and communication barriers (Bockenek et al., 1998) that prevent persons with disabilities from obtaining needed care. The *2005 Surgeon General's Call to Action to Promote the Health and Wellness of Persons with Disabilities* (2005) notes that the preventive health care needs (e.g. screenings) of persons with disabilities are largely unmet.

These problems of high utilization because of poorer overall health and unmet needs because of inability to obtain needed health care may be particularly characteristics of older people and physically disabled persons under age 65 receiving Medicaid-funded home and community based services (Khatutsky et al., 2006). Because of Medicaid coverage rules, this population is quite severely disabled, which may increase their need for and use of services or may increase access barriers that may reduce their ability to obtain those services. Medicaid home and community-based services may function to either increase or decrease the use of services by disabled Medicaid beneficiaries.

On the one hand, some research suggests that personal care services (such as help with eating, bathing and dressing) can have a positive impact on health and should reduce the need for services. In a qualitative study, Nosek (1993) reported that physicians, physical therapists, occupational therapists, social workers in five rehabilitation hospitals believed that paid personal care could reduce hospital stays, threats to safety, poor nutrition and poor personal hygiene. In a small study of individuals with high level tetraplegia, Prince, Manley and Whiteneck (1998) found that clients who used consumer-directed care had better health outcomes, with fewer rehospitalizations and fewer preventable complications.

Other researchers have noted the consequences of not having enough personal assistance. Komisar, Feder and Kasper (2003) found that people with disabilities who have unmet needs for help with ADLs have higher rates of not being able to bathe or shower, not being able to put on clean clothes, falling, wetting or soiling themselves, and going hungry. Similarly, LaPlante et al. (2004) found that people with disabilities who have unmet ADL needs have higher rates of weight loss, dehydration, falls, and burns than persons with disabilities without unmet ADL needs. Consequently, greater unmet need potentially may lead to greater health care utilization.

On the other hand, although the general goal of many home and community-based services is to reduce Medicaid spending, home and community-based services could increase utilization by better linking people with disabilities to the service system. After all, home and community-based services typically involve quasi-medical personnel visiting people with disabilities on a regular and fairly frequent basis. These visits may result in identification of unmet medical problems and may connect persons with disabilities with the transportation or other help they need to access services. The case management component of many HCBS programs may particularly help with this identification of additional needed services (Wiener, Tilly and Alecxih, 2002).

This paper addresses the role of home and community-based services in the use of other Medicaid services. Specifically, it analyzes whether the use of different types of home and community-based services are associated with the use of inpatient services, a broad array of outpatient services, prescription drugs and durable medical equipment (DME) needed to maintain their health. To address this question, we analyze a survey of Medicaid home and community-based services beneficiaries in Alabama, Kentucky, Washington, and Wisconsin.

7.1 Conceptual Framework and Background

In their classic formulation, Aday and Andersen (1974) posit that enabling factors such as insurance and other facilitators of access to care such as family, friends, and transportation are important for receiving needed health care services. Persons with serious functional limitations usually qualify for Medicaid, which provides funding needed for outpatient and prescription drugs and DME, but they may be lacking in familial, transportation, and other personal resources needed to take advantage of Medicaid services. Home and community-based services may be one means for aiding such persons to receive Medicaid funded services.

States may offer Medicaid-financed home and community-based services through three different mechanisms: state plan home health, state plan personal care, and home and community-based services waivers (Wiener, Tilly, and Alecxih, 2002). States' use of these different mechanisms varies greatly (Kitchener, Carrillo, and Harrington, 2004). In addition, states vary on Medicaid eligibility rules for and extent of benefits offered. In fiscal year 2005, expenditures for these three sets of services totaled $34.8 billion, with two-thirds of the spending on waiver services, mostly for persons with intellectual disabilities/developmental disabilities (Burwell, Sredl, and Eiken, 2006).

Federal law requires states to offer state plan home health services to all individuals entitled to nursing home care. These services consist of nursing, physical, speech and occupational therapies, and home health aide services. For other Medicaid eligibles, these services are optional, and states may vary the amount, scope, and duration of benefits as long as they are sufficient to reasonably achieve their purpose (Wiener, Tilly, and Alecxih, 2002).

States have had the option to offer personal care services as a Medicaid state plan benefit since 1975 (Le-Blanc, Tonner, and Harrington 2001). Personal care services involve assistance with activities of daily living, such as eating, bathing, and dressing. As of fiscal year 2005, 37 states offer this benefit (Burwell, Sredl, and Eiken, 2006).

Since 1981, states have been allowed to request waivers (known as home and community-based services waivers or 1915(c) waivers for the provision of the federal Social Security Act authorizing these waivers) of certain federal Medicaid requirements for people who meet the nursing home level of care criteria so that they may obtain home and community-based services. These waivers relax requirements such as providing services statewide and for all eligibility groups in a state. These waivers allow states to provide a broader array of less medically-oriented services not usually covered by Medicaid that facilitate community living, including but not limited to respite care, adult day services, transportation, meals, training, and home modifications (Wiener, Tilly, and Alecxih, 2002). All states except Arizona (which has a research and demonstration waiver) have home and community-based services waivers.

Drawing on Andersen and Newman's (1973) individual and social determinants of medical care, we posit that Medicaid utilization is a function of Medicaid home and community-based services, individual, and state characteristics), where:

- Medicaid Home and community-based services include three dummy variables for state plan personal care, state plan home health, and home and community-based services waivers.

- Individual characteristics include demographic, health and health status, and social characteristics.

- Dummy variables for each state to capture a wide range of characteristics about each state.

All persons in the sample had at least one of the three types of HCBS. This study predicts the marginal effect of having each of the three types of HCBS among the users of each respective HCBS in the data. We use this calculation to show the difference in each dependent variable of having versus not having each type of HCBS.

We hypothesized that availability of home and home and community-based services will be associated with lower inpatient utilization and higher utilization of a broad array of outpatient services and prescription drugs and DME by facilitating access to those services. We also hypothesized that the net number of claims for prescription drugs and DME may either increase or decrease as a result of home and community-based services. Utilization may increase because some needs may not be being met adequately, but they may also decrease because some prescription drugs may be duplicative or unnecessary and additional medical attention may reduce their use.

Because service utilization patterns may differ for younger people with physical disabilities between the ages of 21 to 64 and for older people age 65 and over, we present all analyses for the total sample and then separately for subgroups of younger persons with disabilities and older adults.

7.2 Data

For this study we used a combination of a survey of beneficiaries receiving Medicaid home and community-based services and Medicaid claims data. The final study sample included 1,508 Medicaid home and community-based services survey respondents in Alabama, Kentucky, Washington and Wisconsin. These persons were matched with 12 months of Medicaid claims derived from CMS's Medicaid Statistical Information System to obtain 18,050 person-month observations across the four states.

7.2.1 Survey

Survey data was collected from 1,780 community-residing Medicaid beneficiaries receiving home and community-based services in four states—Alabama, Kentucky, Washington, and Wisconsin. (Snell, Zhao, Lu, Potter, and Ciemnecki, 2005). The states were chosen to represent a range of "developed" and "developing" home and community-based services systems. The survey was conducted by Mathematica Policy Research, Inc., as part of a larger CMS-funded study of Medicaid home and community-based services (Wiener, Tilly, and Alecxih, 2002). The survey was fielded between May 2003 and June 2004, with the sample allocated proportionally among states based on the number of home and community-based services beneficiaries in each state. Because of the major policy interest in differences between older people and younger persons with physical disabilities, the survey sample was stratified by age (younger than 65 years of age vs. 65 years of age or older).

Respondents participated in the survey directly or via proxy (paid and unpaid caregivers) and included participants living in their own homes and residents of assisted living facilities and other group settings. The survey, which took about 36 minutes to complete, was conducted primarily through telephone interviews using a computer-assisted telephone interviewing (CATI) system for 95 percent of the respondents with the remaining 5 percent obtained through in-person interviews. The overall survey response rate was 72 percent, with 28 percent of respondents using a proxy. Most of the proxy responses were provided by unpaid caregivers.

7.2.2 Claims Data

The Medstat Group obtained Medicaid eligibility and claims files through CMS's Medicaid Statistical Information System (MSIS) for each sample state.[13] These files contain Medicaid expenditures organized by site of service (inpatient, other institutional, outpatient services, and prescription drug and durable medical equipment) and contain eligibility data on consumers (periods of eligibility, dual eligibility with Medicare, and receipt of cash assistance). Medstat matched respondents from the survey data with one year of their Medicaid claims, spanning a period 6 months before and after they were surveyed. The survey month was counted as one of the 6 pre-survey months. These claims are dated by date of service, though claims payment and state processing of MSIS claims can lag dates of service. Only 368 of 601 survey respondents (56.4 percent) in Washington gave permission to have their survey data linked to claims, resulting in a final survey sample of 1,547 respondents available for matching to claims across the four states.[14]

7.2.3 Development of Final Sample

To develop our final sample for analysis, we deleted two respondents from Alabama for whom we did not have at least 10 months of eligibility because we did not receive the last quarter of the state's eligibility file in time for the analysis. The match rate to claims data averaged approximately 99 percent across the four states in the analysis, resulting in 1,508 persons with claims totaling 18,050 person-month observations.

7.2.4 Dependent and Independent Variables

Dependent Variables

To analyze the effects of HCBS on the use of non-institutional Medicaid services, we developed four dependent variables for use in the study—number of inpatient discharges, any Medicaid outpatient service use, any prescription drug and durable medical equipment use, and the number of monthly claims for prescription drug and durable medical equipment use (DME).

To measure inpatient service utilization, we developed a count variable indicating the number of inpatient discharges. We found discharge data to be more reliable than a count of inpatient days because of problems in State reporting encounter data and the large proportion of dual eligibles for whom Medicare pays for most of the hospital stay (except for the Part A deductible).

To measure any Medicaid outpatient service use, we created a dummy variable for the use of any medical services (e.g. physician, dentist, nurse, other practitioners, outpatient

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[13] Mathematica also surveyed persons in Maryland and Michigan, but we were not able to obtain needed Medicaid claims data from Maryland in time to conduct the study. Michigan uses a capitated payment system that does not collect information on individual service utilization. Wisconsin home care beneficiaries residing in counties participating in the Family Care demonstration were excluded from the sampling frame.

[14] We found no differences on important factors between those respondents who did and did not give their permission.

hospital/clinic, lab/X-ray, and other non-HCBS services), capitated services (e.g. HMOs, prepaid health plans, primary care case management), social services (transportation, targeted case management, and rehabilitation services), and any expenditures for the Medicare outpatient deductible and coinsurance. A monthly observation was coded 1 for persons who used any of these services during that month and 0 if they did not use services.

To measure Medicaid prescription drug and DME use, we created a dummy variable to measure any use of prescription drugs and DME. The variable was coded 1 if there was prescription drug or DME use and 0 if there was no use. We also created a continuous variable to indicate the number of claims for combined prescription drug and DME use. This variable was coded zero if there was no use in a person-month observation, and coded with the actual number of claims filed during the month if there was positive use of prescription drugs or DME. The mean for persons with any use of prescription drugs and DME was 8.4 claims per month.

Independent Variables

Independent variables were grouped into four domains:

Use of Home and Community-Based Services. We developed separate person-month dummy variables for receiving state plan personal care, state plan home health, and the following home and community-based services waiver services: residential services, personal care, respite care, adult day services, transportation, home delivered meals, and a combination variable for nursing, therapies, training, environmental modifications and supplies, and "other services" where service use was too low to include the individual service separately. Each dummy variable is coded as 1 denoting receipt of the respective type of HCBS and 0 for receipt of HCBS in general, but not the respective type of HCBS. We also created a dummy variable for use of any of type of waiver service for use in calculating the marginal effect of waiver service use.

Demographic characteristics. We developed dummy variables for age groups, gender, and race. Income was not included as a variable because all survey respondents were very low-income Medicaid beneficiaries with little variation across the study sample. We did include indicators of dual eligibility for Medicare and Medicaid and receipt of cash assistance, principally the Supplemental Security Income program.

Health and functional status. We developed measures of self-reported health status, number of limitations in six activities of daily living (ADLs) (bathing, dressing, eating, transferring, walking across the room, and toileting), and number of limitations in four instrumental ADLs (IADLs) including cooking, managing medications, shopping, and doing light housework. We also created a composite of these ADL/IADL items that combined responses about unmet needs for ADL and IADL assistance, a count variable ranging from 0 to 10. Additional health status indicators included any prior nursing home use, any recent pain, any pressure sores, and any bladder/bowel incontinence. A variable for proxy survey respondent was used to control for cognitive impairment in the sample population.

Social characteristics and residence. We developed dummy variables for any social involvement and participation in the last week, whether living in a group setting such as assisted living facility or adult foster home, and state of residence. Our data agreements with the states in the sample prohibit us from identifying individual states in comparison to one another, so we identify states only by number.

7.3 Methods

First, we developed a negative binomial model to estimate the number of inpatient discharges. The negative binomial specification fit the discharge data better than a Poisson model because of slight overdispersion of the data (the mean and the variance were unequal). We estimated this model at the person level to make interpretation of the results easier to explain.

Next, we developed a Probit model to estimate the effect of HCBS on whether a respondent used any outpatient services, excluding HCBS. We also developed a 2-part model (Duan et al., 1983) to estimate the effects of HCBS on the probability of use and the number of claims for combined prescription drugs and DME. We did not develop an ordinary least squares (OLS) model to estimate the amount of non-HCBS outpatient services used because we were not able to develop a uniform measure for counting the many different types of outpatient services, such as visits, lab tests, and x rays. The unit of analysis in all of these regressions is person-months of use.

After estimating our models, we predicted the marginal effect of each of the three Medicaid HCBS variables (state plan personal care, state plan home health, and a dummy variable for use of any waiver services) on each of the four outcomes (number of inpatient discharges, any outpatient services, any prescription drug or DME claims, and the number of prescription drug or DME claims). The marginal effect was calculated as the difference in the mean predicted value of the outcome for using and then not using the HCBS service in question for only those persons in the data using that service. For example, to predict the marginal effect of HCBS state plan personal care on any outpatient services, we estimated the outcome for only those persons with state plan personal care. We then replaced this subgroup's monthly observations for any state plan personal care with a 0, and re-estimated the outcome. The difference between these two predicted values is the marginal effect of having any state plan personal care on any outpatient service use for this subgroup. We then estimated the standard error for these differences using a bootstrapping technique with 500 iterations.

We accounted for three statistical issues in the data to control for potential bias and increase the precision of our estimates. First, except for the regressions on the annual number of inpatient discharges, we controlled for the correlation across a person's monthly observations by estimating a panel data set. Second, for the regression on inpatient discharges, we did not include the variables for state plan home health and ever having been in a nursing home in recognition of the potential endogeneity with inpatient discharges. Third, we incorporated dummy variables for state of residence to control for other unobserved state-level factors that may confound the effect of HCBS in each state.

7.4 Results

We first present the descriptive results and then the multivariate results.

7.4.1 Descriptive Results

On a person-year basis, approximately 21 percent of respondents had any inpatient discharges, with a mean of 0.37 discharges across the entire sample (***Table 19***) and a range from 0 to 12 discharges. Younger persons with disabilities had a mean of 0.41 discharges, while older persons had a mean of 0.32 discharges. Of all persons with any discharges regardless of age, 68.4 percent had only one discharge, 26.4 percent had 2 or 3 discharges, and 5.2 percent had more than 3 discharges.

On a person-month level, approximately 79 percent of the overall sample had used outpatient services, with 84 percent of younger persons with disabilities and 75 percent of older persons having used these services. Approximately 90 percent of persons in the overall sample and both age groups had any prescription drug and DME use. In terms of the number of claims for combined prescription drug/DME use, persons in the overall sample had 8.4 claims per month, with some variance by age group. Younger persons with disabilities had 8.8 claims per month, while older persons had 8.0 claims per month.

Receipt of non-waiver Medicaid HCBS services is similar in the overall sample and both age groups, with about 22 percent use for state plan personal care and state plan home health services. Approximately 78 percent of observations had some form of waiver service use. Waiver personal care was the most used waiver benefit (64 percent), followed by the combination category of nursing, therapies, environmental modifications/supplies and other services (38 percent). Approximately 10-12 percent of observations had used transportation or meal services. The least used services are residential care, adult day, and respite care services, with about 5-7 percent use on a monthly basis.

By design, the sample was almost evenly split between those 65 years of age or older (56 percent) and those younger than 65 years of age (44 percent). Among young adults with physical disabilities, about 36 percent were under 44 years of age, and 64 percent were 45 to 64 years of age. For the older sample, about 24 percent were 85 years of age or older, and the rest were evenly split between younger than 75 years of age (38 percent) and 75 years of age or older (38 percent).

Overall, 26 percent of respondents were male but only 19 percent of older respondents were male, compared to 36 percent of younger adults with physical disabilities. In terms of race, 74.5 percent of respondents were Caucasian, 17 percent were African American, and about 9 percent were Asian and of other race, without much difference in racial distribution between young adults with physical disabilities and those 65 years of age or older.

Medicaid beneficiaries in all states must have substantial functional limitations to qualify for home and community-based services, which is reflected in the low levels of self-reported health and functional status. Overall, about 70 percent of the total sample reported fair or poor health, and only 3 percent reported excellent health (5 percent among young adults with physical disabilities and 2 percent among older adults).

Consistent with the self-reported health status, the survey sample was characterized by fairly high levels of frailty, which are similar among elderly and non-elderly subgroups. On average, survey respondents reported 2.9 limitations in ADLs, with younger persons with disabilities reporting slightly more (3.2) than older persons (2.7). The overall sample had 3.3 limitations in IADLs with little variance by age group. About 30 percent of our study sample received proxy help to fill out the survey (28 percent for younger persons with disabilities and 31 percent for older persons), further indicating the presence of physical or mental health limitations requiring assistance.

Approximately 19 percent of beneficiaries had been in a nursing facility at some previous point in time. Disturbingly, about 84 percent of persons reported some or a great deal of pain in the month prior to the survey, and approximately 10 percent of the sample (13 percent of younger persons with disabilities and 8 percent of older persons) reported having pressure sores within the 6 months prior to participating in the survey. Approximately 64 percent of the sample reported either bowel or bladder incontinence.

The number of unmet needs for personal assistance services is an indicator of whether beneficiaries think they are getting all the services they require. It is rather surprising that survey respondents reported less than one unmet ADL/IADL need (0.8) on average. Younger physically disabled beneficiaries reported higher unmet ADL/IADL needs (0.9) than older persons (0.7).

Social participation is another important measure of whether home and community-based services improve the life of their recipients by allowing them to maintain normal social activities despite their impairments. Overall, 72 percent of survey respondents (76 percent of younger persons with disabilities and 68 percent of older persons) reported getting out of the house for some kind of social or recreational activity at least once during the week prior to the survey.

Although most respondents lived at home, a significant minority lived in group settings. About 9 percent of respondents reported living in a group setting (8 percent for younger persons with physical disabilities and 10 percent for older persons). About 77 percent of the study respondents were dually eligible for Medicaid and Medicare (51 percent among younger persons with disabilities and 97 percent among those aged 65 and over). About 55 percent of the sample received some kind of cash assistance. ***Table 19*** also presents the distribution of survey respondents by their state of residence. Approximately 21 percent of the sample lived in Alabama, 44 percent in Kentucky, 23 percent in Washington State, and 11 percent in Wisconsin.

7.4.2 Multivariate Results

Tables 20 through ***24*** present results of regression models we estimated for service utilization. All regressions models were estimated for the total sample and then separately for young persons with physical disabilities and for those aged 65 and older. In addition to the regression models presented in ***Tables 20*** through ***23***, we also ran additional models (results not presented but available upon request) with the same dependent variables where instead of testing the effect of individual waiver services, we used one general HCBS waiver participation variable indicating receipt of any waiver services in a given month. ***Table 24*** provides calculations of the marginal effects of each type of HCBS (any state plan personal care use, any state plan home health use, and any waiver service use) on each of our dependent variables.

Table 19
Descriptive statistics for the total sample and by age group

In percent unless otherwise indicated	Overall Sample	Under age 65	Age 65 and over
	(n=18,050)	(n=7,924)	(n=10,126)
Dependent variables[1]			
Number of inpatient discharges	0.37	0.41	0.32
Outpatient services (% users)	79.12	83.86	75.25
Prescription drugs/DME[2]			
Any use of prescription drugs and DME (% users)	90.07	90.46	89.76
Mean number of prescription drugs/DME claims for users only	8.36	8.78	8.02
Medicaid program variables (% users)			
State plan personal care	22.50	22.66	22.36
State plan home health	22.02	22.13	21.93
HCBS[3] waiver (any waiver service)	77.87	77.21	78.41
Residential care services	6.33	4.09	8.16
Personal care	63.88	61.95	65.46
Respite care	6.25	7.08	5.58
Adult day services	6.42	6.48	6.37
Transportation	10.16	11.41	9.14
Meals	11.27	9.22	12.94
Nursing/other	37.72	38.65	36.97
Other Independent variables			
Demographic Characteristics			
Age under 44 (%)	15.59	35.60	--
Age 45-64 (%)	28.20	64.40	--
Age 65-74 (%)	21.47	--	38.19
Age 75-84 (%)	21.33	--	37.96
Age 85 and over (%)	13.41	--	23.85
Male (%)	26.42	36.35	18.68
Caucasian race (%)	73.58	76.47	71.33
African American race (%)	17.04	15.38	18.33
Asian or other race (%)	9.38	8.14	10.34
Self-Reported Health and Functional Status			
Responded by proxy (%)	29.59	28.05	30.79
Fair /poor health (%)	70.01	71.64	68.74
Good/ very good health (%)	26.75	23.68	29.14
Excellent health (%)	3.24	4.68	2.12
Number of IADL limitations (#)	3.31	3.35	3.27
Number of ADL limitations (#)	2.89	3.17	2.67
Ever institutionalized (%)	19.35	18.10	20.33
Some / great deal of pain (%)	83.75	82.50	84.72
Pressure sores (%)	9.91	12.67	7.76
Incontinence (%)	63.80	65.01	62.87
Number of unmet IADL /ADL needs (#)	0.81	0.95	0.69

(continued)

Table 19 (continued)
Descriptive statistics for the total sample and by age group

In percent unless otherwise indicated	Overall Sample	Under age 65	Age 65 and over
Social Characteristics and Residence			
Social participation (%)	71.58	76.10	68.05
Live in a group setting (%)	9.26	8.01	10.24
Dual eligible status (%)	76.82	50.83	97.06
Receipt of cash assistance (%)	55.22	56.71	54.05
Washington (%)	23.05	24.89	21.62
Wisconsin (%)	11.16	11.16	11.16
Alabama (%)	21.47	19.76	22.80
Kentucky (%)	44.32	44.19	44.42

NOTES:

[1] Analysis performed on the beneficiary month level

[2] Durable Medical Equipment

[3] Home and Community-based Services

SOURCE: RTI analysis of the MPR HCBS survey and Medicaid claims, 2004.

Table 20
Negative binomial regression on number of inpatient discharges[1]

	Total Sample			Under age 65			Age 65 and over		
Variable name	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign
Variables of Interest									
State plan personal care	-0.129	0.240		-0.180	0.351		0.136	0.338	
Residential care services	-0.102	0.454		-0.959	1.146		0.216	0.540	
Personal care	-0.140	0.184		0.079	0.263		-0.324	0.264	
Respite care	-0.139	0.195		-0.363	0.304		0.016	0.256	
Adult day services	0.002	0.241		0.318	0.357		-0.288	0.351	
Transportation	0.229	0.189		0.376	0.268		0.071	0.280	
Meals	0.162	0.179		0.395	0.290		-0.006	0.230	
Supplies/other[2]	0.380	0.193		0.230	0.260		0.460	0.306	
Demographic Characteristics									
Age under 44	-0.228	0.235		---	---				
Age 45-64	0.256	0.188		0.359	0.216				
Age 65-74 (reference group)	---	---		---	---		---	---	
Age 75-84	0.203	0.187		---	---		0.112	0.186	
Age 85 and over	0.170	0.223		---	---		-0.027	0.227	
Male	-0.321	0.149	*	-0.154	0.203		-0.328	0.230	
Caucasian race (reference group)	---	---		---	---		---	---	
Black race	-0.259	0.167		-0.096	0.254		-0.442	0.226	
Asian or other race	0.023	0.202		0.092	0.308		-0.135	0.274	
Self-Reported Health and Functional Status									
Responding by proxy	-0.135	0.159		-0.500	0.273		0.087	0.199	
Excellent health (reference group)	---	---		---	---		---	---	

(continued)

Table 20 (continued)
Negative binomial regression on number of inpatient discharges[1]

	Total Sample			Under age 65			Age 65 and over		
Variable name	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign
Self-Reported Health and Functional Status (cont.)									
Fair /poor health	1.200	0.507	*	1.802	0.783	*	0.691	0.676	
Good /very good health	0.763	0.514		1.042	0.798		0.449	0.681	
Number of IADL limitations	0.033	0.066		0.036	0.094		0.042	0.093	
Number of ADL limitations	0.031	0.038		0.071	0.055		-0.006	0.054	
Some / great deal of pain	0.098	0.185		0.128	0.293		-0.031	0.238	
Pressure sores	0.334	0.187		-0.165	0.277		0.772	0.267	**
Incontinence	-0.194	0.128		-0.048	0.198		-0.232	0.171	
Number of unmet IADL /ADL needs	0.084	0.032	**	0.067	0.044		0.100	0.049	*
Social Characteristics and Residence									
Social participation	0.100	0.135		0.121	0.214		0.072	0.173	
Live in group settings	0.035	0.252		0.105	0.390		0.047	0.332	
Dual eligible status	-0.471	0.168	**	-0.606	0.192	**	0.234	0.570	
Receipt of cash assistance	0.528	0.144	**	0.447	0.207	*	0.565	0.210	**
State 1	-0.172	0.250		0.186	0.342		-0.553	0.388	
State 2	0.579	0.284	*	0.765	0.405		0.346	0.417	
State 3	0.427	0.260		0.619	0.371		0.443	0.395	
Constant	-4.545	0.644	**	-5.622	0.947	**	-4.370	1.026	**

NOTES:

[1] Analysis performed on the beneficiary month level.

[2] We removed the nursing and therapy waiver services from this variable to eliminate potential endogeneity with the number of inpatient discharges.

* Statistically significant at $p<0.05$

** Statistically significant at $p<0.01$.

SOURCE: RTI analysis of the MPR HCBS survey and Medicaid claims, 2004.

Table 21
Probit regressions coefficients: Probability receiving any non-home and community-based outpatient services[1]

	Total Sample			Under age 65			Age 65 and over		
Variable name	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign
Medicaid Program Variables									
State plan personal care	0.133	0.117		-0.003	0.190		0.253	0.144	
State plan home health	0.142	0.071	*	0.235	0.123		0.066	0.089	
Residential care services	0.831	0.198	**	0.096	0.350		1.185	0.219	**
Personal care	0.497	0.082	**	0.410	0.120	**	0.624	0.115	**
Respite care	0.083	0.102		0.044	0.151		0.065	0.128	
Adult day services	0.590	0.187	**	0.507	0.361		0.596	0.189	**
Transportation	0.797	0.207	**	1.109	0.375	**	0.608	0.237	*
Meals	0.187	0.079	*	0.178	0.130		0.154	0.103	
Nursing/therapies and other	0.119	0.089		0.188	0.125		0.112	0.121	
Demographic Characteristics									
Age under 44	0.123	0.111		-0.050	0.107		---	---	
Age 45-64	0.202	0.095	*	---	---		---	---	
Age 65-74 (reference group)									
Age 75-84	-0.163	0.089		---	---		-0.155	0.095	
Age 85 and over	-0.248	0.098	*	---	---		-0.265	0.106	*
Male	-0.238	0.078	**	-0.243	0.108	*	-0.207	0.107	
Caucasian race (reference group)									
African American race	0.039	0.087		-0.009	0.142		0.135	0.104	
Asian or other race	-0.015	0.099		0.035	0.181		-0.118	0.119	
Self-Reported Health and Functional Status									
Responding by proxy	-0.136	0.078		-0.092	0.137		-0.204	0.097	*
Fair /poor health	0.380	0.166	*	0.623	0.193	**	-0.104	0.224	
Good /very good health	0.365	0.173	*	0.594	0.212	**	-0.074	0.230	
Excellent health (reference group)									
Number of IADL limitations	0.014	0.035		0.003	0.057		0.035	0.045	
Number of ADL limitations	0.034	0.019		-0.019	0.028		0.093	0.023	**
Ever institutionalized	0.130	0.076		0.166	0.123		0.152	0.099	
Some / great deal of pain	-0.069	0.097		-0.072	0.145		-0.023	0.126	
Pressure sores	0.211	0.102	*	0.167	0.147		0.154	0.139	
Incontinence	0.156	0.068	*	0.169	0.105		0.125	0.087	
Number of unmet IADL /ADL needs	-0.014	0.018		-0.021	0.024		-0.008	0.024	
Social Characteristics and Residence									
Social participation	0.071	0.069		0.020	0.116		0.141	0.086	
Live in group settings	0.194	0.118		0.385	0.234		0.146	0.137	
Dual eligible status	-0.612	0.107	**	-0.679	0.117	**	-0.104	0.228	
Receipt of cash assistance	0.112	0.079		0.131	0.115		0.139	0.106	
State 1	-1.697	0.112	**	-1.371	0.177	**	-1.895	0.143	**
State 2	-0.903	0.147	**	-0.694	0.228	**	-0.948	0.185	**
State 3	-3.091	0.126	**	-2.673	0.185	**	-3.440	0.165	**
Constant	1.771	0.255	**	1.716	0.332	**	1.555	0.402	**

NOTES:

[1] Analysis performed on the beneficiary month level.

* Statistically significant at p<0.05;

** Statistically significant at p<0.01.

SOURCE: RTI analysis of the MPR HCBS survey and Medicaid claims, 2004.

Table 22
Probit regressions coefficients: Probability of receiving any prescription drug/DME[1] services[2]

	Total Sample			Under age 65			Age 65 and over		
Variable name	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign
Medicaid Program Variables									
State plan personal care	0.463	0.155	**	0.586	0.233	*	0.437	0.188	*
State plan home health	0.352	0.080	**	0.452	0.134	**	0.232	0.098	*
Residential care services	1.163	0.240	**	0.260	0.330		1.746	0.318	**
Personal care	0.529	0.079	**	0.441	0.112	**	0.620	0.110	**
Respite care	0.086	0.121		0.243	0.167		-0.073	0.170	
Adult day services	0.042	0.134		0.127	0.168		0.103	0.200	
Transportation	0.169	0.092		0.246	0.127		0.027	0.125	
Meals	-0.051	0.118		0.162	0.180		-0.217	0.150	
Nursing/therapies and other	0.426	0.090	**	0.383	0.128	**	0.479	0.116	**
Demographic Characteristics									
Age under 44	-0.194	0.114		-0.222	0.111	*	---	---	
Age 45-64	0.083	0.105		---	---		---	---	
Age 65-74 (reference group)									
Age 75-84	-0.181	0.104		---	---		-0.229	0.104	*
Age 85 and over	-0.414	0.118	**	---	---		-0.515	0.123	**
Male	-0.201	0.083	*	-0.058	0.109		-0.322	0.122	**
Caucasian race (reference group)									
African American race	-0.110	0.094		-0.075	0.154		-0.155	0.116	
Asian or other race	0.047	0.116		0.129	0.184		-0.002	0.146	
Self-Reported Health and Functional Status									
Responding by proxy	-0.105	0.082		-0.107	0.124		-0.084	0.107	
Fair /poor health	0.179	0.183		0.407	0.245		-0.143	0.260	
Good /very good health	0.210	0.186		0.201	0.247		0.032	0.260	
Excellent health (reference group)									
Number of IADL limitations	0.073	0.035	*	0.086	0.050		0.068	0.044	
Number of ADL limitations	-0.037	0.021		-0.056	0.031		-0.015	0.028	
Ever institutionalized	-0.021	0.088		0.077	0.125		-0.088	0.116	
Some / great deal of pain	0.398	0.096	**	0.432	0.140	**	0.309	0.135	*
Pressure sores	-0.133	0.109		-0.228	0.157		-0.084	0.164	
Incontinence	0.119	0.074		0.146	0.111		0.098	0.100	
Number of unmet IADL /ADL needs	-0.018	0.021		-0.005	0.031		-0.047	0.029	
Social Characteristics and Residence									
Social participation	0.107	0.080		0.010	0.133		0.156	0.102	
Live in group settings	0.117	0.143		0.286	0.192		0.022	0.204	
Dual eligible status	0.134	0.095		0.087	0.112		0.134	0.181	
Receipt of cash assistance	0.142	0.079		-0.064	0.120		0.269	0.102	**
State 1	-0.240	0.127		-0.052	0.190		-0.460	0.174	**
State 2	-0.284	0.146		-0.207	0.217		-0.380	0.189	*
State 3	-0.415	0.130	**	-0.352	0.200		-0.485	0.163	**
Constant	0.082	0.255		0.004	0.349		0.491	0.390	

NOTES:

[1] Durable Medical Equipment.

[2] Analysis performed on the beneficiary month level.

* Statistically significant at p<0.05;

** Statistically significant at p<0.01.

SOURCE: RTI analysis of the MPR HCBS survey and Medicaid claims, 2004.

Table 23
Ordinary least squares (OLS) regression coefficients: Number of prescription drug/DME[1] claims[2]

	Total Sample			Under age 65			Age 65 and over		
Variable name	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign	Coeff.	Std. Err.	Sign
Medicaid Program Variables									
State plan personal care	0.463	0.245		0.461	0.413		0.464	0.302	
State plan home health	0.601	0.105	**	1.030	0.167	**	0.295	0.134	*
Residential care services	2.670	0.450	**	3.117	0.877	**	2.590	0.517	**
Personal care	1.472	0.118	**	1.101	0.190	**	1.736	0.150	**
Respite care	0.401	0.181	*	0.134	0.261		0.628	0.250	*
Adult day services	-0.245	0.233		-0.278	0.350		-0.111	0.313	
Transportation	0.951	0.148	**	1.254	0.212	**	0.608	0.209	**
Meals	0.496	0.197	*	0.160	0.352		0.650	0.235	**
Nursing/therapies and other	0.256	0.101	*	0.392	0.150	**	0.117	0.138	
Demographic Characteristics									
Age under 44	-2.560	0.409	**	-2.624	0.427	**	---	---	
Age 45-64	0.508	0.331		---	---		---	---	
Age 65-74 (reference group)									
Age 75-84	-1.402	0.348	**	---	---		-1.408	0.328	**
Age 85 and over	-2.373	0.410	**	---	---		-2.660	0.395	**
Male	-1.110	0.270	**	-1.340	0.398	**	-0.735	0.369	*
Caucasian race (reference group)									
African American race	-0.859	0.331		-1.060	0.537	*	-0.991	0.414	*
Asian or other race	-0.555	0.398		-0.268	0.677		-0.729	0.474	
Self-Reported Health and Functional Status									
Responding by proxy	-0.839	0.290	**	-1.520	0.485	**	-0.353	0.354	
Fair /poor health	2.666	0.655	**	3.644	0.901	*	1.638	0.984	
Good /very good health	1.030	0.664		1.215	0.920		0.567	0.994	
Excellent health (reference group)									
Number of IADL limitations	0.203	0.129	**	0.114	0.203		0.328	0.162	
Number of ADL limitations	-0.099	0.069		-0.092	0.106		-0.088	0.092	
Ever institutionalized	-0.373	0.291		-0.520	0.486		-0.381	0.354	
Some / great deal of pain	0.828	0.328	*	0.564	0.526		0.988	0.411	*
Pressure sores	-0.382	0.386		-1.269	0.570	*	0.504	0.530	
Incontinence	0.430	0.246		0.278	0.403		0.456	0.303	
Number of unmet IADL /ADL needs	0.128	0.070		0.152	0.103		-0.047	0.029	
Social Characteristics and Residence									
Social participation	-0.416	0.259		-0.988	0.444	*	-0.097	0.308	
Live in group settings	0.794	0.431		-0.064	0.729		1.511	0.522	**
Dual eligible status	0.135	0.220		-0.017	0.256		0.572	0.503	
Receipt of cash assistance	0.547	0.183	**	0.526	0.277		0.559	0.246	*
State 1	0.669	0.333	*	1.966	0.534	**	-0.506	0.426	
State 2	-0.402	0.418		0.619	0.674		-1.141	0.522	*
State 3	-1.442	0.348	**	-0.891	0.556		-1.687	0.443	**
Constant	3.889	0.876	**	4.590	1.218	**	3.620	1.308	**

NOTES:
1 Durable Medical Equipment.
[2] Analysis performed on the beneficiary month level.
* Statistically significant at $p<0.05$;
** Statistically significant at $p<0.01$.
SOURCE: RTI analysis of the MPR HCBS survey and Medicaid claims, 2004.

Table 24
Marginal effects of home and community-based services on utilization[1]

	Inpatient Discharges		Outpatient Services		Prescription Drugs/DME					
			Any Use		Any Use (Probit)		# of Claims for Users (OLS)		Probit x OLS	
	Mean	Std Err	Mean	Std Err	Mean	Std Err	Mean	Std Err	Combined Monthly Mean	Combined Annual Mean
State plan personal care	-0.050	0.088	0.048	0.028	0.096	0.041 *	-0.426	0.476	-0.041	-0.491
State plan home health	—	—	0.021	0.006 **	0.048	0.014 **	0.124	0.163	0.006	0.071
HCBS waiver	0.167	0.060 **	0.128	0.018 **	0.195	0.031 **	-0.088	0.27	-0.017	-0.206

NOTES:

[1] Analysis performed on the beneficiary month level.

* Statistically significant at $p<0.05$;

** Statistically significant at $p<0.01$.

SOURCE: RTI analysis of the MPR HCBS survey and Medicaid claims, 2004.

Inpatient Services. HCBS waiver services were positively associated with the number of inpatient hospital discharges, while state plan personal care was not ***(Table 20),*** countering our hypothesis of decreased use. One of the hopes for HCBS was that it might substitute for hospital care as well as for nursing home care either by providing an alternative to social admissions to the hospital, by improving the health status of beneficiaries by linking them to preventive services, or by preventing problems that might cause health problems (e.g., inadequate nutrition).

Among statistically significant demographic factors, males had 0.3 fewer discharges than females in the overall sample. Among health-related factors in the overall sample, persons reporting fair or poor health status had 1.2 more discharges than those reporting excellent health status, while younger persons reporting fair or poor health had 1.8 more discharges. Older persons with pressure sores had 0.8 more discharges. Interestingly, in both the overall sample and among older persons, every additional unmet need was associated with approximately 0.1 more discharges. Regarding social characteristics, dual eligibles had approximately 0.5 fewer discharges in both the overall sample and among younger persons with disabilities. Conversely, persons receiving cash assistance had approximately 0.5 more discharges in the overall sample and both age groups.

Outpatient Services. Many of the HCBS were associated with the use of any outpatient services as shown in results from the probit model ***(Table 21)***. Home health use is a significant and positive predictor of the use of any outpatient services for the overall sample, but not for the separate age groups. State plan personal care use was not significant in any of the three regressions. Most of individual waiver services are significant and positive predictors of any outpatient use for the overall sample, but fewer were statistically significant in the age group regressions. Both residential care and transportation services had large effects. On the other hand, respite care and the combined category of nursing, therapies and other rarely used services were not significant in any regression. In addition, receiving home delivered meals, while statistically significant for the total sample, does not predict a greater likelihood of using outpatient services for either age group separately. All statistically significant coefficients were positive, indicating that use of home and community-based services increases use of outpatient services.

In terms of the remaining variables for the overall sample, age 85 years of age and older, male gender, and dual eligibility status were significant and negative predictors of any outpatient use. Older adults may use fewer services because they do not have enough assistance to get to a provider or are too ill to make the trip. Likewise, beneficiaries who are too disabled to have worked enough to qualify for Medicare may be sicker and unable to get to a provider. Regarding health indicators, reporting less than excellent self reported health, ADL limitations, pressure sores and incontinence increase the likelihood of using outpatient services.

Prescription/DME use. The majority of HCBS were associated with a significantly higher probability of use for prescription drug and DME services ***(Table 22).*** Both state plan personal care and state plan home health are significant and positive predictors of prescription drug and DME utilization for the total sample and for both age groups. Of individual HCBS services, personal care and nursing/therapies/other services appear to be the most consistently associated with any prescription drug and DME use for the total sample and both age groups. Residential care services were significant in the overall sample and for older persons, but not for younger persons with physical disabilities.

Among other indicators, persons under age 45 and over age 75 and male gender negatively affect the likelihood of any prescription drug and DME use, while having IADL limitations and experiencing pain increase the likelihood of using these services in the overall sample. Experiencing some or great deal of pain 6 weeks prior to the study appears to be the only strong and positively consistent predictor across all regressions.

In the OLS regression on the number of prescription drug and DME monthly claims, many of the waiver services and state plan home health were statistically significant, but state plan personal care was not ***(Table 23).*** State plan home health is associated with a higher monthly number of Rx/DME claims in all three regressions, and is especially strong for younger persons with disabilities, with an increase of one claim per month compared to Medicaid beneficiaries with similar characteristics who do not receive state plan home health.

Use of all of the individual HCBS waiver services (except adult day services) is associated with more monthly prescription drug/DME claims. Receiving HCBS waiver residential care services, personal care and transportation all increase the number of prescription drug/DME monthly claims by about one claim per month compared to those who do not receive each particular service. For residential care services, the effect is substantial and produces an increase of about 2.7 claims per month, given a mean use of 8 claims per month. Respite care slightly increases the number of claims for the total sample and for those aged 65 and over. Transportation services appear to be more important for younger persons with disabilities, since they are associated with about 1.2 more claims per month, compared to an increase of only 0.6 claims per month for older persons. Receiving HCBS services such as nursing, therapies and others was associated with a small significant increase in the overall sample and for younger persons with disabilities but not among older persons.

Persons under age 45 as well as age 75 and over, male gender, African American, and proxy respondents are all negatively associated with the number of prescription drug and DME claims. Among positive predictors for the overall sample, the largest effect is for fair or poor health (2.7 additional claims per month), followed by experiencing pain (0.8 additional claims each per month), receipt of cash assistance (0.5 claims per month), and unmet IADL needs (0.2 claims per month).

Several variables were significant for one or both of the age groups, but not in the overall sample. Younger persons with physical disabilities who have pressure sores have 1.3 fewer prescription drug/DME claims per month on average than those without such problems, and those who have at least one social activity per week (social participation) have 1 claim per month less than those who cannot get out of the house as often. For beneficiaries age 65 and over, positive predictors in the order of declining influence, include living in a group setting and reporting pain in the last 6 weeks.

Marginal effects. To assess the effects of three HCBS services—state plan personal care, state plan home health, and receipt of any HCBS waiver services—on utilization of inpatient and outpatient services and on prescription drugs and DME, we calculated marginal effects derived from the regression coefficients presented in ***Tables 20*** through ***23***. ***Table 24*** presents marginal effects on our four dependent variables of the three HCBS variables.

<u>Inpatient services</u>. Waiver services were associated with an increase of 0.16 discharges per year. We found no effect for state plan personal care. Providers of waiver services may notice a consumer's need for hospitalization and may alert clinical staff of the potential need. We did not include state plan home health services in regressions on inpatient services, and therefore do not report any marginal effects results.

<u>Outpatient services</u>. Using versus not using any of the three types of HCBS was associated with higher outpatient care use. Waiver services have the largest effect. Receiving vs. not receiving at least one Medicaid HCBS waiver service was associated with a 12.8 percentage point increase in outpatient care use. This signifies a rather substantial increase, especially given that the analysis is conducted on the person-month level, so HCBS may be increasing the continuity of receiving outpatient services over the year period. Also, receipt of any state plan personal care or any state plan home health services has a smaller but also a statistically significant effect on outpatient use. The marginal effect of receiving state plan personal care increased the probability of using outpatient services by 4.8 percentage points (significant only at the $p<0.10$ level). The receipt of state plan home health increases any outpatient use by 2.1 percentage points.

Prescription drug/DME utilization. Receipt of any of the three types of HCBS has a positive and significant effect on any use of prescription drugs/DME. Again, waiver services have the largest effect of the three types of HCBS examined. Receiving HCBS waiver services of any kind is associated with an almost 20 percentage point increase in any prescription drug/DME use. Similarly, although with a smaller marginal effect, the likelihood of consumers using any prescription drugs and durable medical equipment is almost 10 percentage points higher for beneficiaries using state plan personal care, and is almost 5 percentage points higher for beneficiaries using state plan home health.

Despite the strong association between use of HCBS and higher probability of prescription drug/DME use, none of the three types of HCBS was associated with a higher number of average prescription drug/DME claims. None of the HCBS variables were statistically significant in these calculations, although two of the three coefficients were negative. Apparently, once achieving greater access to this service through HCBS, the number of claims by people using a particular HCBS does not differ from the number of claims for those people without use of that particular HCBS.

We combined the results from the marginal effects calculations from the Probit and ordinary least squares (OLS) regressions on prescription drug and durable medical equipment use to estimate the overall change in use. Given mean use of approximately 8 claims per person per month in the sample, receiving versus not receiving state plan personal care was associated with 0.04 fewer monthly prescription drug/DME claims per month. Using versus not using HCBS waiver services resulted in 0.017 fewer monthly prescription drug and durable medical equipment claims. Using versus not using state plan home health was associated with 0.006 more monthly claims. To summarize, although all three forms of HCBS were associated with a significantly higher probability of use of prescription drugs/DME in the Probit regressions, there was no corresponding significant change in the number of monthly claims in the ordinary least squares (OLS) regressions. As a result, there was almost no change in the net combined effect when the marginal effects from the Probit and ordinary least squares (OLS) models were multiplied together for prescription drug and DME use.

7.5 Discussion

This study examined the association of Medicaid home and community-based services by older people and younger persons with disabilities on the use of a broad range of outpatient services and on prescription drugs and DME. Home and community-based services might increase the use of these other services by identifying health problems needing treatment and by better connecting beneficiaries to services or it might reduce use by improving health status and eliminating unnecessary outpatient visits, prescription drugs, and DME. Our research used a merged survey of Medicaid home and community-based services beneficiaries in four states with Medicaid claims data to assess this issue.

The marginal effect of using versus not using any of the three forms of home and community-based services was positive and statistically significant in the Probit regressions, increasing the probability of using any outpatient services and any prescription drugs and DME. Use of home and community-based services waivers was associated with the largest increase in use for any outpatient services (12.8 percentage points) and any prescription drugs and DME (19.8 percentage points). Use of HCBS state plan personal care services was associated with the next largest increases (4.8 percentage points for any outpatient use and 9.6 percentage points for any prescription drug and DME use). Use of Medicaid home health services was associated with the lowest increase (2.1 percentage points for any outpatient use and 4.8 percentage points for any prescription drug and DME use).

While the means for the person-month observations in the sample for receiving outpatient services and prescription drugs and DME were already high (79 percent and 90 percent respectively), these findings imply that the receipt of home and community-based services increases the identification of health problems and access to these services across the 12 months of the data analyzed. Home and community-based services providers may encourage consumers to see their physician regularly or may notice negative changes in a consumer's overall health status and may encourage the consumer to see their physician. In some cases waivers may fund the transportation services a consumer needs to get to a physician or other health care provider, given that this variable in the Probit regressions for any outpatient use had a moderate and statistically significant effect in the overall sample and in both age groups. Home and community-based services waiver transportation services also increased the percentage of beneficiary months having any claims for prescription drug and DME services. Given these services are prescribed through a physician, perhaps obtaining additional access to one's physician is the mechanism for higher use of prescription drugs and DME.

In spite of this increased use of prescription drug and DME services, there was no statistically significant change in the number of average monthly claims for this service in the ordinary least squares (OLS) regressions, and coefficients for state plan personal care and home and community-based services waivers were negative. As a result, our calculated monthly and annual change in the number of claims for prescription drugs and DME across the entire sample from having different types of home and community-based services was very small and negative for state plan personal care and home and community-based services. In other words, while the overall probability of any use increased, the amount of use decreased for some users, canceling out the increased use.

Finally, we found no marginal change in use for inpatient services associated with use of any waiver services, but not for state plan personal care. This counters the hypothesis that HCBS might substitute for inpatient care or improve health status enough to prevent hospitalization. While an increase in inpatient admissions might have a substantial impact on Medicaid expenditures, these additional admissions might be shorter if HCBS providers identified the need for admission earlier.

This study examined new areas of the impact of home and community-based services and is one of the few studies in long-term care to link surveys and Medicaid claims data. Nonetheless, our research has several limitations. First, the study is limited to Medicaid beneficiaries in four states, and its results cannot necessarily be generalized to the national population of Medicaid beneficiaries receiving these services. However, the study includes states with a range of home and community-based systems and a substantial sample of respondents (Wiener, Tilly and Alecxih, 2002). Second, we had no formal control group given that all persons in the sample received one of the three types of HCBS, though we addressed this limitation by predicting the marginal effect of using versus not using each type of HCBS. Third, we were not able to estimate the change in the amount of outpatient services using measures of encounters or claims. The variation in the types of units (e.g. visits, lab tests, X rays) reported for different outpatient services prevented us from establishing a common unit type across these services. Fourth, we only estimated changes in Medicaid utilization, and not Medicare or other payers. Thus, any Medicare service that does not have coinsurance or is not subject to a deductible (e.g., Medicare home health) which would be paid by Medicaid could not be measured. Fifth, the implementation of the Medicare Part D prescription drug benefit may change the utilization dynamics of the three-quarters of our sample that was dually eligible in ways that are not obvious.

As the Centers for Medicare and Medicaid Services and the States work to increase the use of home and community-based services and to decrease the use of nursing homes, it is increasingly important for policymakers and researchers to consider how noninstitutional long-term care services fit into the broader health care, income support and housing systems. This study demonstrated the utility of that broader approach. Our research showed that home and community-based services, especially waiver services, may substantially increase the proportion of disabled Medicaid HCBS beneficiaries who use outpatient services, prescription drugs, and DME, while at the same time reducing the amount of use for some beneficiaries. The net effect of these opposite effects is either a very small increase or modest declines in overall use of these acute care services. While the mechanisms by which home and community-based services accomplish these effects are not clear, they may reflect case management, especially in home and community-based services waiver programs, and direct care workers visiting beneficiaries on a regular basis who connect consumers with the appropriate health care providers.

CHAPTER 8
THE ASSOCIATION BETWEEN HOME AND COMMUNITY-BASED SERVICES AND MEDICAID SPENDING

Many consumers needing long-term care services desire to receive these services in community settings to maintain their independence and quality of life. Despite this preference, the overwhelming majority of Medicaid spending is for institutional care rather than for home and community-based services. With the passage of the Americans with Disabilities Act in 1991 and the Supreme Court's Olmstead V. L.C. decision ((98-536) 527 U.S. 581(1999)) requiring public agencies to provide services "in the most integrated setting appropriate to the needs of qualified individuals," states are working more aggressively to develop home and community based services (HCBS) to broaden consumer choices for long-term care services. Recently, the Deficit Reduction Act of 2005 (P.L. 109-171) provided financial incentives to states to quicken the pace of change toward HCBS.

Despite the policy preference for HCBS, Medicaid spending for HCBS has only increased slowly, comprising only 37.2 percent of all Medicaid long-term care expenditures in fiscal year 2005 (Burwell, Sredl, and Eiken 2006). Progress in developing HCBS systems has also been uneven across the states (Wiener, Tilly, and Alecxih 2002), with only eight states now providing the majority of their long-term care expenditures through HCBS programs (Burwell, Sredl, and Eiken 2006). Most HCBS spending is for persons with intellectual disabilities, as opposed to younger persons with physical disabilities and older persons.

States are interested in developing HCBS as a means to slow or decrease spending for nursing facility and other long-term care institutions in part because institutional costs include expenses for room and board, whereas HCBS costs do not. States fund HCBS for consumers who meet nursing facility eligibility criteria or who are at risk for such care, and therefore anticipate savings over institutional care. State policymakers though seldom consider the association of HCBS spending on all other Medicaid expenditures for the populations served, inclusive of any institutional services.

8.1 New Contribution

Little is known about the effects of HCBS on non-HCBS related expenditures, such as inpatient, nursing facility, and outpatient services, and prescription drugs and durable medical equipment and supplies. An important issue to be addressed is whether additional HCBS spending decreases or increases other Medicaid expenditures for the population receiving HCBS. If HCBS decreases other Medicaid expenditures, states may be more willing to increase spending on HCBS. On the other hand, if HCBS increases other Medicaid expenditures, states may be reluctant to increase HCBS spending. This study addresses this question by understanding the association of HCBS spending on remaining Medicaid expenditures using a multi-state sample. Van Houtven and Domino (2005) examined all Medicaid expenditures for a waiver population in North Carolina, but no research exists on the association of HCBS spending on all Medicaid expenditures in a multi-state sample in a regular program.

8.2 Background

States may offer HCBS in 3 different ways—state plan home health, state plan personal care, and HCBS waiver services. States' use of these services varies greatly (Kitchener, Carrillo, and Harrington 2004). In addition, states vary on eligibility for and benefits offered in these programs. Expenditures for these three services in fiscal year 2005 totaled $34.8 billion, with two-thirds of the spending on waiver services (Burwell, Sredl, and Eiken 2006).

States are required to offer state plan home health services to all individuals entitled to nursing home care. These services consist of traditional nursing, therapy, and home health aide services. For other Medicaid eligibles, these services are optional, and states may vary the amount, scope, and duration of benefits as long as they are sufficient to reasonably achieve their purpose (Wiener, Tilly, and Alecxih 2002). Little is known about how these services vary across states.

States have had the option to offer personal care services as a Medicaid state plan benefit since 1975 (Le-Blanc, Tonner, and Harrington 2001). Personal care services, offered most frequently in non-residential care settings, involve assistance by non-clinicians with activities such as eating, bathing, and toileting. This benefit is available to all Medicaid categorically eligible groups in a state. As of 2006, 37 states offer this benefit.

Since 1981, states have been allowed to request waivers (known as home and community-based services waivers or 1915(c) waivers for the provision of the federal Social Security Act authorizing these waivers) of certain federal Medicaid requirements such as providing services statewide and for all eligibility groups to provide nursing home comparable services in community settings. In addition to these services, these waivers allow states to provide a broader array of less medically-oriented services not usually covered by Medicaid that facilitate community living, including but not limited to respite care, adult day services, transportation, meals, training, and home modifications (Wiener, Tilly, and Alecxih 2002). All states except Arizona offer waiver services designed to meet the long-term care needs of various populations such as physically disabled persons under age 65, older persons, and persons with intellectual disabilities.

8.3 Conceptual Framework

Prior research has largely focused on whether HCBS reduces nursing facility use and spending and total long-term care spending (Thornton, Dunstan, and Kemper 1988; Kemper, Applebaum, and Harrigan 1987; Wiener and Hanley 1992; Weissert and Hedrick 1994; Greene et al. 1995). Little attention recently has been given to the association of HCBS with other Medicaid spending. The Channeling demonstration (Carcagno and Kemper 1988) of the mid-1980s did so, finding that increased use of HCBS was not associated with a change in other Medicaid and Medicare spending (Wooldridge and Schore 1988). Given states' present day focus on overall costs of their Medicaid programs, states might be more likely to increase HCBS if they had current information about its effects on other Medicaid expenditures.

On the one hand, more HCBS spending might help stabilize consumer health, thus requiring fewer other Medicaid expenditures. For example, higher HCBS spending might decrease inpatient and institutional services if HCBS improved consumer well-being, reducing the need for institutional services. On the other hand, if consumers have unmet need for other Medicaid services, more HCBS spending might help promote greater access to care through regular contact with HCBS providers, who help consumers get additional care when needed, increasing all other Medicaid expenditures. For example, higher HCBS spending might also increase a consumer's ability to access timely outpatient services and obtain regularly needed prescription drugs and durable medical equipment and supplies.

There may be several avenues for higher HCBS spending to affect other Medicaid services. Indeed, higher HCBS spending may decrease some components of other Medicaid expenditures (e.g. inpatient expenditures) while increasing other components (e.g. outpatient expenditures). Depending on the magnitude of the respective changes in the various components of other Medicaid spending, net other Medicaid expenditures may be either lower or higher. If HCBS provides more access to outpatient services and prescription drugs and durable medical equipment, then any decrease in other Medicaid expenditures resulting from higher use of HCBS would have to come from decreased inpatient expenditures.

The purpose of this study is to identify associations of higher HCBS spending with other Medicaid expenditures using individual-level data on younger persons with physical disabilities and older people. Since we use cross sectional data and do not have a control group against which differences in Medicaid spending could be measured, we were not able to estimate the causal effects of HCBS spending on other Medicaid expenditures. We also identify the mean use of the components of other Medicaid expenditures, such as inpatient and outpatient services, for this multi-state sample.

Our study differs from prior studies on the relationship of HCBS to other Medicaid expenditures in three ways. First, some studies examine single programs such as individual waivers, whereas we examine the effects of multiple HCBS programs. Second, we analyze individual data across four states, whereas most other studies use data from single states. Third, we provide estimates for the overall sample and by age subgroups to distinguish between the younger physically disabled population and persons over age 65, who might differ in their level of expenditures because of differences in health status and types of medical conditions.

8.4 Study Design and Data

This effort is part of a larger research project (Wiener, Tilly, and Alecxih 2002) funded by the Centers for Medicare & Medicaid Services. The Lewin Group and its subcontractors, RTI International, the University of Minnesota Research and Training Center on Community Living, Mathematica Policy Research and The Medstat Group studied Medicaid financing and delivery of home and community-based services to older people and younger adults with physical disabilities, as well as to individuals with intellectual disabilities and developmental disabilities. The overall goal of the larger project was to study selected programs to assess their effects on consumer satisfaction and on Medicaid utilization and expenditures. States chosen for inclusion in the study include ones with well-developed community-based systems and states developing their non-institutional services systems.[15]

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[15] States included in the part of the study analyzing satisfaction of older people and younger persons with physical disabilities are Alabama, Kentucky, Maryland, Michigan, Washington, and Wisconsin.

Data for this study consisted of a survey, which was merged with Medicaid claims data.

8.4.1 Survey Data

Mathematica Policy Research, Inc., conducted a survey of Medicaid home and community-based services beneficiaries in the selected states (Snell et al. 2005). The target population for the HCBS survey consisted of all adult Medicaid home and community-based services waiver and personal care option recipients.

The sample was allocated proportionally among states based on the number of home and community-based services beneficiaries in each state. The sample was selected using simple random sampling and weights were computed from the inverse of the selection probability, which varied by state. Respondents were receiving services under seven HCBS programs (***Table 25***). Respondent data was adjusted for non-response, first for the ability to locate a person, and then for whether or not the located person responded. Because of the interest in differences between older and physically disabled persons under age 65, the survey sample was stratified by age (under age 65 and age 65 and over).

Table 25
State Medicaid waivers and benefits used for deriving sample frame

State	Program
Alabama	Elderly and Disabled waiver
Alabama	State of Alabama Independent Living waiver
Kentucky	Home and Community-based Services waiver
Washington	Community Options Entry System (COPES) waiver
Washington	Medicaid State Plan Personal Care benefit
Wisconsin	Community Option Program (COP) waiver
Wisconsin	Medicaid State Plan Personal Care benefit

The survey was fielded between May 2003 and June 2004. The survey respondents participated in the survey directly or via proxy (paid and unpaid caregivers) and included participants living in their own homes and residents of assisted living facilities and other group settings. The survey, which took about half an hour to complete, was conducted primarily through telephone interviews using a computer-assisted telephone interviewing (CATI) system (N = 2,458) with some in-person interviews (N = 143)[16]. The overall survey response rate was

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[16] Four observations were later determined to be duplicates and were removed from the sample.

72 percent, with 28 percent of respondents using a proxy respondent, though the percentage of proxy respondents in the analyses reported was only 16 percent. Survey data were obtained from 2,597 community-residing Medicaid beneficiaries.

8.4.2 Claims Data

The Medstat Group obtained Medicaid eligibility and claims files through CMS's Medicaid Statistical Information System (MSIS) for each sample state. These files contain Medicaid expenditures organized by site of service (inpatient, other institutional, and outpatient services, and prescription and durable medical equipment) and contain eligibility data on consumers (periods of eligibility, dual eligibility with Medicare, and whether receiving cash assistance). For dual eligibles, these files also contain Medicaid expenditures for Medicare deductibles and coinsurance.

Medstat matched respondents from the survey data with one year of their Medicaid claims, spanning a period 6 months before and after they were surveyed. The survey month was counted as one of the 6 pre-survey months. These claims are dated by date of service, though claims payment and state processing of MSIS claims can lag dates of service.[17] The match rate between the claims data and the survey averaged approximately 99 percent across the four states in the analysis.[18]

8.4.3 Dependent Variables

We created two dependent variables to estimate the probability and amount of non-HCBS Medicaid expenditures. The first dependent variable, which was used in Logit estimation, was a dummy variable coded 1 if a respondent had any use of non-HCBS Medicaid expenditures in any given month, and coded zero if no expenditures for that month. The second dependent variable, used in ordinary least squares (OLS) regressions, was a continuous measure for the amount of non-HCBS Medicaid expenditures in any given month.

8.4.4 Independent Variables

Independent variables were grouped into four domains—HCBS programs, demographic characteristics, health and functional status, and social characteristics and residence.

HCBS Program Variables. We created three continuous variables, each denoting the amount of expenditures for Medicaid state plan personal care, home health and waiver services, respectively. We also created 7 additional continuous variables indicating the amount of individual HCBS waiver services for the following service groups: residential care, personal care, respite care, adult day care, transportation, home delivered meals, and a combination

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[17] Mathematica also surveyed persons in Maryland and Michigan, but we were not able to obtain needed claims data from Maryland on a timely basis, and Michigan claims contain capitated expenditures, which we decided not to use because of the potential for bias.

[18] Only 368 of 601 survey respondents in Washington state gave their permission to match their survey responses to claims data. We found no differences on important demographic and health-related factors between those respondents who did and did not give their permission.

variable for nursing, therapies, environmental modifications and supplies, training, and other services where use of the service was to low to include as a separate variable.

Demographic Characteristics. We created dummy variables for age groups, gender, and race.

Health and Functional Status. We developed dummy variables for categories of self-reported health status, coded as fair/poor, good/very good, with excellent as the reference category. Additional health status indicators included prior nursing home use, recent pain, pressure sores, and bladder/bowel incontinence. A variable for proxy survey respondent was used to control for cognitive impairment in the sample population. We created count variables for the number of limitations in six activities of daily living (bathing, dressing, eating, transferring, walking across the room, and toileting) and for the number of limitations in four instrumental activities of daily living (cooking, managing medications, shopping, and doing light housework). We also created a count variable ranging from 0 to 10 denoting unmet needs for ADL and IADL assistance about which respondents were asked.

Social Characteristics and Residence. We developed dummy variables for social involvement and participation; living in a group setting such as assisted living, group or adult foster home; dual eligible status; receipt of cash assistance such as SSI; and state of residence. Several recent studies (Kitchener, Carrillo, and Harrington 2004; Kitchener et al. 2005), as well as many prior studies, have identified the correlates of adoption of, participation in, and total use of HCBS, particularly of waiver services. Rather than incorporate these correlates individually, we controlled for their influence through state dummy variables.

8.4.5 Sample

Our final analytic sample had 1,508 persons with 17,927 monthly observations representing a year of claims for each person. We deleted two respondents from Alabama for whom we did not have at least 10 months of eligibility because we did not receive the last quarter of the state's eligibility file in time for the analysis.

8.5 Methodology

The unit of analysis in regression analyses is a person-month observation derived from 12 months of monthly claims and eligibility data. We verified eligibility for Medicaid for each month of the 12-month sample window. On average, each person had 11.9 person-months of eligibility, meaning almost all persons maintained Medicaid eligibility for the full 12-month analysis period.

We estimated a two-part (Duan et al. 1983) model, estimating a Logit model on the full sample to control for observations with zero expenditures, and then ordinary least squares (OLS) on a log-transformed dependent variable, applying a heteroscedastic smearing factor to our predictions of the dependent variable. We selected this model following recommendations by Manning and Mullahy (2001) for assessing the goodness of model fit to the data. Results of their suggested specification tests showed that the distribution of our dependent variable was skewed right (few consumers have large amounts of expenditures), heteroscedastic in the independent variables (the error term did not have a normal distribution), and very kurtotic (>5) in the standardized residuals (the left tail of the distribution was very thick). In this case, Manning and Mullahy (2001) suggested that the log-transformed ordinary least squares (OLS) model with correction for heteroscedasticity might perform better than a generalized linear model (GLM). Generally, ordinary least squares (OLS) estimates are consistent, but not as precise as GLM estimates. To use this approach, we treated our person-month observations as independent of each other, with subsequent losses in precision. Given the large size of our sample, we found this tradeoff in loss of precision to eliminate potential bias in our estimates acceptable.

We estimated summary statistics at the person, rather than the person-month level, to provide estimates on an annual basis. We estimated fully specified regression models incorporating state effects to capture unobserved heterogeneity within states, such as the effects of population demand, provider supply, and other state policies. As part of our data collection arrangement with the four states, we agreed not to identify any individual state. Thus, the states are identified only by number.

To determine whether additional expenditures for any HCBS program reduced all other Medicaid expenditures, we calculated the difference in the combined mean expected value from our two-part model of other Medicaid expenditures resulting from separate \$100 increases in each HCBS program for consumers already receiving services from each program. First, we estimated the combined expected value for the sample. Then we added \$100 to each of the three HCBS program variables (state plan personal care, state plan home health, and waiver program) one at a time, and then estimated the resulting combined expected value for the sample for each HCBS program separately. The difference between each of these three expected values and the original combined expected value is the increase in other Medicaid expenditures for a \$100 increase in a given HCBS program. A \$100 increase represented an increase in the mean value of each HCBS program of between approximately 10 to 20 percent.

Finally, we were also interested in the change resulting in other Medicaid expenditures from using more types of waiver services (broad array) versus using fewer types of waiver services (narrow array). We designated a narrow use of HCBS as using only personal assistance services or home health services, regardless of whether a consumer received those services from a waiver or state plan. To develop a broader array of services (specifically, those additional waiver services for which one might be eligible), we switched the dummy variables for each of these additional services first on, estimated the combined expected value, then switched it off, re-estimated this value, and took the difference.

We report statistically significant results from our models at conventional levels of significance, first in the overall sample, and then for each age subgroup separately. We thought the two age subgroups would differ in health status and other factors and anticipated that younger disabled adults would have higher expenditures than older persons. Younger people with physical disabilities may also have a different set of medical problems than do older people who are more likely to have Alzheimer's disease or be frail.

8.6 Results

8.6.1 Descriptive Statistics.

The proportion of the sample with any other Medicaid expenditures was almost 100 percent in the overall sample as well as in both age subgroups (***Table 26***). Given this very high proportion of use, the mean for the dependent variable was almost the same in the overall sample regardless of any use ($9,884) and among only those with positive expenditures ($10,218). Mean expenditures among those with any expenditures differed greatly across the two age groups, with younger persons with physical disabilities having almost double the expenditures of older persons ($13,463 versus $7,651).

We also analyzed the service-specific components of the dependent variable to provide information about the principal drivers of use and about differences across the two age groups. The largest difference in mean expenditures across age groups was in the amount of inpatient expenditures. While both age subgroups had the same probability of inpatient use (approximately 21 percent), physically disabled persons under age 65 had 2.5 times the amount of Medicaid expenditures as older persons ($50,290 vs. $20,025). Despite the fact that all sample members were receiving HCBS, only 5.2 percent of the overall sample had any nursing facility expenditures, but older persons had over twice the probability of any use (6.9 percent vs. 3.0 percent) as younger persons, though expenditures across the age groups among those with any use was approximately the same ($38,060 for younger persons vs. $34,478 for older persons). The probability of outpatient expenditures was the same in the overall sample and in both age groups (approximately 98 percent), but among those persons with any use, younger persons had 45 percent higher expenditures than older persons ($6,186 vs. $4,251). The proportion of the overall sample with any prescription drug and durable medical equipment expenditures was 94.5 percent, with little difference across age groups. While mean expenditures in the overall sample among those persons using this service was $3,790, younger persons had 73 percent higher expenditures than older persons ($6,702 vs. $3,218). Finally, total Medicaid expenditures (inclusive of HCBS) were approximately $19,000 in the overall sample, but younger persons had almost 1.5 times the amount of expenditures as older persons ($23,227 vs. $15,823).

The three main HCBS independent variables in our analysis were use of a state's optional personal care program, its home health program, and waiver services. The proportion of sample members with use of these programs was 14.1 percent for state plan personal care services, 45.4 percent for state plan home health services, and 88.8 percent for waiver services (***Table 27***). These proportions are closely related to our sampling strategy where most members of the sample were enrolled in waiver services, and a small subgroup of persons drawn from Washington state and Wisconsin were sampled from those state's personal care programs. A few persons in our waiver sample also had state plan personal care services, with most of these persons in Wisconsin.

While there was little difference in the probability of use by age group for these three HCBS, among those with positive expenditures, physically disabled persons under age 65 consistently had higher mean expenditures than older persons for each HCBS program. Among those with any use, younger persons had 32 percent higher state plan personal care expenditures ($14,818

Table 26
Probability and amount of annual expenditures for dependent variable and related components

	Overall Sample (n=17,927)			Under age 65 (n=7,785)			Age 65 and Over (n=10,042)		
Variable Name	Percentage with Use	Overall Mean Expenditures ($)	Mean Expenditures if Any Use ($)	Proportion with Use	Overall Mean Expenditures ($)	Mean Expenditures if Any Use ($)	Proportion with Use	Overall Mean Expenditures ($)	Mean Expenditures if Any Use ($)
Combined Medicaid (excluding HCBS)	99.80	9,884	10,218	99.85	13,077	13,463	99.76	7,376	7,651
Inpatient	21.42	1,051	34,384	21.18	1,658	50,290	21.61	574	20,025
Nursing Facility	5.17	440	35,394	3.03	275	38,060	6.85	570	34,478
Prescription Drug and DME	97.75	4,602	5,100	98.18	5,569	6,186	97.40	3,842	4,251
Outpatient	94.56	3,790	4,848	95.76	5,574	6,702	93.62	2,389	3,218
Total Medicaid Expenditures	100.00	19,079		100.00	23,227		100.00	15,823	

DME=durable medical equipment; HCBS=home and community-based services.

SOURCE: RTI analysis of 2003/2004 Medicaid claims and survey data. Program: hcbs_claim_21.log.

Table 27
Probability and amount of annual expenditures for main independent variables

	Overall Sample (n=17,927)			Under age 65 (n=7,785)			Age 65 and Over (n=10,042)		
Variable Name	Percentage with Use	Overall Mean Expenditures ($)	Mean Expenditures if Any Use ($)	Percentage with Use	Overall Mean Expenditures ($)	Mean Expenditures if Any Use ($)	Percentage with Use	Overall Mean Expenditures ($)	Mean Expenditures if Any Use ($)
State Plan Personal Care	14.12	1,613	12,880	14.52	1,941	14,818	13.81	1,355	11,228
State Plan Home Health	45.42	2,065	6,158	45.08	2,222	6,616	45.69	1,941	5,798
HCBS Waiver (total)	88.79	7,579	9,216	87.59	8,205	10,050	89.73	7,087	8,570
HCBS Waiver—Residential Care Services	4.34	582	15,819	2.49	320	13,441	5.78	788	16,767
HCBS Waiver—Personal Care	79.80	4,906	7,192	74.30	5,402	8,411	84.06	4,517	6,330
HCBS Waiver—Respite Care	15.06	425	4,202	17.25	448	3,925	13.37	407	4,474
HCBS Waiver—Adult Day Services	12.24	806	8,774	14.10	1,034	9,479	10.80	627	8,005
HCBS Waiver—Meals	16.15	173	1,399	13.43	149	1,456	18.25	191	1,366
HCBS Waiver—Transportation	22.30	19	1,141	25.37	7	473	19.92	28	1,587
HCBS Waiver—Nursing, Therapies, Supplies, Environmental Modifications, Training, and Other Services	100.00	577	1,567	100.00	652	1,774	100.00	518	1,405

HCBS=home and community-based services.

SOURCE: RTI analysis of 2003/2004 Medicaid claims and survey data. Program: hcbs_claim_23_mean.log and hcbs_claim_26.log.

vs. $11,228), 14 percent higher state plan home health expenditures ($6,616 vs. $5,798), and 17 percent higher expenditures for waiver services ($10,050 vs. $8,570). Higher use of these services is consistent with their higher use of the individual components of other Medicaid expenditures. Although waiver services are designed to provide comprehensive services for more disabled persons, we found that among those with any state plan personal care expenditures, their mean expenditures for personal care were higher than mean waiver expenditures among those with waiver use. This difference in part may result from state agency staff moving high-cost persons out of the waiver to avoid exceeding the waiver cost cap.

The proportion of sample members with use of any of the individual waiver services that compose a state's waiver service program was relatively low in the sample for all but two of the services. All waiver respondents used at least one service in the broad service category containing nursing, therapies, environmental modifications, supplies, training, and other waiver services. Average annual mean expenditures for those with use were relatively small at $1,567, with younger persons having 26 percent higher expenditures than older persons ($1,774 vs. 1,405). Approximately 75.3 percent of sample members used any waiver personal care, with 70.0 percent use among younger persons and 79.5 percent among older persons. Younger persons had 33 percent higher expenditures for this service than older persons ($8,411 vs. $6,330), the same percentage higher use as for the non-waiver state plan personal care services used by the two age groups. Excluding waiver home health services and waiver personal care use, two-thirds (65.6 percent) of waiver recipients used some of the broad array of less-medically oriented services offered under the waiver, with younger persons having a higher proportion of use than older persons (73.3 percent vs. 59.6 percent).

In the overall sample, the 5 remaining individual waiver services were used by at most 22 percent of persons (transportation), and by as few as 4 percent of persons (residential services). There was little variation in the proportion of use across age groups for these 5 remaining individual waiver service categories. Among these 5 remaining services, residential services had the highest mean expenditures among those with any use ($15,819), with older persons having 25 percent more expenditures on average than younger persons. Mean expenditures for those persons with any use of one of these services were next highest for adult day services ($8,774), followed by respite care ($4,202), meals ($1,399), and transportation ($1,141).

8.6.2 Remaining Independent Variables in the Analysis.

In reporting the characteristics of the sample on remaining variables (***Table 28***), we report differences by age group only if they are large. Otherwise, we report results for the overall sample only.

Demographic variables. Approximately 43.8 percent of sample members were under age 65. Our sample was purposefully drawn to obtain an approximately equal number of respondents under and over age 65. Sample members were predominately female (73.5 percent), although older persons had a much higher proportion of female respondents than younger persons (81.3 percent vs. 63.5 percent). Approximately 73.5 percent of sample members were Caucasian, and fewer respondents were African American (17.0 percent) or Asian or another race (9.5 percent).

Table 28
Remaining independent variables

Variable Name	Overall sample (n=17,927)	Under age 65 (n=7,885)	Age 65 and over (n=10,042)
Demographics	%	%	%
Age under 45	15.71	35.73	0
Age 45–64	28.27	64.27	0
Age 65–74	21.51	0	38.40
Age 75–84	21.28	0	37.99
Age 85 and over	13.23	0	23.61
Male	26.52	36.46	18.72
Caucasian race	73.54	76.50	71.22
African American race	16.99	15.31	18.30
Asian or other race	9.47	8.19	10.48
Health and Functional Status			
Responded by proxy	29.50	27.99	30.68
Fair/poor health	69.93	71.48	68.72
Good/very good health	26.79	23.80	29.13
Excellent health	3.28	4.72	2.15
Number of IADL limitations	3.3	3.3	3.3
Number of ADL limitations	2.9	3.2	2.7
Ever SNF patient	19.43	18.21	20.38
Some or a great deal of pain last 6 weeks	83.73	82.36	84.81
Pressure sores	9.93	12.47	7.94
Bladder bowel problems	63.88	64.93	63.05
Unmet need index	0.8	0.9	0.7
Social Characteristics and Residence			
Social participation	71.66	76.25	68.05
Live in group setting	9.23	7.96	10.22
Dually eligible	78.30	54.46	97.01
Receiving cash assistance	54.44	55.51	53.59
Washington	23.22	25.07	21.76
Wisconsin	10.99	11.07	10.93
Alabama	21.51	19.73	22.90
Kentucky	44.28	44.12	44.40

ADL= activities of daily living; IADL=instrumental activities of daily living; SNF=skilled nursing facility.

SOURCE: RTI analysis of 2003/2004 Medicaid claims and survey data.
Program: hcbs_claim_24_mean.log.

Health and functional characteristics. Most sample members reported their overall health as being either fair or poor (69.9 percent), with only 26.8 percent reporting their overall health as good or very good and only 3.3 reporting excellent. The overall sample reported approximately 2.9 deficits in the activities of daily living, but younger persons reported substantially more deficits than older persons (3.2 vs. 2.7). The overall sample reported 3.3 deficits in the instrumental activities of daily living, which did not vary by age group. Approximately 19.4 percent reported having ever been receiving nursing facility services, 83.7 percent reported pain in the last 6 weeks, 9.9 percent reported having pressure sores, and 63.9 percent had problems with their bladder or bowel. Sample members reported 0.8 unmet ADL/IADL needs. Approximately 29.5 percent of respondents were proxies for the sample member, which serves as a measure of diminished mental capacity.

Social characteristics and residence. A high proportion of respondents (71.7 percent) reported participating in social activities in the community, though this differed greatly by age group, with 76.3 percent of younger persons and 68.1 percent of older persons doing so. Approximately 9.2 percent of the sample was in residential care settings. Not surprisingly, dual eligibility differed sharply across age groups, with 54.5 percent of younger persons having Medicare as opposed to 97.0 percent of older persons. Approximately 54.4 percent of respondents were receiving some form of cash assistance, most likely Supplemental Security Income, reflecting Medicaid's means-tested eligibility criteria. The largest proportion of sample members resided in Kentucky (44.3 percent), followed by Washington (23.2), Alabama (21.5), and Wisconsin (11.0 percent).

8.6.3 Multivariate Regression Results.

We used our Logit (***Table 29***) and ordinary least squares (OLS) (***Table 30***) multivariate results to predict changes in the mean amount of the dependent variable, other Medicaid expenditures (inpatient, nursing facility, outpatient, and prescription drugs and durable medical equipment), associated with increases of $100 in monthly use (only for persons with use) of each of the HCBS programs in the models. These $100 monthly increases resulted in only very modest changes in other Medicaid expenditures as shown in ***Table 31***, with almost no difference across age groups. We also calculated the marginal effect of having a broad vs. a narrow array of waiver services, which resulted in a net change of +$92 annually.

In the Logit regression in the overall sample, a dollar increase in every HCBS except for waiver respite care was associated with a small but statistically significant increase in the probability of having other Medicaid expenditures. The same was true in the regressions on the separate age groups, except for residential services and the combined home health, environmental modifications, supplies, training, and other category among younger persons and for meals among older persons.

The same was not true for the ordinary least squares (OLS) regressions, where in the overall sample half of the services increased other Medicaid expenditures and half decreased other Medicaid expenditures. State plan personal care, waiver respite care, and adult day services decreased other Medicaid expenditures, while state plan home health, waiver personal care, and meals increased other Medicaid expenditures. The same was often true for

Table 29
Logit regression on any combined Medicaid expenditures (excluding HCBS)

	Overall Sample (n=17,927)		Under Age 65 (n=7,885)		Age 65 and Over (n=10,042)	
Variable Name	Coefficient	Standard Error	Coefficient	Standard Error	Coefficient	Standard Error
Medicaid Program Variables						
State Plan Personal Care	0.00088	0.00015**	0.00075	0.00027**	0.00101	0.00020**
State Plan Home Health	0.00212	0.00042**	0.00355	0.00116**	0.00133	0.00045**
Residential Care Services	0.00203	0.00030**	–0.00017	0.00052	0.00370	0.00063**
Personal Care	0.00122	0.00012**	0.00082	0.00016**	0.00189	0.00021**
Respite Care	–0.00023	0.00028	0.00056	0.00063	–0.00086	0.00034*
Adult Day Services	0.00841	0.00368*	0.00793	0.00397*	—	—
Meals	0.00223	0.00096*	0.01768	0.00348**	–0.00164	0.00112
Nursing, Therapies, Supplies, Environmental Modifications, Training, and Other Services	0.00192	0.00071**	0.00048	0.00057	0.00659	0.00131**
Demographics						
Age under 45	–0.68586	0.17328**	–1.04202	0.17081**	—	—
Age 45–64	0.18806	0.16903	—	—	—	—
Age 65–74 (reference group)	—	—	—	—	—	—
Age 75–84	–0.58744	0.15861**	—	—	–0.63111	0.16373**
Age 85 and over	–1.41694	0.16266**	—	—	–1.43860	0.17362**
Male	–0.57574	0.10120**	–0.43633	0.16239**	–0.71980	0.14435**
Caucasian race (reference group)	—	—	—	—	—	—
African American race	–0.11826	0.11809	1.19218	0.26115**	–0.67254	0.15690**
Asian or other race	–0.35269	0.13821*	0.43652	0.28716	–0.82746	0.17165**
Health and Functional Status						
Responded by proxy	0.14261	0.11322	0.42754	0.21347*	0.18329	0.14594
Fair/poor health	1.25349	0.17003**	1.67526	0.22292**	–0.05074	0.44700
Good/very good health	1.49945	0.18071**	2.33111	0.26037**	0.12131	0.45628
Excellent health (reference group)	—	—	—	—	—	—
Number of IADL limitations	0.18268	0.05528**	0.05546	0.08342	0.24452	0.07433**
Number of ADL limitations	–0.12402	0.02804**	–0.05173	0.04633	–0.14407	0.03994**
Ever SNF patient	0.36226	0.12593**	–0.19859	0.20307	0.82507	0.18976**
Some or a great deal of pain last 6 weeks	0.55581	0.11317**	0.81067	0.18669**	0.46782	0.15870**

(continued)

Table 29 (continued)
Logit regression on any combined Medicaid expenditures (excluding HCBS)

Variable Name	Overall Sample (n=17,927) Coefficient	Overall Sample (n=17,927) Standard Error	Under Age 65 (n=7,885) Coefficient	Under Age 65 (n=7,885) Standard Error	Age 65 and Over (n=10,042) Coefficient	Age 65 and Over (n=10,042) Standard Error
Pressure sores	0.03784	0.15604	–0.13090	0.25262	0.35467	0.22283
Bladder bowel problems	0.44949	0.09464**	0.52545	0.16284**	0.42145	0.12778**
Unmet need index	–0.00686	0.03074	0.09027	0.05676	–0.05031	0.03899
Social Characteristics and Residence						
Social participation	–0.03719	0.10595	–0.39942	0.21492	0.12232	0.13082
Live in group setting	–0.06144	0.18998	1.33431	0.47491**	–0.49658	0.22836*
Dually eligible	–0.17000	0.13756	–0.55498	0.17748**	0.79576	0.25024**
Receiving cash assistance	0.40262	0.11694**	0.05619	0.18177	0.46527	0.16116**
State 1	–2.24898	0.17756**	–1.86463	0.30058**	–2.36949	0.23291**
State 2	–0.63914	0.26425*	–0.43062	0.43646	–0.77905	0.34892*
State 3	–2.37520	0.19274**	–2.55587	0.29523**	–2.67309	0.25464**
Constant	2.39488	0.33336**	2.48112	0.45827**	2.68484	0.63716**

* Statistically significant at $p<0.05$;

** Statistically significant at $p<0.01$.

ADL= activities of daily living; HCBS=home and community-based services; IADL=instrumental activities of daily living; SNF=skilled nursing facility

SOURCE: RTI analysis of 2003/2004 Medicaid claims and survey data. Program: hcbs_claim_25.log.

Table 30
Ordinary least squares (OLS) regression on logged combined Medicaid expenditures (excluding HCBS)

	Overall Sample (n=17,340)		Under Age 65 (n=7,659)		Age 65 and Over (n=9,681)	
Variable Name	Coefficient	Standard Error	Coefficient	Standard Error	Coefficient	Standard Error
HCBS Policy Variables						
State Plan Personal Care	–0.00006	0.00002*	–0.00012	0.00003**	0.00002	0.00004
State Plan Home Health	0.00017	0.00003**	0.00024	0.00004**	0.00009	0.00004*
Residential Care Services	–0.00004	0.00004	–0.00025	0.00009**	0.00003	0.00005
Personal Care	0.00005	0.00002**	0.00004	0.00002	0.00004	0.00002
Respite Care	–0.00015	0.00008*	0.00001	0.00012	–0.00031	0.00010**
Adult Day Services	–0.00024	0.00004**	–0.00034	0.00006**	–0.00005	0.00006
Meals	0.00069	0.00025**	0.00081	0.00040*	0.00028	0.00031
Nursing, Therapies, Supplies, Environmental Modifications, Training, and Other Services	0.00006	0.00006	0.00009	0.00006	0.00011	0.00018
Demographics						
Age under 45	–0.12534	0.03441**	–0.21879	0.03431**	—	—
Age 45–64	0.20121	0.02759**	—	—	—	—
Age 65–74 (reference group)	—	—	—	—	—	—
Age 75–84	–0.23607	0.02802**	—	—	–0.24820	0.02680**
Age 85 and over	–0.37704	0.03331**	—	—	–0.45973	0.03254**
Male	–0.19301	0.02188**	–0.23476	0.03200**	–0.10802	0.03049**
Caucasian race (reference group)	—	—	—	—	—	—
African American race	–0.04740	0.02686	–0.12591	0.04317**	–0.02542	0.03432
Asian or other race	0.02231	0.03233	0.02843	0.05413	0.02098	0.03948
Health and Functional Status						
Responded by proxy	–0.14767	0.02379**	–0.28732	0.04032**	–0.04971	0.02923
Fair/poor health	0.36772	0.05424**	0.55618	0.07531**	0.13350	0.08045
Good/very good health	0.10969	0.05489*	0.08166	0.07673	0.03812	0.08110
Excellent health (reference group)	—	—	—	—	—	—
Number of IADL limitations	0.01732	0.01037	0.01115	0.01640	0.01680	0.01331
Number of ADL limitations	0.01787	0.00580**	0.01835	0.00887*	0.01639	0.00786*
Ever SNF patient	0.02086	0.02342	0.01118	0.03870	0.00726	0.02911
Some or a great deal of pain last 6 weeks	0.26441	0.02663**	0.22915	0.04220**	0.25586	0.03401**

(continued)

Table 30 (continued)
Ordinary least squares (OLS) regression on logged combined Medicaid expenditures (excluding HCBS)

	Overall Sample (n=17,340)		Under Age 65 (n=7,659)		Age 65 and Over (n=9,681)	
Variable Name	Coefficient	Standard Error	Coefficient	Standard Error	Coefficient	Standard Error
Pressure sores	–0.03666	0.03131	–0.18485	0.04603**	0.15056	0.04401**
Bladder bowel problems	0.05170	0.01990**	0.05663	0.03234	0.04988	0.02497*
Unmet need index	0.01831	0.00569**	0.01392	0.00819	0.01463	0.00801
Social Characteristics and Residence						
Social participation	0.03352	0.02102	0.07515	0.03569*	–0.01528	0.02558
Live in group setting	0.39459	0.03735**	0.31232	0.06088**	0.47652	0.04680**
Dually eligible	–0.08817	0.02659**	–0.06244	0.03128*	–0.28149	0.07178**
Receiving cash assistance	–0.02002	0.02102	–0.00838	0.03309	–0.05606	0.02758*
State 1	0.08389	0.03001**	0.28166	0.04619**	–0.14786	0.04017**
State 2	0.28718	0.03683**	0.45766	0.05921**	0.12362	0.04678**
State 3	–0.45415	0.03288**	–0.50711	0.05126**	–0.37133	0.04741**
Constant	5.53781	0.07465**	5.61191	0.10091**	5.98042	0.12491**

* Statistically significant at p<0.05;

** Statistically significant at p<0.01.

ADL= activities of daily living; HCBS=home and community-based services; IADL=instrumental activities of daily living; SNF=skilled nursing facility

SOURCE: RTI analysis of 2003/2004 Medicaid claims and survey data. Program: hcbs_claim_25.log.

Table 31
Changes in other Medicaid expenditures resulting from $100 HCBS increase

HCBS Program	Annual Dollar Change	Annual Percentage Change
State Plan Personal Care	–7	–0.07
State Plan Home Health	+64	+0.65
Waiver Services	+21	+0.21
Broad vs. Narrow Array	+92	+0.93

*Mean of Dependent Variable is $9,884

younger persons, but only 2 services were statistically significant for older persons (state plan home health and waiver respite care).

Given that almost all person-month observations had positive other Medicaid expenditures, we report only the statistically significant results from the ordinary least squares (OLS) regressions for the remaining variables. Many of the demographic factors were often statistically significant at $p<0.05$. In the overall sample and in the regressions on the under and over age 65 subgroups, persons who were at the lower or higher end of the age continuum had a lower amount of other Medicaid expenditures than persons in the 45–64 and 65–74 age groups. Males always had a lower amount of expenditures. African Americans had a lower amount of expenditures in the younger population.

Many of the health and functional characteristics were also statistically significant predictors of the amount of other Medicaid expenditures. Younger persons with a proxy had a lower amount of expenditures in the overall sample and the younger population. Reporting fair or poor health status (as opposed to excellent) was associated with higher other Medicaid expenditures in the overall sample and the younger population, while reporting good or very good health status was associated with higher other Medicaid expenditures in the overall sample. An increase in the number of ADL limitations was associated with higher other Medicaid expenditures in the overall sample and both age groups. Having one of the 4 health-related conditions (prior nursing facility use, pain, pressure sores, or bladder/bowel problems) was often associated with higher other Medicaid expenditures, except for reporting pressure sores in the younger population, which was associated with a lower amount of expenditures. Having one additional unmet need was associated with only slightly higher expenditures in the overall sample.

Among social characteristics, social participation led to higher other Medicaid expenditures only for younger persons. Living in a group setting was associated with higher other Medicaid expenditures in the overall sample and both age groups. Dual eligibility was associated with lower other Medicaid expenditures in the overall sample and both age groups.

Receiving cash assistance was associated with lower other Medicaid expenditures only in the older population.

8.7 Discussion

Many researchers have attempted to measure the cost effectiveness of HCBS over the last two decades. Previous studies almost always analyze its effects on nursing home expenditures alone, and little has been known to date about the cost effectiveness of HCBS considering all other Medicaid expenditures. This study evaluates the association of HCBS with all other Medicaid expenditures in a multi-state sample.

As measured in this study, increases in HCBS spending were not associated with large changes in other Medicaid expenditures, either positively or negatively. A change of $100 per month in expenditures for any HCBS program resulted in a change ranging from –$7 to +$64, which represents less than two-thirds of a percent change in other Medicaid expenditures, which had a mean of $9,884 in the overall sample. The marginal effect of giving consumers a broad vs. a narrow array of HCBS services was approximately $92, still less than 1 percent of other Medicaid expenditures. These findings imply that while state policymakers can increase HCBS spending without incurring large increases in other Medicaid expenditures, they cannot count on large decreases in other Medicaid expenditures. This finding supports CMS's policy of basing budget neutrality on nursing facility expenditures, as opposed to all other Medicaid expenditures.

The results from our Logit regression model show that unit increases of $1 in HCBS programs almost uniformly slightly increased the probability of having other Medicaid expenditures. But the results from our ordinary least squares (OLS) model show that unit increases of $1 for half of the HCBS slightly decreased other Medicaid expenditures and for the remaining half of HCBS slightly increased other Medicaid expenditures. HCBS recipients may be gaining greater access to other Medicaid services, but the absolute change in expenditures is minimal. We were not able to investigate any causal mechanisms by which HCBS acted on components of other Medicaid expenditures.

Use of individual waiver services varied widely, ranging from a high of 100 percent for the combined waiver category representing home health, environmental modifications, supplies, training, and other services, to a low of 4 percent for residential care services. Apart from the heavy use of waiver personal care and waiver home health services, two-thirds of consumers used at least one of the non-medical waiver services, indicating the importance of providing a broad array of services to support community living. Not everyone needs these services, but nursing facility use would potentially be higher without their availability in the waiver.

Only one other study (Van Houtven and Domino 2005) assesses the effect of HCBS use on other Medicaid expenditures, but it only examined the use of waiver services. Consistent with our results, that study found that participation in a waiver program in North Carolina was not associated with lower total Medicaid expenditures (inclusive of HCBS in their study). Our study, which excluded HCBS expenditures from the dependent variable, shows that additional HCBS expenditures are associated with slightly greater access to other Medicaid services. In part, HCBS waivers, in particular, may give consumers case management, which may connect them with the broader health care delivery system. In addition, beneficiaries may receive more services because HCBS providers see them regularly and frequently and may notice the need to go to the doctor or to use other services.

We could not test for selection into HCBS because we did not have a control group in our study. Selection might exist at two levels—at the individual level, where potentially sicker persons enter HCBS, or at the state level, where use of HCBS may be a function of abundant providers or the type of HCBS sponsoring agency. Regarding excess supply of providers, Van Houtven and Domino (2005) did not find a selection effect for inpatient and nursing home expenditures, but did find a selection effect for total Medicaid expenditures, resulting in upward bias in their estimates. If there were upward bias in our estimates, our finding of little or no increase in other Medicaid expenditures serves as an upper bound, meaning that while other Medicaid expenditures are no higher because of HCBS expenditures, they potentially may be associated with lower other Medicaid expenditures.

Van Houtven and Domino also did not find a selection effect into the waiver based on diagnosis categories, though there was some evidence to that end. They did find a selection effect for Medicare eligibility, for which we control in our analysis. We did not include diagnostic information in our models, but did include self-report of other health-related characteristics (e.g. pain, bladder/bowel problems) in an attempt to address the effects of differences in patient condition for which one might seek additional Medicaid services.

Our lack of a control group of persons without HCBS prevented us from conducting analyses to completely assess the cost benefit or cost effectiveness of HCBS. Other researchers (Grabowski 2006; Van Houtven and Domino 2005; Kitchener, Carrillo, and Harrington 2004; Wiener et al. 2004) have noted the need for these additional types of analyses. Those types of analyses were beyond the scope of this study. Other research should consider the effects of HCBS spending on the components of other Medicaid expenditures, as well as the cost benefit or cost effectiveness of HCBS.

CHAPTER 9
CONCLUSIONS

One of the major changes in long-term care has been the growth in use of and expenditures for HCBS, especially through the Medicaid program. Despite this growth, little research has been done concerning who uses services and the experiences of Medicaid beneficiaries who do. As a result, policymakers have had little data on which to make their policy decisions.

This study is a major research effort to examine Medicaid home and community-based services for older adults and younger people with physical disabilities. A companion component of the study examined home and community-based services for persons with intellectual disabilities/developmental disabilities.

In the first phase of the older adults and younger people with physical disabilities component of the project, case studies of the home and community-based service system were conducted in Alabama, Indiana, Kentucky, Maryland, Michigan, Washington, and Wisconsin. In the second phase of the study, surveys were conducted of Medicaid home and community-based services beneficiaries in all of the case study states except for Indiana. In the third and final phase of the project, Medicaid claims data was matched to the survey respondents in Alabama, Kentucky, Washington, and Wisconsin. Medicaid claims data was not available in time for Maryland, and Michigan's capitated payment system did not allow for a detailed analysis of use and expenditures.

The surveys, with and without merged Medicaid claims data, were used to analyze several issues of importance to federal and state policymakers, including a descriptive analysis of home and community-based services beneficiaries and their experiences, satisfaction with personal assistance services, workforce issues, consumer-directed services, medication use, the effect of home and community-based services on Medicaid expenditures and use of acute care services. The results of these studies provide a rich set of findings that help understand these growing services.

From the studies presented in this report, the following implications can be drawn:

- Medicaid home and community-based services are serving a population that it was designed to serve—beneficiaries with fairly high levels of functional and cognitive disabilities and with fair and poor health. Despite state options to provide eligibility for somewhat higher income persons, the vast majority of Medicaid home and community-based services beneficiaries were very low income. Of substantial policy concern is that pain were very prevalent and pressure sores were relatively common, both of these problems could be areas for additional focus by Medicaid officials.

- Medicaid beneficiaries express high levels of satisfaction with Medicaid home and community-based services, an important measure of program success. The study findings regarding racial concordance underline the importance of cultural competence in long-term care. In addition, the lower level of satisfaction by younger people with disabilities with group living arrangements, such as residential care facilities, suggests the need for some caution regarding expanding those waiver services.

- Satisfaction with long-term care depends heavily on the people who provide the services, most of which are hands on and often highly intimate and personal. Again, while not without problems, Medicaid beneficiaries expressed high levels of general satisfaction with their direct care workers. Overall, Medicaid beneficiaries' satisfaction was more related to having somebody provide needed services than necessarily having continuity with the same person overtime.

- One of the most contentious issues in consumer-directed home care is whether the quality of care is as high as it is for agency-directed care. Consumer-directed care typically lacks the training requirements and the professional supervision that is more common in agency-directed care. Our study of Washington state finds no statistical evidence that satisfaction with consumer-directed care is lower than with agency-directed care. In fact, older people with disabilities are more satisfied with consumer-directed care than with agency-directed care. While satisfaction is not synonymous with quality, it is an important component of quality.

- The hallmark of modern care of chronic illnesses is treatment with prescription drugs. A large majority of Medicaid home and community-based services beneficiaries report that they receive the medications that they need and most have help in taking their medications. For the minority of people not receiving the medications they need, perceptions of cost and transportation problems are key variables. These results underscore the need to monitor the effect of cost sharing on Part D use by the "extra help" population and the importance of social services in linking people to the use of prescription drugs.

- Federal and state policymakers are concerned about the health care use of people with disabilities both from the perspective of its high costs and the problems of access that they often have. Using versus not using Medicaid HCBS services appears to improve access to outpatient services, broadly defined, prescription drugs and DME, and inpatient services. At least for prescription drugs, the improvement in access may be offset by a reduction in the number of prescription/DME claims by at least a portion of the population resulting in no net change in monthly prescription/DME claims. For inpatient services, HCBS waiver services are associated with an increase in hospital discharges, suggesting that the services function to link beneficiaries to services.

- One of the goals of home and community-based services is to reduce other Medicaid expenditures so that there are no net costs. This study found that using versus not using HCBS services has a very small impact on non-HCBS expenditures. Thus, using versus not using HCBS services does not increase or decrease total non-HCBS Medicaid services.

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APPENDIX A

MEDICAID HOME & COMMUNITY BASED WAIVER PROGRAM STUDY, AGED AND DISABLED SURVEY QUESTIONNAIRE

MATHEMATICA
Policy Research, Inc.

Medicaid Home & Community Based Waiver Program Study

Aged/Disabled Questionnaire

May 2003

INTRODUCTION

Intro We would like to talk with you about your health and the help you receive at home with day-to-day activities such as bathing, dressing or preparing meals. We will also ask about **paid** help you may receive with daily activities from a home care worker, family or friend.

INTERVIEWER: NOT ALL SAMPLE MEMBERS WILL KNOW IF HELPER/AIDE/WORKER IS PAID. IF SAMPLE MEMBER IS UNCERTAIN, PLEASE SEEK CONFIRMATION FROM THE PERSON WHO KNOWS THE MOST ABOUT SAMPLE MEMBER'S CARE.

This interview takes about 30-40 minutes. If you would like to make yourself comfortable, I can wait a minute or two. If you get tired, we can take a break and I will call you back at your convenience.

A. ASKS FOR DATE OF BIRTH AND PERCEPTION OF HEALTH STATUS. ESTABLISHES/CONFIRMS SAMPLE MEMBER RECEIVING HELP (UNPAID AND/OR PAID)

A1. According to our records your date of birth is [FILL DATE OF BIRTH], is this correct?

<1> YES → **goto A2**
<0> NO → **goto A1a**

<d> DON'T KNOW
<r> REFUSED → **goto A2**

A1a. What is your date of birth? (When were you born?)

MM/DD/YY

<d> DON'T KNOW
<r> REFUSED

A2. In general, compared to other people your age, would you say your health is . . .

<1> excellent,
<2> very good,
<3> good,
<4> fair, or
<5> poor?

<d> DON'T KNOW
<r> REFUSED

REVIEWERS: THE FOLLOWING QUESTIONS PROVIDE DATA THAT INFORM QUESTIONS IN MODULE D.

(A3-A3a-j - ADAPTED FROM NHIS)

A3. Our next questions are about the kinds of help with home and personal care that you may receive.

A3a. Does someone usually help you with light housework or laundry?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3b. (Does someone usually help you) shop for groceries or personal items?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3c. (Does someone usually help you) prepare meals?

INTERVIEWER: 1. IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>

2. IF SAMPLE MEMBER EATS MEALS IN A CONGREGATE SETTING, CODE <1>

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3d. (Does someone usually help you) to take medication or remind you to take it?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>

<1> YES
<0> NO
<7> DON'T TAKE MEDICATION

<d> DON'T KNOW
<r> REFUSED

A3e. (Does someone usually help you) walk or get about?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3f. (Does someone usually help you) get in or out of bed or chairs?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>

<1> YES
<2> BEDBOUND
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3g. (Does someone usually help you) take a bath or shower?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3h. (Does someone usually help you) use the toilet, including getting to the toilet?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>

IF THE SAMPLE MEMBER DOES NOT USE THE TOILET, ANSWER THIS QUESTION ABOUT ANY HELP THEY GET USING AND EMPTYING A COMMODE, BED PAN OR URINAL; MANAGING CLOTHING AND WIPING OR CLEANING THE BODY AFTER ELIMINATION; OR CARING FOR A CATHETER OR COLOSTOMY

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3i. (Does someone usually help you) get dressed or dress you?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3j. (Does someone usually help you) eat or feed you?

INTERVIEWER: IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

IF ANY QUESTIONS A3a-j ARE YES <1> ASK A3L, ELSE SKIP TO A3M.

(Programmer (tA3L): IF A3a-j ALL EQUAL <0>, <d>, <r>, SKIP TO A3M, ELSE ASK A3L)

A3L. You just told me that you receive help with [FILL ITEMS CODED YES IN A3a-j]. Are any of the people who help you . . .

A3La. From an agency or organization?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3Lb. Someone you or your family hired directly?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3Lc. Family or friends who are paid to help you?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

tA3M. **INTERVIEWER: IS A3L1 OR A3L2 OR A3L3 CODED "YES"?**

<1> YES ➞ **goto B1**
<0> NO

<d> DON'T KNOW
<r> REFUSED

A3M. According to our records, you received help in [MONTH] from [PROGRAM] with home and/or personal care. Do you still receive this **help**?

IF NO, PROBE: Did you ever get help from [PROGRAM]?

PROBE: By now we mean during the past 2 weeks, since [FILL DATE].

PROBE: This could be help from an agency or organization, or someone you or your family hired directly, or family or friends paid to help you.

<1> YES
<0> NOT CURRENTLY RECEIVING HELP ➞ **SAMPLE MEMBER ineligible** ➞ **goto end screen**
<9> NEVER RECEIVED HELP ➞ **goto end screen**

<d> DON'T KNOW
<r> REFUSED

A4a. Please describe this help or care to me.

ENTER TEXT AND END WITH //

INTERVIEWER: PROBE FOR DETAIL THAT WILL HELP YOU TO CODE RESPONSES BELOW. IF NECESSARY, READ LISTS TO PROMPT SAMPLE MEMBER.

CODE ALL THAT APPLY

<1> DOES/HELPS DO LIGHT HOUSEWORK/LAUNDRY
<2> SHOPS/TAKES SHOPPING/HELPS SHOP FOR GROCERIES/ PERSONAL ITEMS
<3> HELPS PREPARE/PREPARES MEALS
<4> GIVES/HELPS TAKE MEDICATION/REMINDS (HOW MUCH) TO TAKE
<5> HELPS WALK/MOVE AROUND/MAKES SURE DOESN'T FALL
<6> HELPS GET IN/OUT BED/CHAIRS/MAKES SURE DOESN'T FALL
<7> GIVES (SPONGE) BATH/HELPS WASH/BATHE/SHOWER
<8> HELPS USE TOILET/COMMODE/BEDPAN/ETC. HELPS GET TO TOILET/MAKES SURE DOESN'T FALL
<9> DRESSES/HELPS PUT ON CLOTHES/ZIPS/BUTTONS UP
<10> HELPS EAT/CUTS UP FOOD/PUTS IN MOUTH/HELPS ME DRINK
<11> OTHER (SPECIFY AND END WITH //) [specify]

<d> DON'T KNOW
<r> REFUSED

B. MARITAL STATUS AND LIVING ARRANGEMENTS

B1. Next, I'd like to ask you about your living arrangements. First, please tell me, are you **now** married or living with a partner, widowed, divorced or separated or have you never married?

<1> MARRIED/LIVING WITH A PARTNER
<2> WIDOWED
<3> DIVORCED
<4> SEPARATED
<5> NEVER MARRIED

<d> DON'T KNOW
<r> REFUSED

B2. Do you live . . .

INTERVIEWER: CONFIRM WITH SAMPLE MEMBER IF KNOWN FROM SCREENER.

<1> in your own house, ➞ **goto B2b**
<2> in your own apartment, ➞ **goto B2a**
<3> in a relative's or friend's house or apartment, ➞ **goto B2b**
<4> in adult foster care or in a group home, or
<5> in an assisted living home?
<9> OTHER ARRANGEMENT
(SPECIFY AND END WITH //) ➞ **goto B2c**

<d> DON'T KNOW
<r> REFUSED

B2a. Is your apartment in an assisted living facility?

PROBE: Assisted living facilities are sometimes called "supported housing" or "continuing care communities." Staff are sometimes available to help with things like personal care, housework, and preparing meals.

<1> YES ➞ **goto B2c**
<0> NO

<d> DON'T KNOW
<r> REFUSED

B2b. How many people live with you in (your home/your relative's home)?

PROBE: Do not include yourself.

PROBE: Most or all of the time.

< > NUMBER OF PEOPLE

<0> LIVES ALONE
<d> DON'T KNOW
<r> REFUSED

→ **ALL goto B3a**

B2c. Including yourself, about how many people now live where you live?

PROBE: Please include yourself in that number.

PROBE: Your best estimate is fine.

<2-100> NUMBER OF PEOPLE

<d> DON'T KNOW
<r> REFUSED

B2d. Do you have your own room or do you share a room?

<1> OWN
<2> SHARE

<d> DON'T KNOW
<r> REFUSED

→ **goto proxy decision**

B3a. Who chose your living arrangement? Was it you, a family member, a friend, a care manager (service coordinator) or the Medicaid program?

INTERVIEWER: CODE ALL THAT APPLY

<1> OWN CHOICE
<2> FAMILY MEMBER/FRIEND
<3> CARE MANAGER (SERVICE COORDINATOR)/MEDICAID PROGRAM
<4> NO CHOICE JUST WORKED OUT THIS WAY
<5> OTHER (SPECIFY AND END WITH //) [specify]

<d> DON'T KNOW
<r> REFUSED

B3b. Do you like living where you live now or would you like to live somewhere else?

<1> LIKES LIVING WHERE LIVES ➞ **goto B3d**
<0> WOULD LIKE TO LIVE SOMEWHERE ELSE

<d> DON'T KNOW ⎤
<r> REFUSED ⎦ → **goto B3d**

B3c. Why would you like to live somewhere else?

INTERVIEWER: CODE ALL THAT APPLY

PROBE: Any other reasons?

<1> LONELY/WANT TO LIVE WITH OTHER PEOPLE
<2> FEEL UNSAFE HERE/BAD NEIGHBORHOOD
<3> FEEL TOO ISOLATED
<4> WANT MORE ASSISTANCE/CARE
<5> WOULD PREFER TO LIVE WITH FAMILY
<6> WOULD PREFER TO LIVE ALONE
<7> TOO EXPENSIVE
<8> TOO HARD TO KEEP UP
<9> TOO MANY RULES AND REGULATIONS
<10> NO AUTONOMY/SOMEONE ALWAYS TELLING YOU WHAT TO DO/ CAN'T DO WHAT I LIKE WHEN I LIKE
<11> NO PRIVACY
<0> OTHER (SPECIFY AND END WITH //) [specify]

<d> DON'T KNOW
<r> REFUSED

B3d. Would you say that in your neighborhood there is . . .

PROBE: By neighborhood, we mean right around where you live. About five blocks in any direction.

<1> a lot of crime,
<2> some crime, or
<0> little or no crime?

<d> DON'T KNOW
<r> REFUSED

IF QUESTION B2 = LIVES IN ADULT FOSTER CARE, A GROUP HOME OR IN AN ASSISTED LIVING HOME OR SOME OTHER ARRANGEMENT, CONTINUE WITH B3e, OTHERWISE goto C1

(tB3e. IF B2 = <4>, <5>, <9> OR IF B2a = <1>, ASK B3e, ELSE goto C1)

B3e. How would you describe the people who live where you live? Would you say they are [FILL BASED ON BDAT] all age sixty or older, all people younger than age sixty with disabilities, or a mixture of ages?

<1> SIXTY AND OLDER
<2> ALL YOUNGER PEOPLE WITH DISABILITIES
<3> A MIXTURE

<d> DON'T KNOW
<r> REFUSED

C. HEALTH

C1. Next, I have a few more questions related to your health.

Have you **ever** been a resident or a patient in a nursing home?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

C2. How would you describe your eyesight wearing glasses or contact lenses if necessary? Would you say you have . . .

<1> no trouble seeing,
<2> a little trouble seeing, or
<3> a lot of trouble seeing?

<d> DON'T KNOW
<r> REFUSED

C3. How would you describe your hearing using a hearing aid if necessary. Would you say you have . . .

<1> no trouble hearing,
<2> a little trouble hearing, or
<3> a lot of trouble hearing?

<d> DON'T KNOW
<r> REFUSED

C4. This next question is about pain. In the past four weeks, would you say you have had . . .

<1> no pain
<2> some pain, or
<3> a great deal of pain?

<d> DON'T KNOW
<r> REFUSED

C5. At any time in the past six months, that is, since [FILL MONTH], have you had pressure sores? These are also called bed sores or decubitus (*dikyu'bitus*) ulcers.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

C6. Answers to the next questions are important. They can help us make improvements to general health care and services for people who use them.

During the last six months, that is, since [FILL MONTH], have you sometimes had trouble controlling your bladder or bowels?

<1> YES
<2> IN DWELLING CATHETER
<3> COLOSTOMY BAG
<0> NO PROBLEM ➞ **goto D1**

<d> DON'T KNOW
<r> REFUSED ➞ **goto D1**

C6a. Was this a problem with controlling your bladder, your bowels, or both?

<1> BLADDER
<2> BOWELS
<3> BOTH

<d> DON'T KNOW
<r> REFUSED

D. INFORMAL AND FORMAL HELP WITH ADL/IADLs. IDENTIFIES PRIMARY INFORMAL CAREGIVER AND PAID CAREGIVERS, UNMET NEED INCLUDING SPECIAL EQUIPMENT

D1. Now, I'd like to ask you about some help or care you may have received during the last week from people, who are **not** paid to help you. I will be asking about family members, friends, and volunteers. I will ask about paid helpers later.

During the last week, did someone, who is **not** paid, help you with personal care, like bathing, taking medication, using the toilet, or with activities like eating, getting around indoors, light housework, shopping, paying bills, doing laundry or taking you places?

PROBE: That's since [FILL DAY OF WEEK] of last week.

<1> YES
<0> NO ➞ **goto dd1**

<d> DON'T KNOW
<r> REFUSED

D2. Now, please think about all the different family members, friends, or others who were **not** paid and who helped you in the last week. How many different people is that? Please include help you get from people who live or stay with you.

PROBE: That's since [FILL DAY OF WEEK] of last week.

PROBE: Please include any help from a (child/parent).

PROBE: How many people helped you with personal care like bathing, using the toilet or with taking medication, or with activities like eating, getting around indoors, light housework, shopping, paying bills, doing laundry or taking you places?

<1-15> NUMBER OF UNPAID HELPERS

<d> DON'T KNOW
<r> REFUSED

D3. Did (this person/any of these [FILL NUMBER IN D2] people) live or stay in the same (household/place) as you? [(FILL IF B2 = <1>, <2> OR <3> AND B2a = <0>)]

PROBE: Please include anyone staying in your household at least three nights last week.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

tD4. IF D3 = YES AND D2 RESPONSE IS GREATER THAN 1, ASK D4, ELSE goto D5

D4. How many of the [FILL NUMBER IN D2] people we just talked about live in the same (household/place) as you?

FILL IF B2 = <1>, <2> OR <3> AND B2a = <0> **PROBE:** Do not include people who come and stay overnight just to help you but usually live elsewhere.

PROGRAMMER: D4 D2

<0> NO/NONE
<1-15> UNPAID HELPERS IN SAME (HOUSEHOLD/PLACE)

<d> DON'T KNOW
<r> REFUSED

D5. You told me that [FILL someone/[NUMBER IN D2] people] who (is/are) **not** paid helped you during the last week. How (is this person/are) [each of] these people) related to you?

PROBE: That's since [FILL DAY OF WEEK] of last week.

PROBE: Including (someone/people) who live(s) in the same (household/place) as you who helped you during the last week.

PROBE: Please do **not** include anyone who is **paid** to help.

PROBE: That is help with personal care like bathing, using the toilet or with taking medication, or with activities like eating, getting around indoors, light housework, shopping, paying bills, doing laundry or taking you places?

INTERVIEWER: CODE ALL THAT APPLY

<1> SPOUSE
<2> MOTHER
<3> FATHER
<4> DAUGHTER
<5> DAUGHTER-IN-LAW
<6> SON
<7> SON-IN-LAW
<8> SISTER
<9> BROTHER
<10> SISTER-IN-LAW
<11> BROTHER-IN LAW
<12> NIECE
<13> NEPHEW
<14> GRANDPARENT
<15> GRANDCHILD
<16> OTHER RELATIVE
<17> NON RELATIVE

<d> DON'T KNOW
<r> REFUSED

tD6. PROGRAMMER: IF D2 = MORE THAN ONE, ASK D6, ELSE goto D8

D6. Thinking about the people you've told me about who helped you last week and are **not** paid, is there one person who helps you the most?

PROBE: Help with personal care like bathing, using the toilet or with taking medication, or with activities like eating, getting around indoors, light housework, shopping, paying bills, doing laundry or taking you places.

<1> YES
<0> NO

goto dd1

<d> DON'T KNOW
<r> REFUSED

D7. How is this person related to you?

<1> SPOUSE
<2> MOTHER
<3> FATHER
<4> DAUGHTER
<5> DAUGHTER-IN-LAW
<6> SON
<7> SON-IN-LAW
<8> SISTER
<9> BROTHER
<10> SISTER-IN-LAW
<11> BROTHER-IN LAW
<12> NIECE
<13> NEPHEW
<14> GRANDPARENT
<15> GRANDCHILD
<16> OTHER RELATIVE
<17> NON RELATIVE

<d> DON'T KNOW
<r> REFUSED

dd1. **INTERVIEWER: DOES THE SAMPLE MEMBER SEEM FATIGUED, CONFUSED OR NEED REINFORCEMENT?**

REINFORCEMENT PROBE:

- Your answers are very helpful.
- You're doing fine.

FATIGUE PROBE:

- Are you feeling tired or can we continue?
- Would you like to take a break? I can hold on.
- Would you like to continue the interview at another time?

<1> NOT FATIGUED, NO REINFORCEMENT GIVEN
<2> FATIGUED AND WANTS TO CONTINUE
<3> GAVE REINFORCEMENT ONLY
<4> FATIGUED, GAVE REINFORCEMENT AND WANTS TO CONTINUE
<5> FATIGUED AND WANTS TO BE CALLED BACK ➞ **goto CALL BACK**

D8. The next questions are about help or care you may receive from people who are **paid** to help you. This could be help from an agency or organization, someone you or your family hired directly, or family or friends who are paid to help you.

tD8a. IF B2 = <5> OR B2a = <1> (ASSISTED LIVING), goto D10a, ELSE ASK D8a.

D8a. You told me earlier you receive help with [FILL ITEMS CODED YES HELP IN A3a-j AND/OR ITEMS CODED <1> TO <11> IN A4a]. How many different people who were **paid** helped with these activities last week? Please include people from [STATE PROGRAM] people who help as part of their job, someone you or your family hired directly, or friends or family members who are paid to help out.

PROBE: That's since [FILL DAY OF WEEK] of last week.

[FILL IF B2 = <4> **PROBE:** The people who usually care for or help you.

<1-15> NUMBER OF PAID HELPERS
<0> NO **PAID** HELP LAST WEEK ➞ **goto D16**

<d> DON'T KNOW
<r> REFUSED ➞ **goto D16**

tD9. PROGRAMMER: IF B2 = <4>, goto D10a, ELSE ASK D9

D9. During the last week, did (this person/any of these [FILL NUMBER IN D8] people) live in the same (household/place) as you? Please include anyone staying (in your household/where you live) at least three nights last week.

INTERVIEWER: CONFIRM IF KNOWN FROM PREVIOUS DISCUSSION WITH SM/PROXY.

PROBE: People who are **paid** to help.

PROBE: That's since [FILL DAY OF WEEK] of last week.

[FILL IF B2 = <3>, <4>, <9> OR B2a = 1 **PROBE:** The people who usually care for or help you.]

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

tD9a. IF D9 = YES AND D8a RESPONSE IS GREATER THAN 1, ASK D9a, ELSE goto D10.

D9a. How many of the [FILL NUMBER IN D8] people who are paid to help you with [FILL ITEMS CODED YES HELP IN A3a-j AND/OR ITEMS CODED <1> TO <11> IN A4a] live in the same (household/place) as you all or part of the week?

PROGRAMMER: D9a D8a

<0-10> PAID HELPERS IN SAME (HOUSEHOLD/PLACE)

<d> DON'T KNOW
<r> REFUSED

D10. [FILL Is the person/Are any of the people] who are **paid** to help(s) you with [FILL ITEMS CODED YES HELP IN A3a-j AND/OR ITEMS CODED <1> TO <11> IN A4a] a family member, friend or neighbor?

<1> YES ➞ **goto D11**
<0> NO

<d> DON'T KNOW
<r> REFUSED
→ **goto D12**

D10a. You told me earlier, you received help with [FILL ITEMS ETC.]. [FILL Is the person/Are any of the people] who (is/are) **paid** to help you a family member, friend or neighbor?

<1> YES
<0> NO ➞ **goto D12**

<d> DON'T KNOW
<r> REFUSED
→ **goto D12**

D11. How (is this person/are [each of] these people) related to you?

INTERVIEWER: CODE ALL THAT APPLY--IF FRIEND OR NEIGHBOR, CODE <17>?

<1> SPOUSE
<2> MOTHER
<3> FATHER
<4> DAUGHTER
<5> DAUGHTER-IN-LAW
<6> SON
<7> SON-IN-LAW
<8> SISTER
<9> BROTHER
<10> SISTER-IN-LAW
<11> BROTHER-IN LAW
<12> NIECE
<13> NEPHEW
<14> GRANDPARENT
<15> GRANDCHILD
<16> OTHER RELATIVE
<17> NON RELATIVE

<d> DON'T KNOW
<r> REFUSED

D12. Please think about the **paid** help and care you receive with [FILL ITEMS CODED YES HELP IN A3a-j AND/OR ITEMS CODED <1> TO <11> IN A4a]. (Does the same person/Do the same people) usually help you with these activities or do people change from week to week?

<1> SAME PEOPLE
<2> CHANGES FROM WEEK TO WEEK ➞ **goto D14**

<d> DON'T KNOW
<r> REFUSED

D13. Still thinking about **paid** help, please give me the first name of the person who usually helps you the most with [FILL ITEMS CODED YES HELPED IN A3a-j AND/OR ITEMS CODED <1> TO <11> IN A4a].

PROBE: It makes it easier for me to refer to people if I have their first names.

INTERVIEWER: IF SAMPLE MEMBER SAYS HELP RECEIVED EQUALLY FROM MORE THAN ONE HELPER, ENTER NAMES OF *TWO* WHO HELP THE MOST.

ENTER TEXT

<00> MORE THAN TWO AND ALL HELP EQUALLY

<d> DON'T KNOW
<r> REFUSED

D14. **NO QUESTION D14 IN THIS VERSION.**

D15. Now let's talk some more about the **paid** help you receive.

Thinking about the **paid** help you receive with [FILL ALL ADLs/IADLs CHECKED IN A3a-j AND/OR A4a <1> - <11>], how often do you decide when and how things are done? Would you say . . .

<1> all of the time,
<2> most of the time,
<3> some of the time, or
<0> never?

<d> DON'T KNOW
<r> REFUSED

UNMET NEED

D16. Have there been times in the past month when you didn't put on clean clothes as often as you would have liked because no one was there to help you?

PROBE: That's from [FILL DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D17. Have there been times in the past month when you have not bathed or showered because someone wasn't there to help you?

PROBE: That's from [FILL DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D18. Have there been times in the past month that you didn't eat because no one was there to help you eat or feed you?

PROBE: That's from [FILL DAY, MONTH] through today.

PROBE: Including cutting food into easy pieces and/or feeding you.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D19. Have there been times in the past month when you didn't move out of a bed or chair because no one was there to help you?

PROBE: That's from [FILL DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D20. Have there been times in the past month when you didn’t walk or move about indoors because no one was there to help you?

PROBE: That’s from [FILL DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON’T KNOW
<r> REFUSED

D21. During the past month, were you unable to eat or have the kind of food that you want to eat because no one was available to prepare or cook meals?

PROBE: (VERIFY IF YES)
And that’s because no one was available to prepare or cook meals?

PROBE: That’s from [FILL DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON’T KNOW
<r> REFUSED

D22. During the past month, did you have a bladder or bowel accident because no one was there to help you?

PROBE: That’s from [FILL (DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON’T KNOW
<r> REFUSED

PROGRAMMER: IF SAMPLE MEMBER LIVES IN ADULT FOSTER CARE, IN A GROUP HOME, OR AN ASSISTED LIVING HOME OR SOME OTHER ARRANGEMENT (IF B2 = <4>, <5> OR <9> OR B2a = <1>), goto D25, ELSE goto D23.

D23. During the past month, did you miss a meal because no one was able to help you shop for groceries?

PROBE: That's from [FILL DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D24. During the past month, were there times that your housework, such as dishes, straightening up, or laundry, didn't get done because there was no one to help you?

PROBE: That's from [FILL DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D25. The next questions are about any medicine you may take.

INTERVIEWER: INCLUDE PRESCRIPTIONS AS WELL AS OVER THE COUNTER MEDICINE.

Do you take medications on a **regular** basis?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D26. Have there been times in the past month, when you have had problems with taking **any** medication because no one was available to help you?

PROBE: That's from [FILL DAY, MONTH] through today.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D27. In the past month, was there any time when you didn't buy or obtain medicine that you thought you needed?

PROBE: That's from [FILL DAY, MONTH] through today.

<1> YES
<0> NO ➞ **goto D29**

<d> DON'T KNOW
<r> REFUSED ➞ **goto D29**

D28. What was the main reason you didn't buy or obtain medicine?

<1> TOO SICK/FRAIL/DISABLED/NOBODY TO GO FOR ME/ PHARMACIES DON'T DELIVER
<2> TRANSPORTATION PROBLEM
<3> COST TOO MUCH/COULDN'T AFFORD
<4> PLAN WOULDN'T PAY FOR PRESCRIPTION
<5> SAMPLE MEMBER TOO BUSY TO TAKE TIME
<6> PHARMACY/PHYSICIANS HOURS INCONVENIENT
<7> THOUGHT I'D GET BETTER WITHOUT IT
<8> OTHER (SPECIFY AND END WITH //)

<d> DON'T KNOW
<r> REFUSED

D29. Now I'd like to ask you about special equipment.

Is there any special equipment you **need** but **do not have** to help you with . . .

PROGRAMMER: SET UP CODE ALL THAT APPLY MENU

<1> dressing, like special fasteners on clothes,
<2> bathing or showering, like a shower seat, tub stool, or grab bar,
<3> eating, like special utensils or dishes,
<4> getting in or out of bed or chairs, like a wheelchair, railing, walker or cane,
<5> walking or moving about, like a cane or walker,
<6> using the toilet, like a raised toilet seat or grab bar, or help getting to the toilet?
<7> anything else? [specify]
<n> NO OTHER RESPONSES

<d> DON'T KNOW
<r> REFUSED

td29a In D29 if any responses <1> to <7> coded 1, goto D29a, else goto td30

D29a. (You said that you do not have the special equipment you need to help you with [FILL ACTIONS]). Please tell me why you do not have the equipment you need.

<1> CAN'T AFFORD/TOO EXPENSIVE
<2> INSURANCE DOESN'T COVER/MEDICAID WON'T PAY
<3> IT LOOKS/SEEMS TOO DIFFICULT TO USE
<4> CAN'T FIND/DON'T KNOW WHERE TO GET IT
<5> NOT ENOUGH SPACE
<6> TOO EMBARRASSED TO GET IT
<7> RESTRICTIONS WHERE I LIVE ABOUT INSTALLING IT
<8> FAMILY DOESN'T WANT IT INSTALLED
<9> OTHER (SPECIFY AND END WITH //) [specify]

<d> DON'T KNOW
<r> REFUSED

tD30. **IF SAMPLE MEMBER LIVES IN AN ADULT CARE HOME, A GROUP HOME OR ASSISTED LIVING ENVIRONMENT (B2 = <4> <5> OR <9> OR B2a = <1>), goto D31, ELSE ASK D30.**

D30. Sometimes people get meals delivered to their home. Do you regularly get meals delivered to your home by an agency or organization like Meals on Wheels?

INTERVIEWER: REGULARLY = ON A ROUTINE BASIS WITH AT LEAST FOUR MEALS DELIVERED IN LAST MONTH.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

tD31a. **IF SAMPLE MEMBER LIVES IN ASSISTED LIVING FACILITY, GROUP HOME OR FOSTER CARE HOME, ASK D31, ELSE ASK D31a.**

D31. Do you usually eat meals with others where you live in a dining room or lunch room?

PROBE: At least one meal a day

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

→ **goto D32**

D31a. Do you usually eat meals at an adult day care facility or at some other program where you spend the day?

PROBE: At least one meal a day.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

D32. During the past month, how often have you been unable to go where you wanted because of lack of transportation? Would you say . . .

PROBE: That's from [FILL DAY, MONTH] through today.

<1> many times,
<2> a few times, or
<0> never?

<d> DON'T KNOW
<r> REFUSED

D32a. In the past month, have you used a special bus, cab or van service for people who have difficulty using regular transportation?

PROBE: That's from [FILL DAY, MONTH] through today.

PROBE: Sometimes people are given free passes to use this type of service.

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

E. ASSISTANCE (NOT ASKED OF SAMPLE MEMBERS IN ASSISTED LIVING ENVIRONMENT)

IF QUESTION B2 = LIVES IN ADULT FOSTER CARE, A GROUP HOME OR AN ASSISTED LIVING HOME OR SOME OTHER ARRANGEMENT, goto MODULE F, OTHERWISE CONTINUE WITH E1

(tE1. IF B2 = <4>, <5> OR <9> OR B2a = <1>, goto MODULE F ELSE goto E1)

E1. I have a few more questions about the **paid** help you receive with personal care or help at home.

About how long have you received **paid** help or care at home? Would you say . . .

PROBE: Your best estimate is fine.

<1> less than three months
<2> three to six months
<3> six to twelve months
<4> one to two years
<5> two to three years
<6> more than three years

<d> DON'T KNOW
<r> REFUSED

E2. About how many different **paid** helpers have worked with you in the past [FILL: (6 months, that is, since [FILL WITH TODAY'S MONTH MINUS 6 MONTHS])?
IF E1=2 through 6, d, or r (3 months, that is, since [FILL WITH TODAY'S MONTH MINUS 3 MONTHS])?
IF E1=1]

PROBE: Your best guess is fine.

<1-20> NUMBER

<d> DON'T KNOW
<r> REFUSED → **goto E2b**

E2a. Did the [FILL NUMBER FROM E2] **paid** (helpers/helper) who helped you with [FILL ALL ITEMS CODED YES HELPED IN A3a-j AND/OR ITEMS CODED <1> TO <11> IN A4a] usually work for an agency or organization, were they independent workers who were hired directly by you or a family member, or did both kinds of people help you?

<1> WORKED FOR AGENCY OR ORGANIZATION
<2> INDEPENDENT WORKERS
<3> BOTH

<d> DON'T KNOW
<r> REFUSED

E2b. When you need to replace a **paid** helper, who takes care of finding a replacement?

INTERVIEWER: CODE ALL THAT APPLY

INTERVIEWER: NOTE: IF A SAMPLE MEMBER/FAMILY MEMBER CALLS THE AGENCY OR ORGANIZATION FOR A REPLACEMENT, CODE <3> FOR AGENCY OR ORGANIZATION

<1> SAMPLE MEMBER
<2> SAMPLE MEMBER'S FAMILY/FRIEND/NEIGHBOR/PROXY RESPONDENT
<3> AGENCY
<4> CASEWORKER/STATE/COUNTY
<5> OTHER (SPECIFY AND END WITH //) [specify]
<0> NEVER NEEDED TO REPLACE ➞ **goto E3**

<d> DON'T KNOW
<r> REFUSED

E2c. What have you usually done until a replacement was found?

INTERVIEWER: CODE ALL THAT APPLY

<1> FOUND REPLACEMENT RIGHT AWAY
<2> RELIED ON FAMILY/FRIENDS/NEIGHBORS
<3> DONE WITHOUT
<4> SOUGHT TEMPORARY PLACEMENT IN FACILITY
<5> USED TEMPORARY **PAID** HELP
<6> OTHER (SPECIFY AND END WITH //) [specify]

<d> DON'T KNOW
<r> REFUSED

E2d. Have you ever had a problem or difficulty finding a replacement?

PROBE: Whatever you considered a problem or difficulty.

<1> YES
<0> NO →

<d> DON'T KNOW
<r> REFUSED

E2e. What were the problems or difficulties you experienced?

INTERVIEWER: CODE ALL THAT APPLY

<1> AIDE DIDN'T WANT TO WORK THE HOURS SM NEEDED
<2> AIDE/HELPER NOT WILLING TO PROVIDE KIND OF HELP I NEEDED
<3> INSUFFICIENT PAY/HELPER/AIDE WANTED MORE MONEY
<4> HELPER/AIDE NEEDED MORE HOURS
<5> GENDER OF POTENTIAL HELPER/AIDE
<6> NEIGHBORHOOD SM LIVES IN/HARD TO GET PEOPLE TO WORK THERE
<7> TRANSPORTATION
<8> RACE/ETHNICITY OF POTENTIAL HELPER/AIDE
<9> DIDN'T LIKE/TRUST ANY OF THE PEOPLE WHO WANTED TO WORK FOR ME
<10> OTHER (SPECIFY AND END WITH //) [specify]

<d> DON'T KNOW
<r> REFUSED

PROGRAMMER: IF D12 = <2>, goto E5, ELSE ASK E3

E3. Thinking about last week, how many days, Monday through Friday, did ([FILL NAME(S) FROM D13]/your **paid** helper(s)) help you or care for you?

<0-5> DAYS

<d> DON'T KNOW
<r> REFUSED

E3a. Thinking about last week, did you get **paid** help on Saturday or Sunday?

PROBE: Was that just Saturday or Sunday or both days?

<1> SATURDAY ONLY
<2> SUNDAY ONLY
<3> BOTH SATURDAY AND SUNDAY
<0> NEITHER

<d> DON'T KNOW
<r> REFUSED

E4a. Thinking about Monday to Sunday last week, about how many hours would you say ([NAME(S) FROM D13]/your **paid** helper(s)) spent helping you with [FILL ITEMS CODED YES HELPED IN A3a-j AND/OR ITEMS CODED <1> to <11> in A4a]?

PROBE: Your best estimate is fine.

INTERVIEWER: HELP SAMPLE MEMBER COMPUTE HOURS. IF HELP LIVES IN, PROBE FOR HOURS ON DUTY/SHIFT HOURS.

<2-168> HOURS PER WEEK ➞ **goto E7**

<d> DON'T KNOW
<r> REFUSED

E4b. Perhaps you could estimate? Was it . . .

PROBE: Your best estimate is fine.

<1> 2-4 hours,
<2> 5-10 hours,
<3> 11-20 hours,
<4> 21-40 hours,
<5> 41-60 hours,
<6> 61-80 hours,
<7> 81-120 hours,
<8> 121 or more?

<d> DON'T KNOW
<r> REFUSED

E5. In general, would you say the number of hours of **paid** help that you get from your helpers, weekly are . . .

<1> far too few,
<2> not quite enough,
<3> just about right,
<4> a little more than you need, or
<5> much more than you need?

<d> DON'T KNOW
<r> REFUSED

E6. Is there someone else who helps you when your usual **paid** helper(s) (doesn't/don't) show up?

PROBE: [FILL NAME(S) FROM D13.]

<1> YES
<0> NO
<n> PAID WORKER ALWAYS SHOWS UP ➞ **goto ee1**

<d> DON'T KNOW
<r> REFUSED

E7. Who helps you when ([FILL NAME(S) FROM D13]/your **paid** helpers) (is/are) not available?

INTERVIEWER: CODE ALL THAT APPLY

<1> DAUGHTER/SISTER
<2> SON/BROTHER
<3> DAUGHTER IN-LAW/SISTER IN-LAW
<4> SON-IN-LAW/BROTHER-IN-LAW
<5> MOTHER
<6> FATHER
<7> OTHER FEMALE RELATIVE
<8> OTHER MALE RELATIVE
<9> NEIGHBORS OR FRIENDS/OTHER NON-RELATIVE
<10> VOLUNTEER FROM AGENCY OR ORGANIZATION
<11> **PAID** SUBSTITUTE
<12> OTHER (SPECIFY AND END WITH //)
<0> NO ONE

<d> DON'T KNOW
<r> REFUSED

ee1. **INTERVIEWER: DOES THE SAMPLE MEMBER SEEM FATIGUED, CONFUSED OR NEED REINFORCEMENT?**

REINFORCEMENT PROBE:

- Your answers are very helpful.
- You’re doing fine.

FATIGUE PROBE:

- Are you feeling tired or can we continue?
- Would you like to take a break? I can hold on.
- Would you like to continue the interview at another time?

<1> NOT FATIGUED, NO REINFORCEMENT GIVEN
<2> FATIGUED AND WANTS TO CONTINUE
<3> GAVE REINFORCEMENT ONLY
<4> FATIGUED, GAVE REINFORCEMENT AND WANTS TO CONTINUE
<5> FATIGUED AND WANTS TO BE CALLED BACK ➞ **goto CALL BACK**

F. SOCIAL/RECREATIONAL ACTIVITIES, EDUCATION AND EMPLOYMENT

F1. Next, I have some questions about activities outside the home.

In the last week, please tell me on how many days you went out, either alone or with someone? Would you say . . .

PROBE: That is, since [FILL DAY OF WEEK] last week.

<0> never, ➞ **goto tF3**
<1> on one or two days,
<2> on three or four days,
<3> on five or six days, or
<4> every day?

<d> DON'T KNOW
<r> REFUSED

F2. Thinking about your most recent outing, did you . . .

INTERVIEWER: CODE ALL THAT APPLY

<1> visit or meet friends or relatives,
<2> go shopping,
<3> go to see a doctor or other health care provider,
<4> go for a walk, including a trip in a wheelchair,
<5> eat out,
<6> go to a movie, play, concert or other entertainment, or
<7> do something else?

<d> DON'T KNOW
<r> REFUSED

PROGRAMMER (tF3): IF SAMPLE MEMBER IS AGE 65 OR OLDER, goto SECTION G, ELSE ASK F3

F3. The following questions are about education and employment.

In the last 6 months, that is, since [FILL MONTH], have you attended any school or participated in any training programs or taken any classes? Please include regular high school, GED classes, vocational or trade school, or other types of school as well as training programs to learn job skills.

PROBE: That is, since [FILL MONTH, YEAR].

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

F4. In the last 6 months, that is, since [FILL MONTH], have you done any work for pay . . .

PROBE: That is, since [FILL MONTH, YEAR].

PROBE: Include any work you might have done in your own business where you got a regular paycheck.

<1> YES ➞ **goto Module G**
<0> NO

<d> DON'T KNOW
<r> REFUSED

F4a. In the last six months, did you do any **unpaid** work?

PROBE: That is, since [FILL MONTH, YEAR].

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

F5. Would you like to work at a **paid** job?

<1> YES
<0> NO ➞ **goto Module G**

<d> DON’T KNOW
<r> REFUSED

F6. Why didn’t you work at a paid job in the last six months? Was it because you couldn’t get the help you needed with personal care, or transportation, or is there some other reason that you didn’t work at a paid job in the last six months?

INTERVIEWER: CODE ALL THAT APPLY

<1> PERSONAL CARE,
<2> TRANSPORTATION, OR
<3> ANOTHER REASON? (SPECIFY)

<d> DON’T KNOW
<r> REFUSED

G. SATISFACTION WITH LIFE (TO BE ASKED OF SAMPLE MEMBER ONLY)

G1aint. **INTERVIEWER: ARE YOU SPEAKING WITH SM?**

<1> YES ➞ **goto G1**
<0> NO ➞ **goto G1bint**

G1bint. **ASK TO SPEAK WITH SAMPLE MEMBER--EXPLAIN THESE QUESTIONS ARE ABOUT FEELINGS THAT MANY PEOPLE CAN ANSWER EVEN THOUGH THEY MAY NOT BE ABLE TO ANSWER FACTUAL QUESTIONS.**

<1> SAMPLE MEMBER UNABLE TO ANSWER FOR SELF ➞ **goto H1a**
<2> PROXY AGREED AND SAMPLE MEMBER AVAILABLE ➞ **goto G1**
<3> SAMPLE MEMBER LIVES ELSEWHERE OR UNAVAILABLE **PROGRAMMER: SET CASE FOR CALL BACK FOR MODULE G AND goto tH1**
<r> PROXY REFUSED ➞ **goto H1A**

G1. These next few questions are about how you feel and how things have been with you in the past month.

How much of the time during the past month did you feel full of energy? Was it . . .

PROBE: That's from [FILL DAY, MONTH] through today.

<1> most or all of the time,
<2> some of the time, or
<3> hardly ever?

<d> DON'T KNOW
<r> REFUSED

G2. How much of the time (during the past month) have you felt so down in the dumps nothing could cheer you up? Was it . . .

PROBE: That's from [FILL DAY, MONTH] through today.

<1> most or all of the time,
<2> some of the time, or
<3> hardly ever?

<d> DON'T KNOW
<r> REFUSED

G3. How much of the time (during the past month) have you felt calm and peaceful? Was it . . .

PROBE: That's from [FILL DAY, MONTH] through today.

<1> most or all of the time,
<2> some of the time, or
<3> hardly ever?

<d> DON'T KNOW
<r> REFUSED

G4. How much of the time (during the past month) did you feel worn out? Was it . . .

PROBE: That's from [FILL DAY, MONTH] through today.

<1> most or all of the time,
<2> some of the time, or
<3> hardly ever?

<d> DON'T KNOW
<r> REFUSED

G5. How much of the time (during the past month) have you been a happy person? Was it . . .

PROBE: That's from [FILL DAY, MONTH] through today.

<1> most or all of the time,
<2> some of the time, or
<3> hardly ever?

<d> DON'T KNOW
<r> REFUSED

G6. How much of the time (during the past month) did you feel that you were being pushed around in life? Was it . . .

PROBE: That's from [FILL DAY, MONTH] through today.

<1> most or all of the time,
<2> some of the time, or
<3> hardly ever?

<d> DON'T KNOW
<r> REFUSED

G7. **INTERVIEWER: IN YOUR OPINION IS SM ABLE TO CONTINUE WITH THE QUESTIONS?**

<1> YES
<0> NO

G7a. WAS THE INTERVIEW BEING CONDUCTED WITH . . .

<1> PROXY, OR
<2> SM?

H. SATISFACTION WITH CARE (TO BE ASKED OF SAMPLE MEMBER OR INFORMAL CAREGIVER)

tH1. **PROGRAMMER:** **IF G1 = <3> SET CASE FOR CALL BACK FOR MODULE H AND goto K1, ELSE goto H1**

H1. **INTERVIEWER:** **ARE YOU SPEAKING WITH SAMPLE MEMBER OR PROXY RESPONDENT?**

<1> THE SAMPLE MEMBER ➞ **goto H1b**
<2> PROXY ➞ **goto H1a**

H1a. **INTERVIEWER:** **IS PROXY A PAID CAREGIVER NAMED IN D13 (PROGRAMMER [FILL NAMES FROM D13]) AND/OR IDENTIFIED IN SCREENER?**

<1> PROXY IS A PAID CAREGIVER ➞ **goto K1**
<2> PROXY IS UNPAID CAREGIVER ➞ **goto H1b**

H1b. Our next questions are about how satisfied you are with the help you receive and how much control you feel you have over day-to-day decisions.

For this series of questions, please think of the help and care you receive from ([FILL NAME(S) IN D13]/your **paid** helper(s)).

Please tell me how happy overall you are with the **paid** care and help you receive? Would you say . . .

<1> very happy,
<2> somewhat happy,
<3> somewhat unhappy, or
<4> very unhappy?

<d> DON’T KNOW
<r> REFUSED

H2. How much control do you feel you have over your life? Would you say you have . . .

<1> a lot of control,
<2> some control,
<3> a little control, or
<4> no control?

<d> DON'T KNOW
<r> REFUSED

H3. When you have had a problem with a **paid** helper, has it ever been difficult to get it resolved or fixed?

PROBE: Whatever you consider a problem.

<1> YES
<0> NO
<7> NEVER HAD A PROBLEM

<d> DON'T KNOW
<r> REFUSED

tH4. PROGRAMMER: IF SAMPLE MEMBER IN GROUP, FOSTER HOME OR ASSISTED LIVING ARRANGEMENT (B2 = <4>, <5>, <9> OR B2a = <1>) OR IF MORE THAN ONE NAME IN D13, goto H6, ELSE ASK H4

H4. Who makes sure [FILL NAME IN D13] comes when scheduled and does the job the way it should be done? Is it you, a care manager (service coordinator), a supervisor, a family member or friend or someone else?

<1> SAMPLE MEMBER
<2> CARE MANAGER (SERVICE COORDINATOR)
<3> FAMILY MEMBER/FRIEND/NEIGHBOR
<4> AGENCY/SUPERVISOR
<5> OTHER (SPECIFY AND END WITH //) [specify]
<0> NO ONE

<d> DON'T KNOW
<r> REFUSED

H5. Who signs your main helper's time sheet?

<1> SAMPLE MEMBER
<2> CARE MANAGER (SERVICE COORDINATOR)
<3> FAMILY MEMBER/FRIEND/NEIGHBOR
<4> AGENCY/SUPERVISOR
<5> OTHER (SPECIFY AND END WITH //) [specify]
<0> NO ONE

<d> DON'T KNOW
<r> REFUSED

H6. In general, how well do you and ([FILL NAME(S) IN D13]/your **paid** helper(s)) get along? Would you say you get along . . .

<1> very well,
<2> well,
<3> not very well, or
<4> not at all well?

<d> DON'T KNOW
<r> REFUSED

H7. In general, do you have any trouble communicating with ([FILL NAME(S) IN D13]/any of your **paid** helpers))?

<1> YES, HAVE TROUBLE COMMUNICATING
<0> NO, DO NOT HAVE ANY TROUBLE ➞ **goto H9**

<d> DON'T KNOW
<r> REFUSED

H8. Is this because of . . .

<1> language difficulties,
<2> hearing or speech problems, or
<3> something else? (SPECIFY)

<d> DON'T KNOW
<r> REFUSED

H9. In the past month, how often have you had problems with ([FILL NAME(S) IN D13]/any of your **paid** helpers) ignoring you? Would you say . . .

PROBE: That's from [FILL DAY, MONTH] to today.

<0> never,
<1> seldom,
<2> sometimes,
<3> often, or
<4> very often?

<d> DON'T KNOW
<r> REFUSED

H10. How often, if at all, in the past month, did ([FILL NAME(S) IN D13]/any of your **paid** helpers) get impatient with you or rush you? Would you say . . .

PROBE: That's from [FILL DAY, MONTH] to today.

<0> never,
<1> seldom,
<2> sometimes,
<3> often, or
<4> very often?

<d> DON'T KNOW
<r> REFUSED

tH10a. IF C6 = <0>, ASK tH11, ELSE goto tH10a

H10a. When you need help with bladder or bowel care, (do/does) ([FILL NAME(S) IN D13]/your **paid** helper(s)) assist you quickly enough? Would you say . . .

<1> always,
<2> almost always,
<3> seldom, or
<4> never?

<d> DON'T KNOW
<r> REFUSED

tH11. PROGRAMMER: IF E2a = 1 OR 3, ASK H11, ELSE goto H12

H11. Have you or a family member **ever** complained to a care manager (service coordinator) or someone at the agency employing them that your **paid** helpers ignored, or were impatient with you?

<1> YES
<0> NO → **goto H12**

<d> DON'T KNOW
<r> REFUSED

H11a. Did the care manager (service coordinator) or someone at the agency resolve the problem?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

H12. How often, if at all, did ([FILL NAME(S) IN D13]/one of your **paid** helper(s)) treat you badly in the past month? Would you say . . .

<0> never,
<1> seldom,
<2> sometimes,
<3> often, or
<4> very often?

<d> DON'T KNOW
<r> REFUSED

H13. In general, do you think ([FILL NAME(S) IN D13]/your **paid** helper(s)) (is/are) competent and well-trained?

<1> YES
<2> SOME HELPERS ARE, SOME ARE NOT
<0> NO
<3> SOMETIMES/IT DEPENDS

<d> DON'T KNOW
<r> REFUSED

H14. Do you think ([FILL NAME(S) IN D13]/your **paid** helper(s)) (is/are) respectful of you and the way you like things done . . .

<1> YES
<2> SOMETIMES/DEPENDS
<0> NO

<d> DON'T KNOW
<r> REFUSED

tH14a. PROGRAMMER: IF SAMPLE MEMBER IN GROUP, FOSTER HOME OR ASSISTED LIVING ARRANGEMENT (B2=<4>, <5> OR <9> OR B2a=<1>), goto H15, ELSE ASK H14a

H14a. Do you often have the following problems with your paid helper(s).

INTERVIEWER: CODE ALL THAT APPLY

<1> helpers do not show up on days they are scheduled or at all?
<2> helpers show up late?
<3> helpers do not work as hard as they should?

<d> DON'T KNOW
<r> REFUSED

tH14b. PROGRAMMER: IF <1>, <2>, OR <3> CODED IN H14a, ASK H14b, ELSE goto H15

H14b. When these things happen, how much of a problem overall is it for you? Would you say is it . . .

<1> a big problem,
<2> a little problem, or
<3> no problem at all?

<d> DON'T KNOW
<r> REFUSED

hh1. **INTERVIEWER: DOES THE SAMPLE MEMBER SEEM FATIGUED, CONFUSED OR NEED REINFORCEMENT?**

REINFORCEMENT PROBE:

- Your answers are very helpful.
- You're doing fine.

FATIGUE PROBE:

- Are you feeling tired or can we continue?
- Would you like to take a break? I can hold on.
- Would you like to continue the interview at another time?

<1> NOT FATIGUED, NO REINFORCEMENT GIVEN
<2> FATIGUED AND WANTS TO CONTINUE
<3> GAVE REINFORCEMENT ONLY
<4> FATIGUED, GAVE REINFORCEMENT AND WANTS TO CONTINUE
<5> FATIGUED AND WANTS TO BE CALLED BACK ➞ **goto CALL BACK**

I. CONSUMER DIRECTION (NOT ASKED OF SAMPLE MEMBERS IN ASSISTED LIVING ENVIRONMENT)

tI1. PROGRAMMER: IF SAMPLE MEMBER LIVES IN OWN HOME (B2 = <1>, <2>) OR HOME OF RELATIVE (B2 = <3> AND B2a = <0>), goto tI2, ELSE goto Section K

tI2. PROGRAMMER: IF SAMPLE MEMBER'S PAID HELP CHANGES FROM WEEK TO WEEK (D12 = <2>),OR MORE THAN ONE NAME IN D13, goto I5, ELSE ASK I1

I1. Now I'd like to ask you about how you selected [FILL NAME FROM D13].

Were you given a list of agencies or individuals to choose from when selecting [FILL NAME FROM D13]?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

I2. Who chose [FILL NAME FROM D13]?

<1> CHOSEN BY AGENCY
<2> CHOSEN BY SAMPLE MEMBER
<3> CHOSEN BY SAMPLE MEMBER'S FAMILY/FRIENDS/ NEIGHBORS/PROXY RESPONDENT

<d> DON'T KNOW
<r> REFUSED

I3. Did you or a family member know [FILL NAME FROM D13] before (he/she) became your (main) **paid** helper?

<1> YES ➞ **goto I3a**
<0> NO ➞ **goto I4**

<d> DON'T KNOW
<r> REFUSED

I3a. How did you know [FILL NAME FROM D13] before (he/she) became your (main) **paid** helper?

<1> HELPER IS FAMILY MEMBER
<2> HELPER IS FRIEND OR NEIGHBOR
<3> HELPER REFERRED BY FAMILY MEMBER OR FRIEND
<4> HELPER WAS A SUBSTITUTE IN THE PAST/
WORKED FOR ME PREVIOUSLY
<5> OTHER (SPECIFY AND END WITH //)

<d> DON'T KNOW
<r> REFUSED

I4. Did you or a family member have the opportunity to interview [FILL NAME FROM D13] before (he/she) became your **paid** helper?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

I5. How much choice do you have in deciding what tasks ([FILL NAMES FROM D13]/your **paid** helpers) assist(s) you with or (do/does) for you? Would you say you have . . .

<1> total choice, → **goto I6**
<2> some choice, or
<3> no choice?

<d> DON'T KNOW
<r> REFUSED

I5a. How happy are you with the amount of choice you have in deciding what tasks ([FILL NAMES FROM D13]/your **paid** helpers) will (do/does) for you? Would you say you are . . .

<1> very happy,
<2> happy,
<3> somewhat happy, or
<4> not happy at all?

<d> DON'T KNOW
<r> REFUSED

I6. How much choice do you have over what time and which days ([FILL NAMES FROM D13]/your **paid** helpers) come(s)? Would you say you have . . .

<1> total choice, ➞ **goto Section J**
<2> some choice, or
<3> no choice?

<d> DON'T KNOW
<r> REFUSED

I6a. How happy are you with the amount of choice you have over scheduling ([FILL NAMES FROM D13]/your **paid** helpers)? Would you say you are . . .

<1> very happy,
<2> happy,
<3> somewhat happy, or
<4> not happy at all?

<d> DON'T KNOW
<r> REFUSED

J. CASE MANAGEMENT

J1. Now I'd like to ask you some questions about how your overall care is managed.

Is there someone who you think of as the one who is in charge of your overall care, (including your home care)? This person would also coordinate your personal or social services.

<1> YES
<0> NO ➞ **goto Section K**

<d> DON'T KNOW
<r> REFUSED

J2. Who is in charge of your overall care, including your home care?

INTERVIEWER: CODE ALL THAT APPLY

<1> DOCTOR
<2> CARE MANAGER (SERVICE COORDINATOR)
<3> OTHER PROVIDER
<4> FAMILY MEMBER
<5> FRIEND
<6> SAMPLE MEMBER ➞ **IF ONLY <6> SKIP TO J4**
<7> OTHER (SPECIFY AND END WITH //) [specify]

<d> DON'T KNOW
<r> REFUSED

J3. During the last six months, that is, since [FILL MONTH] about how often did you see or talk to the [FILL FROM J2] ([the person/people] who helps you coordinate your personal or social services)?

INTERVIEWER: USE AS PROMPT

<1> DAILY
<2> SEVERAL TIMES A WEEK
<3> ONCE A WEEK
<4> ONCE A MONTH
<5> ONCE EVERY TWO OR THREE MONTHS
<6> ONCE IN THE LAST SIX MONTHS
<7> NOT AT ALL

<d> DON'T KNOW
<r> REFUSED

J4. How do you feel about the amount of care coordination you receive? Would you say . . .

<1> you need a lot more,
<2> you need a little more,
<3> the amount of care coordination you receive is about right, or
<4> you receive too much care coordination?

<d> DON'T KNOW
<r> REFUSED

K. DEMOGRAPHICS

K1. I just have a few general questions about you and your helper(s) and then we'll be done.

What is the highest grade or level of school that you have completed?

<1> 8TH GRADE OR LESS
<2> SOME HIGH SCHOOL, BUT DID NOT GRADUATE
<3> HIGH SCHOOL GRADUATE OR GED
<4> SOME COLLEGE OR 2 YEAR DEGREE
<5> 4-YEAR COLLEGE GRADUATE
<6> MORE THAN 4 YEAR COLLEGE DEGREE
<7> OTHER (SPECIFY AND END WITH //)

<d> DON'T KNOW
<r> REFUSED

K2. Do you consider yourself to be of Hispanic or Latino origin, such as Mexican, Mexican-American, Puerto Rican, Cuban or other Spanish background?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

K3. What race do you consider yourself to be? Are you . . .

INTERVIEWER: CODE ONE OR MORE.

INTERVIEWER: IF SAMPLE MEMBER SAYS MULTI-RACIAL ASK HIM/HER TO PICK CATEGORIES THAT BEST DESCRIBE HIS/HER RACIAL OR ETHNIC BACKGROUND.

<1> American Indian Or Alaska Native
<2> Asian (E.G., Indian, Chinese, Japanese, Korean, Vietnamese)
<3> Black Or African American
<4> Native Hawaiian Or Other Pacific Islander
<5> Caucasian, Or
<6> Something Else (Specify And End With //)

<d> Don't Know
<R> Refused

INTERVIEWER: ASK ONLY IF NECESSARY, OTHERWISE CHECK APPROPRIATE CATEGORY.

K4. Are you male or female?

<1> MALE
<2> FEMALE

<d> DON'T KNOW
<r> REFUSED

tH15. PROGRAMMER: ASK H15 ABOUT (FIRST) MAIN PAID HELPER (AND H16 ABOUT SECOND MAIN HELPER). IF NO MAIN PAID HELPER(S), goto hh1

H15. Is [FILL NAME (1) FROM D13] of Hispanic or Latino origin, such as Mexican, Mexican-American, Puerto Rican, Cuban or other Spanish background?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

H15a. What race is he or she?

INTERVIEWER: CODE ONE OR MORE

INTERVIEWER: IF SAMPLE MEMBER SAYS MULTI-RACIAL ASK HIM/HER TO PICK CATEGORIES THAT BEST DESCRIBE HIS/HER RACIAL OR ETHNIC BACKGROUND.

<1> American Indian Or Alaska Native
<2> Asian (E.G., Indian, Chinese, Japanese, Korean, Vietnamese)
<3> Black Or African American
<4> Native Hawaiian Or Other Pacific Islander
<5> Caucasian, Or
<6> Something Else (Specify And End With //) [Specify]

<D> Don't Know
<R> Refused

tH16. PROGRAMMER: CHECK D13. IF NO SECOND MAIN PAID HELPER, goto hh1, ELSE ASK H16

H16. Is [FILL NAME (2) FROM D13] of Hispanic or Latino origin, such as Mexican, Mexican-American, Puerto Rican, Cuban or other Spanish background?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

H16a. What race is he or she?

INTERVIEWER: CODE ONE OR MORE

INTERVIEWER: IF SAMPLE MEMBER SAYS MULTI-RACIAL ASK HIM/HER TO PICK CATEGORIES THAT BEST DESCRIBE HIS/HER RACIAL OR ETHNIC BACKGROUND.

<1> American Indian Or Alaska Native
<2> Asian (E.G., Indian, Chinese, Japanese, Korean, Vietnamese)
<3> Black Or African American
<4> Native Hawaiian Or Other Pacific Islander
<5> Caucasian, Or
<6> Something Else (Specify And End With //) [Specify]

<D> Don't Know
<R> Refused

K5. And in the past year, approximately how much was your personal income from all sources before taxes were deducted? Please include income from wages before tax, Social Security Supplemental Security Income, rents, interest and dividends. Please stop me when I get to the appropriate category . . .

PROBE: Other studies have shown that income can affect how people use services so this is important information.

PROBE: Your best estimate is fine.
All information is kept confidential and only used for this study.

INTERVIEWER: ACCEPT $ AMOUNT IF SAMPLE MEMBER ONLY KNOWS NET.

INTERVIEWER: READ 1 - 9 SLOWLY

<1> less than $5,000,
<2> $5,000 or more but less than $10,000,
<3> $10,000 or more but less than $15,000,
<4> $15,000 or more but less than $20,000,
<5> $20,000 or more but less than $25,000,
<6> $25,000 or more but less than $30,000,
<7> $30,000 or more but less than $40,000, or
<8> $40,000 or more?

<d> DON'T KNOW
<r> REFUSED

K5a. **INTERVIEWER: IS THE AMOUNT IN K5 BEFORE OR AFTER TAXES?**

<1> BEFORE TAXES (GROSS)
<2> AFTER TAXES (NET)

L. DISRUPTIVE BEHAVIORS

L1. INTERVIEWER: ARE YOU SPEAKING WITH:

<1> THE SAMPLE MEMBER
<2> A PROXY ➞ **goto L3**

L2. INTERVIEWER: THANK RESPONDENT AND ASK TO SPEAK TO CONTACT PERSON IDENTIFIED IN SCREENER QUESTION ? AS PERSON WHO KNOWS MOST ABOUT SAMPLE MEMBER'S CARE AND/OR HELPS (HIM/HER) THE MOST.

L3. Sometimes people who depend on others for help behave in ways that make it difficult to care for them.

Does [FILL SAMPLE MEMBER] sometimes wander away, behave offensively to others, or behave in a way likely to cause injury to (him/her)self or others?

<1> YES
<0> NO ➞ **goto thnx**

<d> DON'T KNOW
<r> REFUSED

L4. How often must someone supervise [FILL SAMPLE MEMBER] because of this behavior? Is it . . .

<1> not at all,
<2> weekly or less often,
<3> several times a week,
<4> daily, or
<5> 24 hours a day?

<d> DON'T KNOW
<r> REFUSED

thnx. Thank you very much for your time. Those are all the questions I have. Your opinions and the experiences you have shared are very important to this research.

APPENDIX B
CMS MEDICAID HCBS STUDY MSIS ANALYTIC FILE DOCUMENTATION

CMS Medicaid HCBS Final MSIS Analytic File Documentation

Created: August 24, 2005
Updated: February 28, 2006 (added WA Aged-Disabled file information)

ID/DD States: AL, KY, OK, and WY

A/D States: MI, WA, KY, MD, AL, and WI

Analytic File Structure

- The analytic file is a person-month organization with minimal static information and monthly information from the eligibility and claims files.
- CMS MSIS VALIDS files for all five MSIS file types are used (i.e., EL, IP, LT, OT, and RX).
- Assumptions reflect analyzing 12 months of MSIS enrollment and claims experience tied to the survey date.
    - **A/D States:** There is 6 months of experience prior to the survey month. (The survey month is counted as one of the 6 pre-survey months.) There is six months of post-survey experience.
    - **ID/DD States:** There is 12 months of experience prior to the survey month.
    - Months are defined using the survey date (e.g., if survey is June 14 then the first post-survey month will be June 15 through July 14).

Eligibility (EL) File:

Header variables:

- Linking ID to Survey Files:
    - A/D States: RTI ID
    - ID/DD States: SURVCODE
- DOB = Date of Birth
- DT_DEATH = Date of Death
- DUAL ELIG = Dual Eligible Flag
- SURVD = survey date
- STATE = state postal abbreviation
- STATECD = (MR-DD: 1 = KY, 2 = OK, 3 = WY; A/D: 1 = KY, 2 = WI, 3 = WA)

Monthly information – month value in relation to survey window, eligibility indicator, maintenance assistance status, four plan type summary variables:

MONTH = Month value numbered 1 – 12 of annual window. Some individuals DO NOT have 12 records.

ELIGIBLE = Flag indicates Medicaid enrollment status for month:

- 0 - if Not Eligible for Medicaid in month

- 1 - if Eligible for Medicaid in month

RMMAS = Maintenance assistance status – **remapped per RTI specifications as follows:**

- 0 - if 0 and labeled Not Eligible for Medicaid
- 1 - if 1 and labeled Receiving Cash Assistance or 1931
- 2 - if 2, 3, 4, or 5 and labeled Not Receiving Cash Assistance
- 9 - if 9 and labeled Status Unknown.

Four managed-care plan type summary variables:

- MCO = Patient enrolled in MCO
  - 0 - if not enrolled in an MCO in month
  - 1 - if enrolled in an MCO in month
- LTC = Patient enrolled in LTC
  - 0 - if not enrolled in an LTC managed-care plan in month
  - 1 - if enrolled in an LTC managed-care plan in month
- PACE = Patient enrolled in PACE
  - 0 - if not enrolled in a PACE plan in month
  - 1 - if enrolled in an PACE plan in month
- PCCM = Patient enrolled in PCCM
  - 0 - if not enrolled in PCCM in month
  - 1 - if enrolled in PCCM in month

Claims Files

IP File – Monthly Variables:

- DTOS01 = IP Medicaid expenditures,
- IPCOIN = Monthly sum of Medicare coinsurance
- IPDED = Monthly sum of Medicare deductible
- IIPDAY = IP days
- IIPDIS = IP discharges
- IPTSTAT = Monthly IP Patient Status – assigned using CMS's last/best criteria. This means that the latest "known" value is selected. This prevents the assignment of a missing or unknown value to the analysis variable if the last value happened to be unknown or missing.

LT File:

Allowable LT MSIS Type-of-Service values (value is in parenthesis):

Mental hospital services for the aged (02)
Inpatient psychiatric facility services for individuals age 21 years and under (04)
ICF services for the mentally retarded (05)
NF's – all other (07).

For each LT TOS value above, monthly LT variables will be created to capture:

- Medicaid expenditures
    - DTOS02 = Mental hospital services for the aged
    - DTOS04 = Inpatient psychiatric facility services for individuals age 21 years and under
    - DTOS05 = ICF services for the mentally retarded
    - DTOS07 = NF's – all other
- LTCOIN = Monthly sum of Medicare coinsurance,
- LTDED = Monthly sum of Medicare deductible,
- Units that correspond to these TOS values
    - MRDAY = ICF-MR-DAYS
    - NFDAY = NURSING-FACILITY-DAYS
    - LIPDAY = MEDICAID-COVERED-INPATIENT-DAYS.
- LIAB = Patient liability,
- LPTSTAT = Monthly LT patient status – assigned using last/best criteria.

RX File:

Allowable RX MSIS Type-of-Service values (value is in parenthesis):

Prescribed Drugs (16)
Other Services (19).

For each RX TOS value above, monthly RX variables will be created to capture:

- Medicaid expenditures ,
    - DTOS16 = Prescribed drugs
    - RDT0S19 = Other services (these are DME, supplies written as prescriptions)
- Number of claims,
    - CTOS16 = Prescribed drugs
    - RCTOS19 = Other services (these are DME, supplies written as prescriptions)
- Number of encounters
    - ETOS16 = Prescribed drugs
    - RET0S19 = Other services (these are DME, supplies written as prescriptions)

OT File:

Allowable OT MSIS Type-of-Service values (value is in parenthesis):

Physician (08)
Dental (09)
Other Practitioner (10)
Outpatient Hospital (11)
Clinic (12)
Home Health (13)
Lab and X-ray (15)
Other Services (19, this TOS is also allowed in RX file)

Capitated Payments to HMO or HIO Plan (20)
Capitated Payments to Prepaid Health Plan (21)
Capitated Payments for Primary Care Case Management (22)
Sterilizations (24, this TOS is also allowed in IP file)
Abortions (25, this TOS is also allowed in IP file)
Transportation Services (26)
Personal Care Services (30)
Targeted Case Management (31)
Rehabilitation Services (33)
PT, OT, Speech, Hearing Language (34)
Hospice (35)
Nurse Midwife Services (36)
Nurse Practitioner Services (37)
Private Duty Nursing (38).

Project OT Type-of-Service scheme:

For the 7 PROJECT TOS values below, monthly OT variables capture Medicaid expenditures. The three non-waiver project TOS categories also have an associated dichotomous flag to reflect the presence of one or more claims during the month. In addition, each monthly record includes Medicare coinsurance and deductible values.

OT File – Monthly Variables:

- CAPEXP = Capitated expenditures (TOS 20-22)
- MEDEXP = Medical Services expenditures (TOS 08, 09, 10, 11, 12, 15, 24, 25, 35, 36, 37, 38, AND the non-HCBS part of TOS 19)
- SOCEXP = Social Services expenditures (TOS 26, 31, 33)
- Non-waiver personal care (TOS 30)
  - NWPC = Flag
  - NWPCEXP = Expenditures
- Non-waiver home health (TOS 13)
  - NWHH = Flag
  - NWHHEXP = Expenditures
- Non-waiver therapies (TOS 34)
  - NWTH = Flag
  - NWTHEXP = Expenditures
- HCBSEXP = Summary HCBS (state-specific codes – the HCBS part of TOS 19)
- OTCOIN = Monthly sum of Medicare coinsurance
- OTDED = Monthly sum of Medicare deductible

HCBS Monthly Variables: The following dichotomous HCBS flags, expenditure and encounter data elements are based upon the state-specific procedure code maps provided to Medstat:

Flag values:

- 0=no claims/encounters in the month
- 1=one or more claims/encounters in the month

Encounter values are set using Wayne Anderson's instructions for each WA state-specific service code and pay unit combination.

- Residential Services
  - RES_SERV = Flag
  - RS_UNT = Encounters **(WA Aged/Disabled file only)**
  - RS_EXP = Expenditures
- Personal Assistance
  - PER_ASST = Flag
  - PA_UNT = Encounters **(WA Aged/Disabled file only)**
  - PA_EXP = Expenditures
- Respite Care
  - RESPITE = Flag
  - RE_UNT = Encounters **(WA Aged/Disabled file only)**
  - RE_EXP = Expenditures
- Day Services
  - DAY_SERV = Flag
  - DS_UNT = Encounters **(WA Aged/Disabled file only)**
  - DS_EXP = Expenditures
- Nursing Services
  - NURSING = Flag
  - NU_UNT = Encounters **(WA Aged/Disabled file only)**
  - NU_EXP = Expenditures
- Therapy Services
  - THERAPY = Flag
  - TH_UNT = Encounters **(WA Aged/Disabled file only)**
  - TH_EXP = Expenditures
- Environmental Mods
  - ENV_MODS = Flag
  - EM_UNT = Encounters **(WA Aged/Disabled file only)**
  - EM_EXP = Expenditures
- Supplies and Equipment
  - SUP_EQUI = Flag
  - SE_UNT = Encounters **(WA Aged/Disabled file only)**
  - SE_EXP = Expenditures
- Transportation
  - TRANSPO = Flag
  - TR_UNT = Encounters **(WA Aged/Disabled file only)**
  - TR_EXP = Expenditures
- Meals
  - ME_EXP = Flag
  - ME_UNT = Encounters **(WA Aged/Disabled file only)**
  - MEALS = Expenditures

- Training
    - TG_EXP = Flag
    - TG_UNT = Encounters **(WA Aged/Disabled file only)**
    - TRAINING = Expenditures
- Case Management, Service Coordination **(MR-DD only)**
    - CASEMGMT = Flag
    - CM_UNT = Encounters **(WA Aged/Disabled file only)**
    - CM_EXP = Expenditures
- Services from Health Professionals beyond the State Plan **(MR-DD only)**
    - HLTHSERV = Flag
    - HS_UNT = Encounters **(WA Aged/Disabled file only)**
    - HS_EXP = Expenditures
- Other
    - OTHER = Flag
    - OT_UNT = Encounters **(WA Aged/Disabled file only)**
    - OT_EXP = Expenditures

<u>Analytic File Construction Notes:</u>

1. No edits to data values from these MSIS VALIDS files were performed. For example, if a respondent has a date of death value and services were paid after the date of death, those data would be included in the analytic file.
2. Kentucky transportation reminder: KY has a statewide non-emergency transportation waiver in place. We did have encounter records for both the A/D and MR-DD populations. The appropriate HCPC service codes were used to increment transportation service use (TRANSPO data element). The comparable expenditures data element (TR_EXP), however, will be zero dollars in this instance. MSIS encounter data do not have Medicaid expenditures since services are prepaid. These "prepayments" are accumulated under the CAPEXP data element in KY. This is because the transportation capitated payments are submitted to MSIS on a capitated payment record (i.e., not a fee-for-service claim or managed-care encounter).
3. All adjustments to these data were performed prior to the MSIS data being sent to the analytic routines. Having said that, if negative dollars appear on a monthly record, this would reflect incomplete administrative data to perform appropriate adjustments.
4. In the rare instance of a waiver respondent having claims data without evidence of Medicaid eligibility, we did the following:
    a. Assigned the respondent's DOB and SURVD from other records
    b. Assigned as follows:
        i. Dt_death – 8-fill
        ii. Dual_elig – 99 – Medicare status unknown
        iii. Plan types: MCO, LTC, PCCM, PACE – zeroes
        iv. Remapped MAS – 0
        v. Eligibility flag – 0
    c. Number of **monthly records** when this occurred:
        i. KY MR-DD = 7
        ii. OK MR-DD = 1
        iii. WY MR-DD = 25
        iv. KY A/D = 50 (0.6%)

   v. WI A/D = 3
   vi. WA A/D = 9

5. HCBS bucket hits were verified against the state-specific procedure code look-up tables provided by the analytic team. Consequently, if a bucket has zero hits (e.g., NURSING) when there is a service code in the map, this means that no claims/encounters contained the corresponding service code during the appropriate analytic window.
6. Claims/encounter data that spanned monthly analytic windows – dollars, days and/or other utilization data elements were apportioned between the monthly analytic windows using available service dates. For example, if an inpatient hospital stay occurred across month 1 and month 2, the inpatient IPDIS data element will be zero in the first month, and, one in the second month. This prevents a single stay or comparable non-inpatient service from being counted twice. This practice applies to all MSIS file types that have claims/encounters where the MSIS begin and end dates of service are not equal, IF these dates are not wholly contained within the monthly analytic window.
7. Explicit pharmacy file reminder note: DME & supplies obtained via prescriptions are captured in the RDTOS19, RCTOS19, RETOS19 data elements.

APPENDIX C
SATISFACTION WITH PAID PERSONAL ASSISTANCE SCALE (SPPAS)

Variable from the HCBS survey, 2004

How Happy Overall With the Paid Care Received (H1b)	
Very Happy	1
Somewhat Happy	2
Somewhat Unhappy	3
Very Unhappy	4
Has It Ever Been Difficult To Get Problems Resolved Or Fixed (H3)	
No /never had a problem	1, 7
Yes	0
How Well Get Along With Paid Caregiver (H6)	
Very Well	1
Well	2
Not Very Well	3
Not at all well	4
Any Trouble Communicating With Paid Caregiver (H7)	
No	0
Yes	1
Problems of Paid Caregiver Ignoring Survey Participant (H9)	
Never	0
Seldom	1
Sometimes	2
Often	3
Very often	4
Problems With Paid Caregiver Treating Survey Participant Badly (H12)	
Never	0
Seldom	1
Sometimes	2
Often	3
Very Often	4
Is Paid Caregiver Competent and Well Trained (H13)	
Yes	1
Sometimes /depends; some helpers are, some are not	2, 3
No	0
Is Paid Caregiver Respectful (H14)	
Yes	1
Sometimes/depends	2
No	0