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# Medicaid Waiver Personal Care Services: Results of a Statewide Survey

Anne P. Glass, Ph.D., Karen A. Roberto, Ph.D., Nancy Brossoie, Ph.D., Pamela B. Teaster, Ph.D., and Donna Q. Butler, Ph.D.

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*Through a statewide telephone survey of 819 beneficiaries (or their proxies), we collected data regarding client and aide demographics, as well as clients' satisfaction, outcomes, perspectives on staff performance, and complaints associated with home-based personal care services provided under the Virginia Medicaid Elderly and Disabled (E&D) waiver. Most respondents indicated that services improved their lives, and they were generally satisfied. Opportunities for improvement exist, however, especially related to the amount of time spent with the client, the need for training, and communication issues. Ongoing use of client/family caregiver surveys is warranted to allow continued monitoring of service provision.*

## INTRODUCTION

The Virginia Medicaid E&D waiver serves personal care needs of low-income clients who meet nursing home admission criteria, thus allowing individuals to remain at home. This waiver enrolls far more people than any other Medicaid waiver program in Virginia and provides personal care, respite, adult day health services, and personal emergency response systems, often collectively referred to as home and

community-based services (HCBS). Personal care by aides who come to the home to assist with activities of daily living and household tasks is the predominant service provided. We present findings from a statewide survey of beneficiaries' perceptions of quality and performance of personal care services received, as well as client and aide demographics.

Among aged/disabled waiver programs nationwide, the percent of Medicaid beneficiaries nearly doubled between 1992 and 1999, from 0.6 to 1.1 percent (Wiener, Tilly, and Alechxih, 2002). Enrollment grew another 30 percent between 1999 and 2002, at a concomitant spending increase of 73 percent (Houser, Fox-Grage, and Gibson, 2006). The percentage of Medicaid long term care spending for HCBS doubled from 12 percent in 1995 to 25 percent in 2006 (Kassner et al., 2008). Such aged/disabled waiver services are cost-effective; annual average spending was \$8,440 per participant in 2004, compared to \$23,585 for those in nursing facilities (Kassner et al., 2008).

However, HCBS remain a little-understood component of long term care. Surveys show less awareness of HCBS compared to nursing homes and home health (DePallo and Stowell-Ritter, 2002). Analysts have repeatedly bemoaned the paucity of HCBS research (Applebaum, Mollica, and Tilly, 1997-1998; Institute of Medicine, 2001; U.S. General Accounting Office, 2003), particularly related to quality. Applebaum and colleagues (1997-1998) stressed that despite a nagging concern about quality, "...little is known about the

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extent of—quality problems, particularly for the personal care services designed for individuals with chronic disability.” The Institute of Medicine (2001) devoted 22 pages to regulatory oversight of nursing homes. In contrast, the single page addressing personal care or HCBS emphasizes, “...this is clearly an area that needs more research attention.” More recently, research indicates that client satisfaction with in-home care is influenced by problems with consistent service availability, worker training, and care practices (Anderson, Wiener, and Khatutsky, 2006), as well as racial and cultural concordance between provider and client, and the amount of clients’ choice and control (Khatutsky, Anderson, and Wiener, 2006). The tendency of this population to respond positively to satisfaction surveys presents another challenge (Applebaum, Straker, and Geron, 2000; New England States Consortium, 2002), but it is essential to solicit the input of service beneficiaries (Centers for Medicare & Medicaid Services, 2003; Glass et al., 2005; Institute of Medicine, 2001). The Agency for Health Care Research and Quality has been directed to develop quality measures for Medicaid HCBS that incorporate performance, client functioning, and satisfaction (Kasper et al., 2007).

Among many problems with current quality measurement, there is a fundamental lack of consensus about defining quality of HCBS in general, and of personal care services in particular. Some research indicates that unmet needs should also be considered when evaluating satisfaction (Caro, 2001; Khatutsky, Anderson, and Wiener, 2006; Lima and Allen, 2001; Morrow-Howell, Proctor, and Roszario, 2001). Confusion surrounding HCBS is compounded because Medicaid programs vary by State (Applebaum, Straker, and Geron, 1997-1998; Wiener, Tilly, and Alechxih, 2002). No consensus exists even among

providers about how they identify quality of care problems (Brossoie et al., 2005; Kane, Frytak, and Eustis, 1997). The fact that care provided in the home is just one element of an individual’s environment, with many other factors involved, further complicates the quality of care conundrum.

The purpose of this study was to document clients’ or their proxies’ perspectives on how E&D waiver services are provided in Virginia, and to obtain performance, satisfaction, and quality of life outcome data on those services. The results of a large statewide survey are reported here.

## **METHODS**

### **Sampling Design**

This research was approved by the Virginia Tech Institutional Review Board. A stratified random sampling method was employed for the survey administration. The Department of Medical Assistance Services (DMAS) provided a database of E&D waiver client contact records, with 12,150 names. The database included clients’ ages, sex, and physical addresses, with no other descriptive information. Web-based searches were conducted to obtain telephone numbers. In addition, with permission from DMAS, some telephone numbers were obtained through cross-comparison with a State agency database of individuals requiring fuel assistance.

To achieve a representative statewide sample, client records were randomly selected within a matrix based on Virginia’s 21 planning districts; participants were selected according to sex and age (i.e., age 18 to 64, 65 or over). Seventy percent of records within each cell were selected for inclusion in the calling pool, ensuring a completion rate of approximately 15 percent across cells and representation of the different types of DMAS

clients receiving services. The records were randomized within each cell (i.e., client planning district, sex, and age) prior to selection.

The Center for Survey Research (CSR) at Virginia Tech conducted the survey. A total of 3,374 telephone numbers were attempted for survey administration. Sample records were excluded from the eligible sample pool under the following circumstances: households in which only a paid aide was available to respond for the sample member ( $n = 43$ ); respondents indicating a language or hearing barrier, such that they could not respond or request that another individual in the household respond ( $n = 92$ ); non-working telephone numbers ( $n = 607$ ); non-residential numbers ( $n = 14$ ); valid telephone numbers that were incorrect for the sample member ( $n = 486$ ); and a household member reporting that the sample member was now either deceased ( $n = 191$ ) or in a nursing home ( $n = 39$ ).

After eliminating all ineligible records, 1,902 eligible sample members remained. CSR attempted to reach them at different times and days of the week. After 10 unsuccessful attempts, CSR assigned a final disposition of no answer for 327 (17.2 percent). CSR contacted a total of 1,575 eligible respondents, with 334 refusals (17.6 percent) and 1,241 interviews completed, for a total response rate of 65.2 percent. However, further inspection revealed that 418 individuals did not meet the study criteria of having an aide coming to their home at the time of the interview. In addition, four participants were under 18 and subsequently excluded, resulting in a final sample of 819 respondents.

Family caregivers responded for clients with physical and mental limitations prohibiting them from speaking for themselves; caregivers represented 47.3 percent of respondents. Analysis of cli-

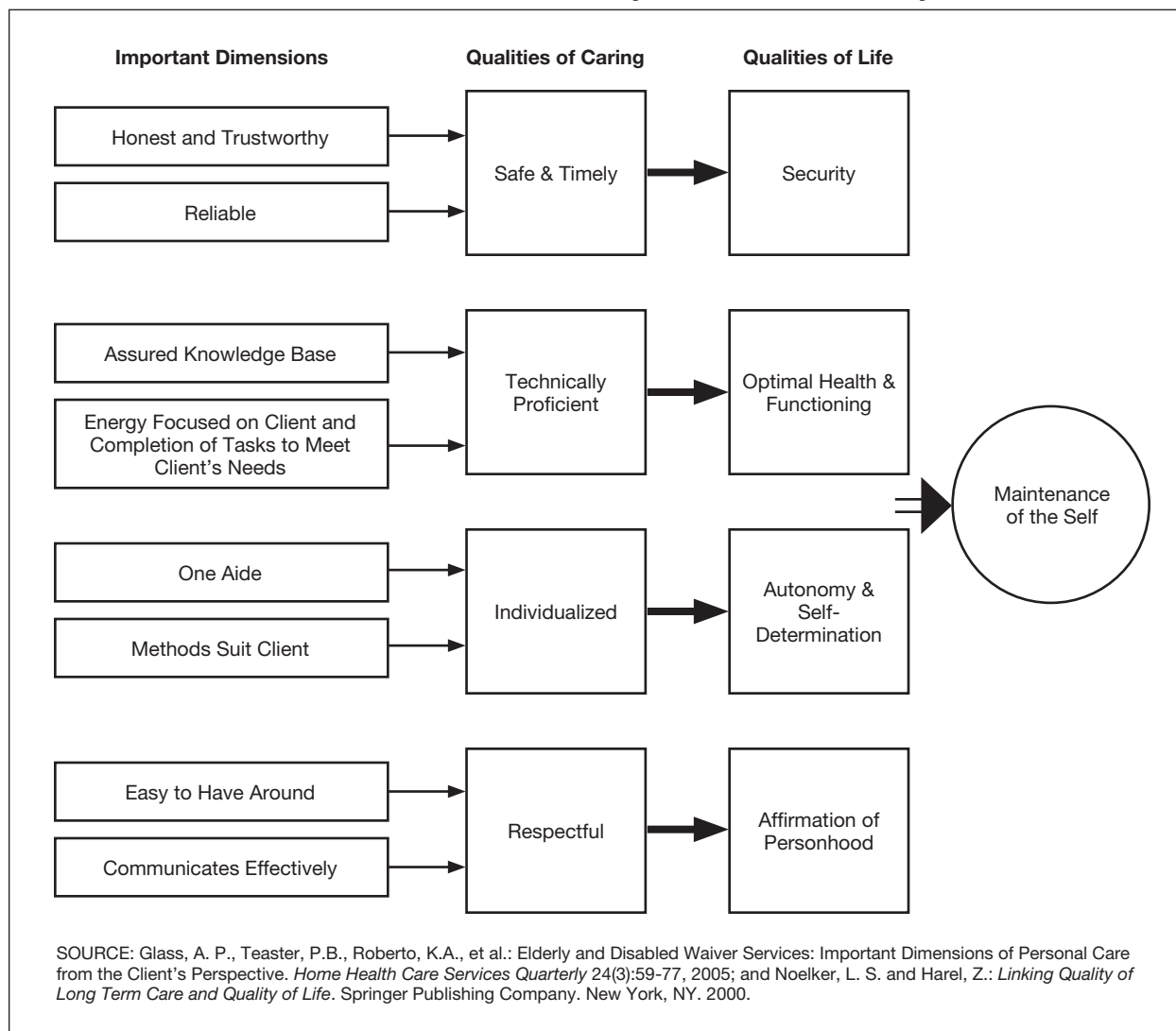
ents' responses versus those of caregiver proxies revealed few significant differences of interest (additional information may be obtained from the authors). The telephone survey was completed by clients (or proxies) receiving services between July 31, and September 1, 2003.

## Survey Instrument Design

We developed a telephone survey for this study to assess clients' perceptions of E&D services. Because little is known about services provided in the home, we initially conducted a caregiver focus group and 25 indepth interviews with E&D waiver clients and family caregivers representing urban and rural areas (Glass et al., 2005) to learn what was most important to them about their service provision. Most were satisfied with their current aides, but some had experienced problems with past aides. Through our analysis, we identified positive dimensions of the client-aide relationship (e.g., the aide is nice) as well as the type and prevalence of potential problems (e.g., the aide does not show up).

From that phase, eight key dimensions emerged. Quality is enhanced when the aide: (1) is honest and trustworthy; (2) reliably appears on the assigned days, at the assigned times, and stays the full time allotted; (3) comes well trained with an appropriate knowledge base; (4) focuses energy on the client; (5) is consistent; (6) uses methods suiting the client; (7) is easy to have around; and (8) communicates effectively. These dimensions correlate with Noelker and Harel's (2000) model of HCBS quality (Figure 1) that we have reported earlier (Glass et al., 2005). This model was used in developing our survey, and we ensured that all eight dimensions were reflected by representative variables. We included a few items that overlap with

**Figure 1**  
**Model of Home and Community-Based Services Quality**



work by Geron and colleagues (2000) (e.g., the aide knows what to do), but our framework and the information we collected guided our selection and wording of questions as we developed the instrument. Our focus was solely on personal care, and we used this opportunity to gain a broader understanding of the care process, including some items for research purposes only, and to test the broader statewide applicability of the original study.

The final survey included items in four core areas: (1) clients and their service

provision; (2) aide's performance; (3) client's functional status and assistance received; and (4) outcome measures, complaints, and overall satisfaction. We also included 10 items from the CMS survey (2003): 5 assessing the client's need for assistance with daily activities (i.e., functional status) and 5 focusing on clients' perceptions of the people paid to help.

We first piloted the instrument with 10 older adults to assess the wording of survey items and the length of time required for completion. Changes were made as

needed. Additionally, during the initial stages of implementation, we worked with CSR staff to resolve questions about the items as they arose. The survey took an average of 12 minutes to administer.

Before consenting to participate, respondents were informed about the study and who was administering it. We found in our earlier pilot project that sending letters out before contacting individuals did not seem to be very effective; the letters seemed to have little impact. Scripts providing more specific details on the study's purpose, how participant names were selected, and confidentiality were provided to interviewers to be read if asked by respondents. All respondents expressing concern about confidentiality were assured that the information gathered would not be released, especially to their aides.

## Data Collection

All survey telephone calls were made by CSR staff using a computer-assisted telephone interviewing system. The program provided scripted survey items and precluded out-of-range responses, while facilitating real-time data entry of all responses gathered on the telephone. Each CSR interviewer participated in a gerontology training session, highlighting the characteristics of E&D waiver clients with which they might be confronted (e.g., frailty, hearing and cognitive impairments, possibly low literacy), and techniques to facilitate the interviews. Interviews were monitored by a CSR phonebank supervisor to ensure accuracy and proper interview protocol. Clarifying notes for specific survey items appeared on the interviewer screens, thus ensuring that identical prompts were used for respondents requesting additional information about survey items or response categories.

## Data Analysis

We first screened the data for accuracy. The entire dataset was examined for reasonable means and standard deviations (SD), out-of-range values, and outliers. Don't know responses are not included. Next, preliminary data analyses were conducted to compare the study sample characteristics with the total population of Virginia's E&D waiver clients to insure that there were no major differences between the two groups. The study sample provides a balanced representation of E&D waiver clients as demonstrated by a comparison on the variables available for analysis; sex and age are compared below. More information about the regional analysis is reported elsewhere (Glass et al., 2004).

We employed descriptive statistics to create the sample profile. We use respondent to refer to those who actually answered the questions, whether they were clients or family caregivers. For items that refer specifically to client descriptors, such as demographic and functional data, the word client is used in reporting the findings; results describe the clients, whether they responded or had a proxy speak for them. For other items, such as opinion items, the word respondents is used to report the opinions of those who actually responded to the question.

## RESULTS

### Client and Aides

Clients were primarily females (76.1 percent), similar to the State database (75.5 percent), with a mean age of 67.0 ( $SD = 20.05$ ;  $R = 18-103$ ). About two-thirds were age 65 or over with a mean age of 79.9 ( $SD = 8.28$ ); 36.1 percent were younger individuals (age 18 to 64,  $M = 44.06$ ) with disabilities, comprising a higher percentage than

for the State (29.2 percent), to ensure this population would not be overshadowed. The sample was about evenly split between White (47.0 percent) and Black/African American (49.6 percent) respondents. Less than 1 percent of any other group—Asian, Hispanic, Native American, mixed/multi-racial, or other—was represented.

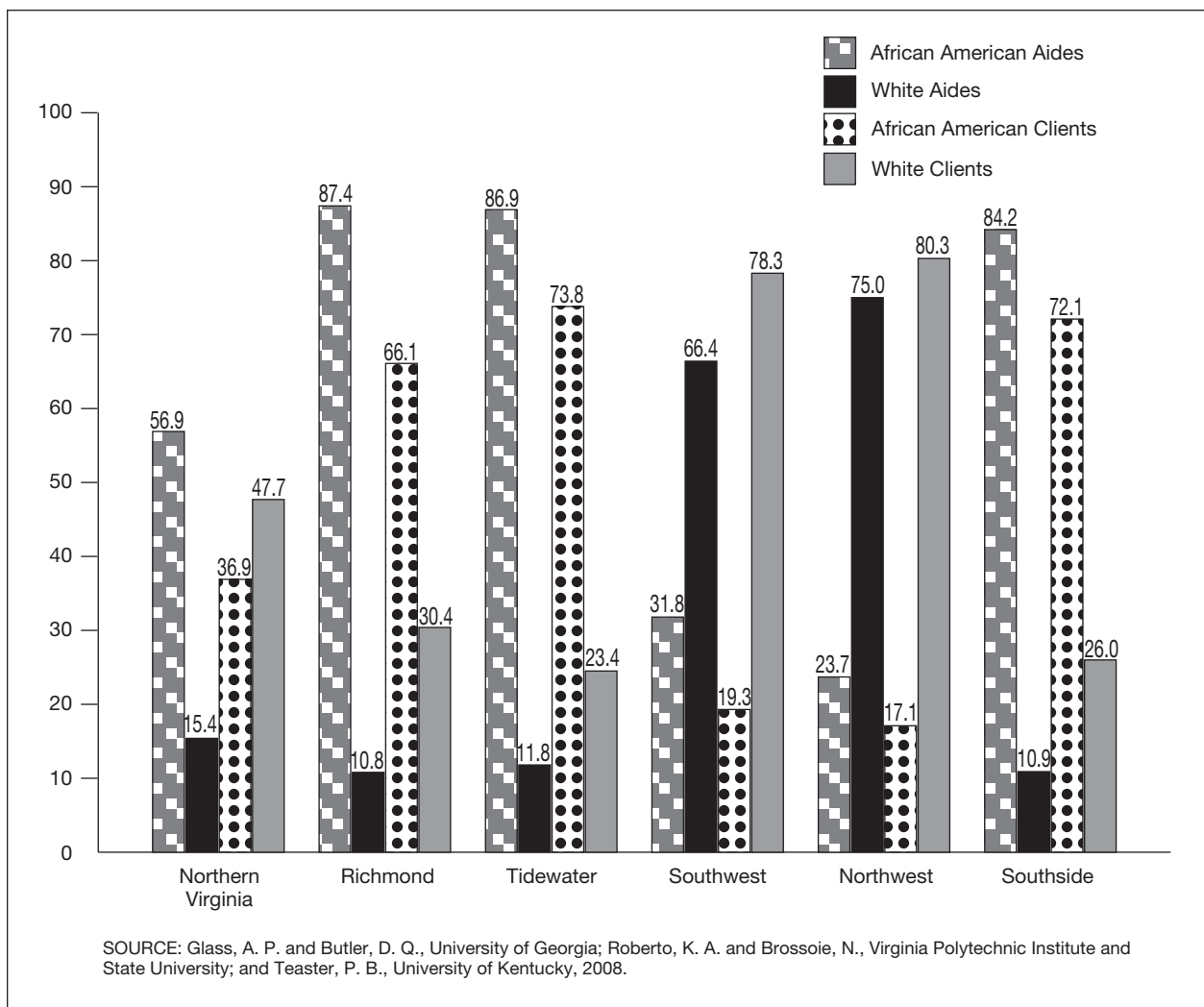
Respondents reported having from 1 to 25 different aides during the past year ( $M = 5.51$ ,  $SD = 5.07$ ). They reported currently having two aides on average ( $M = 2.09$ ,  $SD = 1.09$ ;  $R = 1-6$ ). For aide-related questions,

respondents were asked to focus on the aide they considered primary.

Most aides ( $n = 783$ , 95.6 percent) were female. Nearly two-thirds ( $n = 478$ ; 61.1 percent) were judged by respondents to be age 30 to 50, with fewer being younger (18.0 percent) or older (20.7 percent). One hundred (12.3 percent) clients knew the individuals before they became their aides. One-third of the aides ( $n = 257$ ; 32.4 percent) were White; almost two-thirds ( $n = 503$ ; 63.4 percent) were Black/African American. Fourteen aides (1.8 percent)

**Figure 2**

**Virginia Medicaid Waiver Personal Care Services: Black/African American and White Aides and Client Distribution, by Location**



were Hispanic; with less than 1 percent of any other group represented. The regional analysis showed that outside of Northern Virginia, in all areas where there were predominantly Black/African American aides, there was a parallel Black/African American client population, and a similar pattern of White aides and clients was observed in other parts of the State, suggesting general race concordance across the State (Figure 2). Further, older clients were more likely to be female and Black/African American and to have female and Black/African American aides.

### Service Provision

Respondents had received services for an average of 5.3 years ( $SD = 57.23$  months). Services with their current primary aide averaged 1.76 years ( $M = 21.07$  months,  $SD = 23.49$ ). One out of four clients had retained their current aide for more than 2 years. The majority who answered ( $n = 561$ , 75 percent) had their current aide for less than 2 years. One-third ( $n = 242$ , 32 percent) had their current aide for 6 months or less.

Most respondents (90.1 percent) had an aide assist them every weekday. Others indicated that their aides came some weekdays, but not all. About 40 percent

of clients had an aide on Saturdays, and 30 percent had care on Sundays. On both weekdays and weekends, the reported number of service hours ranged from 1-24 [ $M = 5.36$  hours ( $SD = 2.78$ ) on weekdays; 5.11 hours ( $SD = 3.35$ ) on weekends.] For most (86.9 percent), the aide came once daily. Over 78 percent of respondents reported that the same aide usually came; the remainder indicated many different aides came.

Over 85 percent of respondents indicated that the clients needed help with housework, meals, and bathing (Table 1). For those who reported needing help with an activity, bathing, housework, and getting in and out of bed were the activities with which the highest percentages reported receiving an aide's help. Over 78 percent of clients needed assistance in getting groceries, yet only 45 percent of those individuals reported receiving help, clearly suggesting an unmet need. When asked if there was anything that clients needed help with that an aide currently did not do for them, 106 (13.3 percent) respondents replied yes, naming a total of 127 unmet needs (Table 2). Some activities mentioned are beyond the scope of services allowed under this program, such as transportation to medical appointments and assistance with special needs.

**Table 1**  
**Medicaid Waiver Personal Care Recipients: Assistance with Activities**

Activity	Reports Needing Assistance		Reports Receiving Help, of Those Reporting Need for Assistance	
	(n)	(Percent)	(n)	(Percent)
Doing Housework	739	90.20	681	92.20
Making Meals	707	86.30	628	88.80
Taking a Bath or Shower	706	86.20	677	95.90
Getting Groceries	642	78.40	286	44.50
Getting In or Out of Bed	441	53.80	404	91.80

NOTE:  $n = 819$ .

SOURCE: These items from the *Consumer Experience Survey—Elderly & Disabled* (Centers for Medicare & Medicaid Services: *Consumer Experience Survey—Elderly & Disabled*. The Medstat Group. Washington, DC. 2003.) were included in the Virginia Medicaid Elderly & Disabled Waiver statewide survey data collected 2003.

**Table 2**  
**Medicaid Waiver Personal Care Recipients: Reported Unmet Needs**

Client Unmet Need	(n)	(Percent)
Help with Physical Therapy, Range of Motion, Exercise	18	14.2
More Help with Housecleaning	17	13.4
More Hours/Help on Weekends	16	12.6
Additional Help with Activities of Daily Living	13	10.2
Help at Night/Putting Client to Bed	8	6.3
Shopping	8	6.3
Shaving and Nail Care	6	4.7
Taking Client Outside	5	3.9
Cooking/Evening Meals	5	3.9
Transportation to Medical Appointments	5	3.9
Assistance with Special Needs such as Intravenous Therapy, Oxygen, Tube Feedings	5	3.9

NOTES: n = 106 respondents. They identified 127 unmet needs, but only those named by more than one respondent are included in the table.

SOURCE: Glass, A. P. and Butler, D. Q., University of Georgia; Roberto, K. A. and Brossoie, N., Virginia Polytechnic Institute and State University; and Teaster, P. B., University of Kentucky, 2008.

### Characteristics of the Current Aide

Seven aide attribute statements were read; respondents identified their level of agreement with each using the response set strongly agreed, somewhat agreed, somewhat disagreed, and strongly disagreed (Table 3). Overall, responses were positive. Over 90 percent strongly agreed that the aide was interested in the client, and over 88 percent strongly agreed that the aide was good company, had good caregiving skills, could be trusted, and was honest. Having good housekeeping skills received the lowest rating with

82.6 percent of respondents strongly agreeing, and 6.8 percent somewhat or strongly disagreeing.

Respondents were also asked about the frequency with which the aide exhibited specific traits, using the response selection, often, sometimes, rarely, and never (Table 4). Three of the six positive traits were described as occurring often by more than 90 percent of respondents. The aide works hard received the lowest rating; rated often by 84.5 percent of respondents. Negative traits that occurred most often included aide does not understand what you want (9.5 percent), does not show up

**Table 3**  
**Medicaid Waiver Personal Care Survey Respondents: Comparison of Positive Aide Attributes**

Attribute	(n)	Strongly Agree	Percent		
			Somewhat Agree	Somewhat Disagree	Strongly Disagree
Takes an Interest in Me	811	90.4	7.0	1.4	1.2
Good Company	808	89.2	8.7	1.4	0.7
Good Caregiving Skills	809	88.5	9.1	1.6	0.7
Can Be Trusted	800	88.5	9.5	0.9	1.1
An Honest Person	795	88.2	10.6	0.5	0.8
A Nice Person	810	87.3	11.2	0.9	0.6
Good Housekeeping Skills	789	82.6	10.5	3.5	3.3

SOURCE: Glass, A. P. and Butler, D. Q., University of Georgia; Roberto, K. A. and Brossoie, N., Virginia Polytechnic Institute and State University; and Teaster, P. B., University of Kentucky, 2008.



**Table 4**  
**Medicaid Waiver Personal Care Survey Respondents: Comparison of Aide Attributes**

Positive Traits	(n)	Frequency of Traits			
		Often	Sometimes	Rarely	Never
			Percent		
Knows What to Do When Comes	812	95.7	3	0.9	0.5
Completes All Tasks Needed	811	91.6	5.5	2.0	0.9
Does the Work Expected	810	90.6	6.2	1.4	1.9
Does Things the Way You Want Them Done	809	89.1	7.9	1.6	1.4
Arrives on Time	809	87.0	9.3	2.5	1.2
Works Hard	806	84.5	9.7	2.9	3.0
<b>Negative Traits</b>					
			Percent		
Smokes in House Without Permission	810	0.0	0.2	0.0	99.8
Shows Up With Another Person	810	1.2	2.0	2.6	94.2
Is Difficult to Understand	809	2.8	4.9	3.2	89.0
Talks on the Telephone More Than Should	793	3.7	4.9	4.5	86.9
Leaves Before Scheduled to Leave	806	4.7	5.2	10.2	79.9
Does Not Seem to Understand What You Want	804	9.5	5.6	10.4	74.5
Does Not Show Up	812	6.0	10.1	26.0	57.9

SOURCE: Glass, A. P. and Butler, D. Q., University of Georgia; Roberto, K. A. and Brossoie, N., Virginia Polytechnic Institute and State University; and Teaster, P. B., University of Kentucky, 2008.

(6.0 percent), and leaves before scheduled to leave (4.7 percent). The least problematic trait was aide smokes in house without permission.

Five other questions, with dichotomous yes/no responses, were included from the CMS survey (2003). All four positively worded statements received at least 90 percent yes responses: “The people paid to help you...“pay attention to [YOU]” (96.9 percent); ...“spend the time with [YOU] that they are supposed to” (96.0 percent); ...“listen carefully to what [YOU] ask them to do” (94.5 percent); and ...“seem well-trained” (90.0 percent). The one negatively worded statement, “The people paid to help me yell at me,” received 3.3 percent affirmative answers, representing 27 individuals.

### Choice

When asked about satisfaction with the amount of choice they had about which aide comes, 66 percent of the respondents

reported that they were very satisfied. A similar percentage (67.7 percent) said they were very satisfied with the amount of choice they had about when the aide comes, with 9.7 and 7.8 percent respectively reporting being either somewhat or very dissatisfied. For assignment of which aide comes, 72.4 percent of respondents reported that the agency makes the decision; 23.1 percent said they had some say. Respondents reported more involvement in scheduling when aides visit, with 35.4 percent saying they chose the time. Over one-half (56.0 percent) indicated that the agency chose the time.

### Complaints

One-third ( $n = 277$ ; 34.1 percent) of respondents reported complaining about services. Most (81.3 percent) complaints involved aides; the aide was subsequently replaced. For those ( $n = 215$ ) reporting how often they had complained, the mean was 4.48 times ( $SD = 6.64$ ). Over

one-third (38.6 percent) had complained only once. Three-fourths (71.1 percent) of complainants ( $n=196$ ) indicated their grievances were settled to their satisfaction; 80 reported the complaint was not resolved satisfactorily, and all but one gave reasons for their dissatisfaction (Table 5).

## OUTCOME MEASURES AND OVERALL SATISFACTION

The majority of respondents strongly agreed that they (whether clients or caregivers) are better able to deal with the cli-

ents' health problems because of receiving services (79.1 percent) (Table 6) and that their life is better because of receiving services (83.8 percent). Less than five percent (4.5 percent) were somewhat or strongly dissatisfied. Just over 9 percent of respondents indicated that they somewhat or strongly agreed that having an aide in the home causes stress. Three-fourths of the respondents (74.1 percent) said that they were very satisfied overall with services.

When asked whether the services received by the client matched the client's plan of care, 717 (88.9 percent) of the 807

**Table 5**  
**Medicaid Waiver Personal Care Survey Respondents: Reasons Given for Respondent Dissatisfaction with Complaint Resolution**

Reasons Given for Dissatisfaction	(n)	Percent
Problems Obtaining Aides (e.g., <i>took too long to get new aide/did not send new aide/would not replace aide/aide did not show up and no replacement/substitutes incompetent/had to change aides too many times/same problems over and over/ problem getting aides on weekends or evenings/too much turnover/cannot find good help/hard to find aide/pay too low</i> )	34	43.0
Problems With Agency (e.g., <i>agency did not make promised changes or follow agreed service plan/agency did not live up to expectations/client might change agencies/poor communications/ agency does not care/gets mad with family and does not do anything/not enough checking up on aides/agency did nothing about aide lying</i> )	24	30.4
Problems With Aides (e.g., <i>unreliable/aide stole money or other items/sending people who cannot provide needed services like lifting/aide older than client/drawing blood/aides take 2 hour breaks and do not do jobs/aides have no instruction/do not clean/aide using drugs/molestation by former aide</i> )	15	19.0
Other (e.g., <i>was told to complain to another dept. but did not /DMAS issue/Medicaid still working on problem for a month/do not agree with nurse/too many complaints to remember/do not know</i> )	6	7.6

NOTES:  $n = 79$ . DMAS is Department of Medical Assistance Services.

SOURCE: Glass, A. P. and Butler, D. Q., University of Georgia; Roberto, K. A. and Brossoie, N., Virginia Polytechnic Institute and State University; and Teaster, P. B., University of Kentucky, 2008.

**Table 6**  
**Medicaid Waiver Personal Care Survey Respondents: Quality of Life Outcome Measures**

Outcome Measure	(n)	Strongly Agree	Somewhat Agree	Somewhat Disagree	Strongly Disagree
Percent					
Better Able to Deal With (YOUR) Health Problems	794	79.1	18.3	1.5	1.1
(YOUR) Life is Better Because of Receiving Services	811	83.8	13.8	2.1	0.2
Having an Aide in the Home Causes Stress for (YOU).	722	3.6	5.8	5.4	85.2

NOTES: (YOUR) or (YOU) refers to the individual receiving the services in measure one, and to the respondent, whether client or family caregiver, in measures 2 and 3.

SOURCE: Glass, A. P. and Butler, D. Q., University of Georgia; Roberto, K. A. and Brossoie, N., Virginia Polytechnic Institute and State University; and Teaster, P. B., University of Kentucky, 2008.

responding believed that services matched their plans. However, 38 (4.7 percent) said they did not match, 31 (3.8 percent) did not know if services matched their plans, and 21 (2.6 percent) said they were not familiar with the plan of care.

## DISCUSSION

Overall, respondents were pleased with the performance of their personal care aides and appreciative of the care provided. Few respondents had problems with their current aides seeming dishonest or unpleasant. If they did have such problems, client complaints were generally resolved by replacing the aide.

The one problematic issue consistently reported dealt with time and reliability, specifically late arrivals, aides who left before scheduled, and those who did not show up at all. These problems cause significant inconvenience for family caregivers (Glass et al., 2005) and could possibly place a client at risk for poor health and safety outcomes. Training is another opportunity for improvement. Respondents suggested that some aides do not appear to be sufficiently trained in housekeeping and/or caregiving skills. A third issue is communication, particularly in large urban regions where many cultures and ethnic groups interface. Aides do not always perform tasks the way the clients wish. Sometimes aides do not seem to understand what the client wants. There were also some questions about how hard the aide worked.

Approximately 10 percent of respondents said their services did not match their plans of care; they did not know if their services matched their plans; or they were not familiar with the plan of care. This result is of concern, as the plan of care is integral. It should be readily available in the household, and agency staff, clients, and family

caregivers should confirm services are provided in accordance with the plan. Furthermore, the plan should be updated as warranted when significant changes in the client's condition occur. Thus, maintaining an item addressing this issue is recommended in future surveys.

We used our theoretical framework to compare the following reported performance. This evaluation allowed us to examine how well the E&D waiver services were meeting clients' expectations and to test the validity of the model.

- *Honest and trustworthy.* The attributes regarding the aide's honesty and the aide can be trusted received the least disagreement. For each of these items, however, about 1 in 10 respondents said that they only somewhat agreed rather than strongly agreed, suggesting there are still some doubts.
- *Aide reliably appears on the assigned days, at the assigned times, and stays the full time allotted.* The issue of time—the aide showing up on time and staying the full time allotted—surfaced as a major element in our earlier exploration of quality of personal care services (Glass et al., 2005). It is troubling that three of the problem areas identified in this survey related to time issues. The aide not showing up appeared to be the most common problem, followed by leaving before scheduled, and not arriving on time.
- *Assured knowledge base.* The quality of aides' housekeeping skills was the attribute receiving the most dissatisfaction from respondents, suggesting that it might deserve more attention. Aides' caregiving skills were considered good overall.
- *Energy focused on client and completion of tasks to meet client's needs.* Aides were usually interested in the client and completed necessary tasks. Aides did

not commonly bring along companions such as children or boyfriends, who could serve as distractions from getting the work done. Two concerns did arise, however, with aides not always considered to be working hard, and with aides talking on the telephone while on duty.

- *One consistent aide.* The majority of clients reported the same aide usually came. However, only one in four had the same aide for more than 2 years, and clients reported having an average of six aides during the past year, indicating that clients must often adjust to new aides. The assignment of a regular aide is probably largely a matter of staffing; some agencies may be constrained in this area.
- *Aide's methods suit client.* This aspect did not appear to be a problem. Aides generally performed tasks the way the client wanted them done.
- *Easy to have around.* Clients and aides spend many hours together; it is critical that the experience is as positive as possible. Most clients indicated that their aides were good company.
- *Communicates effectively.* Communication between aides and care recipients is crucial to client satisfaction. Overall, respondents felt that aides understood what was wanted from them (85 percent) and that they were able to understand the aides (92 percent). Northern Virginia was the most diverse region of the State, with over 15 percent of the clients and more than one-fourth of the aides described as a race other than Black/African American or White. The diversity there confirmed the issues that originally surfaced in our first phase of indepth interviews (Glass et al., 2005). Respondents here described having problems with aides from so many other nationalities. Some clients and/or aides had trouble with the English language, and some aides

had entered the country so recently that they were not yet familiar with modern conveniences that most Americans take for granted, such as microwave ovens. It is no surprise, then, that a far higher percentage of respondents in Northern Virginia reported difficulties (21.2 percent reported sometimes/often) in understanding the aide—three times the percentage for the State overall. This region also had the highest percentage (37.9 percent) reporting that the aide does not seem to understand what the client wants, at least occasionally. These findings highlight the need for agencies, particularly in this region, to give additional attention to cross-cultural training (Glass et al., 2004).

Together, the eight aspects provide a holistic picture of quality. Based on responses from our sample, however, it appears discordance in some of the aspects, such as reliability and training, are more common and problematic than others.

## CONCLUSION

Conducting this statewide survey provided a unique opportunity to understand personal care services provided under Virginia's E&D waiver. The instrument and subsequent data collected went beyond satisfaction measures to explore performance and quality of life outcome data, as well as aide and client demographics.

The study has limitations. The database received from DMAS contained no data about race, disability status, or telephone numbers. We cannot know if the sample was completely representative or what the responses might be from clients for whom we were unable to find telephone numbers. In some instances, family caregivers answered for clients, and we do not know how the client would have responded. Cognitive testing was not included. This survey

was conducted only once, and we were not able to test reliability. Our goal was primarily to provide a snapshot of how personal care services were being delivered.

The findings confirmed that the E&D waiver personal care services offered in Virginia are of great assistance to a population in need, and generally, clients and their family caregivers are appreciative. There are opportunities for improvement in how services are provided, however, especially related to time (i.e., aides showing up as scheduled and staying the full time assigned), training, communication, having a consistent aide, and how hard the aides work. The findings also indicate that providers should provide additional information to clients clarifying exactly what services are covered, as well as the role of the treatment plan. Ongoing use of a client/family caregiver survey is warranted to allow continued monitoring and improvement of service provision. Questions should be included about the use of the treatment plan. We recommend that such Medicaid waiver programs include telephone interviews with a certain percentage—5 to 10 percent—of their clients, perhaps when onsite agency reviews are conducted. Such a structured contact would yield a more balanced picture of performance. Additionally, agencies could use a shorter form of the same instrument, which we subsequently developed, to conduct surveys of their own to help them evaluate performance, outcomes, and client satisfaction.

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Reprint Requests: Anne P. Glass, Ph.D., University of Georgia, 255 E. Hancock Ave., Athens, Georgia 30602-5775. E-mail: [aglass@geron.uga.edu](mailto:aglass@geron.uga.edu)