
**Older People and Younger Persons with Physical Disabilities Who Use
Medicaid Home and Community-Based Services in Six States:
A Preliminary Analysis**

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This report presents initial findings on a survey of Medicaid home and community-based services beneficiaries presented at the May 2005 Home and Community-Based Waiver Conference held in Orlando Florida. The content of the presentation used survey data gathered from 2,597 community-residing Medicaid beneficiaries receiving home and community-based services in six states – Alabama, Kentucky, Maryland, Wisconsin, Washington, and Michigan (Snell, Zhao, Lu, Potter, & Ciemnecki, 2005).¹ 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, & Alexih, 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. Because of the major policy interest in differences between older and younger persons with disabilities, the survey sample was stratified by age (younger than 65 years of age vs. 65 years of age or older). The tables presented in this initial report show those under age 65 compared to respondents age 65 and older and are based on unweighted results.

The survey included questions on beneficiaries’ socio-demographic characteristics, health and functional status, and their use of and experience with home and community-based services. 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 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 percent, with 28 percent of respondents using a proxy.

Table 1 presents key socio-demographic characteristics of the survey sample, including age, gender, marital status, education level, income level and living arrangements. The sample’s low income is consistent with Medicaid eligibility standards. Both the Medicaid and older age of the elderly sample is consistent with the majority of respondents having a high school or less education. Among the elderly, the high percentage of females is not surprising, however among the non-elderly the higher percentage of females was not expected.

Table 2 presents selected measures of health and functional status among the survey sample. As would be expected in a population receiving home and community-based services, the majority are in fair or poor health, have impairments in more than two activities of daily living (eating, bathing dressing, toileting and transferring) and over three instrumental activities of daily living (e.g., managing money, light housework). The non-elderly indicate a greater use of special equipment compared to the elderly (29 versus 23 percent). A high prevalence of pain

¹ Wisconsin home care beneficiaries residing in counties participating in the Family Care demonstration were excluded from the sampling frame.

² Four observations were later determined to be duplicates and were removed from the sample.

and bladder control issues is evident for both age groups. While older HCBS recipients have a higher prior use of nursing homes (19 versus 15 percent), those under age 65 were more likely to have pressure sores in the last six months (12 versus 7 percent).

Table 1
Socio-demographic Characteristics of Medicaid HCBS Users in Six States

Characteristic	Under 65	Age 65+
Average Age	47.2	77.7
Sex		
Female	65.4%	81.7%
Male	34.6%	28.3%
Race/Ethnicity		
White	73.4%	71.6%
Black	17.6%	19.3%
Other race	9.1%	9.1%
Hispanic	2.7%	2.7%
Marital Status		
Not Married	84.0%	81.7%
Married or have partner	16.0%	18.3%
Education		
High school or less	75.1%	84.5%
Some/all 4 year college	22.9%	11.4%
More than college grad	2.0%	4.2%
Income		
Less than \$5,000	21.9%	24.5%
\$5,000 - \$10,000	64.1%	63.6%
More than \$10,000	14.0%	12.0%
Living Arrangements		
Choice of living arrangement	66.7%	64.6%
Live in group setting	7.5%	13.3%

Source: RTI tabulation of survey data collected by
Mathematica Policy Research.

Table 2
Health and Functional Status of Medicaid HCBS Users in Six States

Characteristic	Under 65	Age 65+
Health Status		
Excellent, Very Good, Good	30.5%	30.2%
Fair	25.4%	30.7%
Poor	44.1%	39.0%
Functional Status		
Average number of ADLs	2.74	2.47
Average number of IADLs	3.29	3.25
Need special equipment	29.0%	22.6%
Other Health Related Measures		
Ever been a nursing home patient	15.2%	19.1%
Some/great deal of pain last 4 wks	81.8%	84.3%
Any pressure sores last 6 months	12.3%	7.2%
Any bladder and/or bowel trouble	58.6%	60.0%

Source: RTI tabulation of survey data collected by Mathematica Policy Research.

Table 3 provides information about the use of unpaid and paid services. Approximately one-half of the sample had on average two unpaid caregivers with a slightly higher average number of paid caregivers over the last six months. A somewhat higher percentage of younger sample members reported higher unmet need (29.9 versus 26.7 percent).

Table 3
Service Use Among Medicaid HCBS Users in Six States

Characteristic	Under 65	Age 65+
Unpaid Assistance		
Any informal care in last week	54.3%	51.8%
Number of unpaid helpers	2.26	2.06
Number of different paid helpers last 6 mos	2.82	2.56
Any unmet needs	29.9%	26.7%

Source: RTI tabulation of survey data collected by Mathematica Policy Research.

Table 4 shows the distribution of the length of time sample members received paid help with over one-half receiving paid help for more than three years. Most paid workers were employed by an agency.

Table 4
Service Use Among Medicaid HCBS Users in Six States

Characteristic	Under 65	Age 65+
Length of Time Receiving Paid Help		
Less than 3 months	1.7%	1.5%
3-6 months	2.9%	2.2%
6-12 months	2.3%	4.9%
1-2 years	15.5%	14.6%
2-3 years	18.0%	25.1%
More than 3 years	59.6%	51.7%

Source: RTI tabulation of survey data collected by Mathematica Policy Research.

Table 5 indicates that the majority of sample members thought they were receiving the right amount of paid care; however, about one-quarter of elderly sample members and one-third of younger sample members thought they did not have enough paid care. About a third of younger people and about a quarter of older people thought they had a “big problem” with their paid workers.

Table 5
Adequacy and Issues Related to Paid Care for Medicaid HCBS Users in Six States

Characteristic	Under 65	Age 65+
Adequacy of Hours of Paid Help		
Far too few	11.22%	6.97%
Not quite enough	22.55%	20.07%
Just about right	61.51%	65.64%
Little more than needed	3.07%	4.96%
Much more than needed	1.65%	2.36%
Degree of Problems with Paid Helpers		
Big problem	35.8%	23.9%
Little problem	42.1%	31.6%
No problem at all	22.0%	44.5%

Source: RTI tabulation of survey data collected by Mathematica Policy Research.

Table 6 indicates that two-thirds of respondents reported they had total choice concerning the tasks that paid caregivers performed, while 80 percent or more were “happy” or “very happy” about their degree of choice. Only about one-half third of respondents reported they had total choice concerning the scheduling of paid caregivers, while 75 percent or more were “happy” or “very happy” about that degree of choice. Twice the percentage of younger sample members had difficulty finding a replacement worker than did older sample members (20.5 versus 10.0 percent).

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)³. These items measure overall satisfaction, as well as interpersonal aspects of care provided by paid caregivers, 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 indicates that both the younger and older sample members report similar high levels of satisfaction (93.05 versus 94.47).

Table 6
Choice and Satisfaction Concerning Paid Care
Among Medicaid HCBS Users in Six States

Characteristic	Under 65	Age 65+
Amount of Choice in Deciding Tasks Done		
Total choice	66.8%	66.4%
Some choice	22.9%	23.2%
No choice	10.3%	10.4%
Happiness in Amount of Choice of Tasks Done		
Very happy	37.6%	42.3%
Happy	43.6%	37.8%
Somewhat happy	15.5%	18.2%
Not at all happy	3.3%	1.7%
Choice Over Scheduling		
Total choice	50.8%	49.8%
Some choice	28.7%	22.5%
No choice	20.5%	27.7%
Happiness in Amount of Choice in Scheduling		
Very happy	34.9%	36.5%
Happy	41.2%	46.0%
Somewhat happy	19.5%	14.2%
Not at all happy	4.4%	3.3%
Difficulty finding replacement	20.5%	10.0%
Satisfaction with paid care	93.05	94.97

Source: RTI tabulation of survey data collected by Mathematica Policy Research.

Table 7 provides two measures of social involvement – participation in social activities. About 6 percent of those under age 65 worked in the past six months and a little more than 6 percent engaged in unpaid work. About one-half of those under age 65 would like to work. A higher percentage of the younger than older beneficiaries had some participation in social activities (80.4 versus 70.8 percent).

³ Paid caregivers acting as proxy respondents were not asked service satisfaction questions.

Table 7
Work and Social Engagement Among Medicaid
HCBS Users in Six States

Characteristic	Under 65	Age 65+
Consumer Work History Last 6 months		
Any work for pay	5.9%	NA*
Any unpaid work	6.6%	NA
Would like to work at a paid job	50.4%	NA
Some participation in social activities	80.4%	70.8%

NA=Not applicable. Older people in the sample were not supposed to be asked these questions.

Source: RTI tabulation of survey data collected by Mathematica
 Policy Research.

In summary, younger persons generally had:

- Poorer health and more ADLs
- More issues with the paid workers, the degree of choice they had with regard to scheduling and tasks provided, and finding replacements.

Most recipients were satisfied with the paid care they received, however, workforce problems greatly affect satisfaction with paid care.

The next steps for the project include using the survey data to examine personal characteristics and workforce characteristics association with satisfaction with paid care, as well as consumer direction. The survey data will also be linked to Medicaid claims data to examine utilization of institutional and outpatient care and expenditures for HCBS and all other Medicaid services.