Personal Care Satisfaction Among Aged and Physically Disabled Medicaid Beneficiaries

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We analyzed survey data from 2,325 Medicaid home and community-based services (HCBS) beneficiaries in six States to estimate satisfaction with personal care services. We constructed an eight-item scale rating various aspects of paid assistance and estimated satisfaction for the total sample and for older and younger persons with disabilities. Younger persons with significant health problems and those residing in group settings were less satisfied. Higher unmet need for assistance with activities of daily living (ADLs), and instrumental activities of daily living (IADLs) was associated with decreased satisfaction, and matching race between a client and paid caregiver was associated with significantly increased satisfaction in all age groups.

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 interpersonal aspects of care, such as interactions

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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 ADLs and IADLs. 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 an 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 programs 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 (2003) 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; Kane, 1999). Little empirical research exists to assess these assumptions and their effect 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 et al., 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 Black respondents, who have comparable or higher satisfaction ratings than White respondents (Haviland et al., 2003). Other studies found that White 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.

METHODS

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).[1] 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

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

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.[2] 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).[3] 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 IADL and 2.2 ADL limitations on average compared to 3.8 IADL 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).

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 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.

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

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

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 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 levels 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).[4] 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 Washington State hired a paid caregiver who was a family member, friend, or neighbor, only a 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 original items required rescaling. For the item "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" category with "some helpers are, and some are not." 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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[4] Paid caregivers acting as proxy respondents were not asked service satisfaction questions, and were not included in the study sample.

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 or 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	0.020*
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 age 65 or over for each category.

NOTE: Results are weighted by wgt_pltnr.

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

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.[5] Income was not included as a variable because all survey respondents were very low-income Medicaid

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

Table 2

Variable Construction and Means of Descriptive Characteristics of the Sample: 2004

Characteristic	Variable Construction	All Survey Respondents	Respondents Under Age 65	Respondents Age 65 or 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				
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	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	Dummy variable =1 if survey participant and main paid caregiver report the same race or Hispanic 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 IADL 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***

Refer to footnotes at the end of the table.

Table 2—Continued

Variable Construction and Means of Descriptive Characteristics of the Sample: 2004

Characteristic	Variable Construction	All Survey Respondents	Respondents Under Age 65	Respondents Age 65 or Over
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 age 65 or over for each category.

NOTES: Results are weighted. ADL is activity of daily living. IADL is instrumental activity of daily living.

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

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 IADLs (cooking, managing medications, shopping, and doing light housework). We also created a composite of 10 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 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 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.

RESULTS

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 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 (48 percent). Among young adults with physical disabilities, about 37 percent were under age 45 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 White respondents, 16 percent were Black respondents, and slightly over 8 percent were Asian, without much difference in racial distribution between young adults with physical disabilities and respondents 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 non-elderly subgroups; on average, survey respondents reported 2.4 limitations in ADLs and slightly more than three limitations in IADLs. 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.

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 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.

Table 3

Correlation of Variables Comprising the Satisfaction with Paid Personal Assistance Scale: 2004

Variable	(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 Services Survey, 2004.

Table 4

Predicting Satisfaction with Paid Personal Assistance Scale Censored Normal Regression Results

	Model I		Model II		Model III	
	All Survey Respondents		Respondents Under Age 65		Respondents Age 65 or 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 IADLs	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 $p < 0.01$.

NOTES: IADLs is instrumental activities of daily living. ADLs is activities of daily living.

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

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.

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 45) 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 White respondents; among older persons, minority racial status, and being a Black respondent in particular, was related to significant decreases in satisfaction with these services compared to White respondents.

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 a 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.

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 domains 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/IADL 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; Shin and Moon, 2005). In providing services to persons with disabilities, policymakers should pay greater attention to cultural competence of the providers.

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 et al., 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 and colleagues (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 IADL 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 younger persons with disabilities, 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.

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