MATHEMATICA
Policy Research, Inc.

Study of Medicaid Home and Community Based Services Waiver Program Survey Methodology

September 23, 2005

Larry P. Snell
Zhanyun Zhao
Cathy Lu
Frank Potter
Anne B. Ciemnecki

CONTENTS

I. OVERVIEW

The Lewin Group, Inc (Lewin) is conducting a study of the Medicaid Home and Community Based Service Waivers (HCBS) for the United States Department of Health and Human Services' Centers for Medicare & Medicaid Services (CMS). Collaborating on the project as subcontractors are: Mathematica Policy Research (MPR), Research Triangle Institute (RTI), the University of Minnesota, the MEDSTAT Group (MEDSTAT), and Human Services Research Institute (HSRI).

CMS is responsible for the federal administration of the Medicaid program (it also administers the Medicare program). Medicaid is a joint federal and state program that helps pay medical costs for some people with low incomes and limited resources. Medicaid HCBS waiver programs provide states with greater flexibility to serve individuals with substantial long-term care needs at home, or in the community, rather than in institutions. The number of, and expenditures for, these waivers continue to grow dramatically despite little research documenting the effects of services on cost, quality of care, or quality of life of both recipients and their families. Therefore, CMS wished to evaluate selected programs to assess their effects on quality of care, satisfaction with services, general health and functional status, quality of life, care management and cost of providing services. CMS also hoped to identify features of programs that are associated with favorable outcomes. The growing availability of home and community-based care is transforming the nature of formal (paid) long-term care services in the United States. These newly available services permit individuals to receive long-term care in their homes or communities rather than in nursing homes. In the past, a lack of alternatives forced individuals in need of long-term care to choose between relying almost exclusively on their family and friends, or being institutionalized. Now, many individuals receive formal services

that enable them to live alone at home, receive assistance with daily activities that support and relieve their informal (unpaid) caregivers, move to a more "home-like" facility, such as an adult foster home.

Home and community-based services, such as skilled nursing in the home and help with bathing, have become a more important part of the package of services offered by Medicaid. The provision of home and community-based support services is thought to prevent or delay institutionalization.

This report summarizes the methods MPR used to conduct the survey for the evaluation, the processes used to select samples for the Home and Community Based Services and the processes used to adjust the sampling weights to account for non-response.

Data were collected by telephone and through in-person interviews during a fifty eight week field period between May 5, 2003 to June 14, 2004, in six participating states. Three states, Alabama, Kentucky, and Maryland, had "developing" programs; three states, Michigan, Washington and Wisconsin, had "developed" programs.

The survey samples were drawn from the state Medicaid files. Four of the states (Maryland, Michigan, Washington, and Wisconsin) opted to provide the personal care option and all six states had HCBS waiver programs (although as discussed latter, the waiver sample for Michigan was inadvertently left out). In Alabama, Michigan, and Washington, the sample consisted of HCBS program participants during November 2001. In Maryland, the sample consisted of participants during December 2001. In Kentucky, the sample members could have participated at any time during 2001. In Wisconsin, sample members participated during December 2000. In Wisconsin, records for HCBS waiver maintained at the counties and are submitted to the state only once a year in approximately August. When negotiating sample acquisition with the state, we chose to obtain what was available rather than wait for the 2001 sample. Although we requested sample from the November 2001 timeframe, several of the states

several of the states could not provide samples until the summer of 2002.

Telephone interviews used Computer Assisted Telephone Interviewing (CATI) technology. In total 5,405 cases were released to interviewing. Substantial effort was devoted to updating contact information on the sample frames. To obtain telephone numbers and updated addresses, MPR used Marketing Systems Group (MSG) who sent the file to Experian for NCOA (National Change Of Address) updates, then MSG used their database to append new phone numbers or verify existing telephone numbers. In total, just eight percent could not be located for an interview or to confirm eligibility.

To be eligible to participate in the survey, sample members could not be deceased or living in a convalescent or nursing home or institution for more than 30 days. They had to be receiving home support services and still residing in the state where they were sampled or in Wisconsin, still residing in the county where they were sampled. Because of the age of the sampling frames, nearly one-third of sampled respondents were not interviewed—most (59 percent) were deceased. Many (17 percent) were institutionalized. A total of 2,601 36-minute interviews were completed, of which 2,458 (95 percent) were completed by phone using CATI. The remainder were completed in person. Cooperation rates among respondents were high, 92 percent of those who were located and eligible agreed to be interviewed. Four of the interviews turned out to be duplicates and were dropped from the analysis. In the end, the analysis is based on 2,597 program participants.

II. SAMPLE SELECTION AND ALLOCATION

This chapter describes the sampling design. The target population for the HCBS study consisted of all adult Medicaid home and community-based services waiver and state plan personal care option recipients, aged 18 and older in six states. Persons who were mentally retarded (MR) or developmentally disabled (DD) were excluded from this population by the states based on HCBS waiver type. A simple random sample was selected in each of the six states.

Across the six states, the lists provided by the individual states contained 87,526 persons and 204 were determined ineligible.[1] From the final sampling frame of 87,322 persons, an initial sample of 14,995 persons was selected and the final fielded sample contained 5,405 persons.[2] We located 4,973 persons (92 percent) of the sample and 4,364 persons (88 percent) of the located persons responded or were ineligible to respond. The overall response rate was 80.7 percent.

The sample was selected using a sequential random sampling procedure and initial weights were computed from the inverse of the selection probability.

Prior to sample selection, we investigated the use of geographical clustering of the sample because of the high cost of in-person interviewing of those who could not be interviewed by telephone. Based on the review of the profile of the sampling frame information, we

---

[1]Ineligible persons included persons living outside the study state as well as persons who were mentally retarded or had a developmental disability.

[2]The initial sample was randomly partitioned into subsamples called waves. The number of waves used in any one state varied according to response and eligibility among sample members.

recommended against the clustering of all samples because the cost saving from clustering would be too small to justify the loss of sampling precision.

We describe the processing procedures of the sampling frame first, followed by procedures of sample allocation. The procedures for calculating the weights and nonresponse adjustment are described in Chapter IV.

A. SAMPLING FRAMES: DESCRIPTION AND PROCESSING PROCEDURES

By September 2002, we received the lists of the HCBS recipients from each individual state government. For each state list, we conducted a review of the data records and the data elements. In this review, we identified potentially ineligible cases with out-of-state addresses, persons under the age of 18, and given the information available, the appropriate waiver type classification. For the under age 18 cases, we found few of these and they were often associated with future birthdates or were sufficiently close to age 18 at the time. It was decided not to delete them from the sampling frame nor the samples with the understanding that they would be identified during the interviewing process if in fact they were under age. We deleted all out-of-state cases prior to sample selection.

This was a very complex sample with multiple agencies in multiple states, each submitting the data differently. Of particular note are four of the states nuances in either the files or the processes to obtain the file which is described below:

- The *Maryland* file contained participants with mental retardation and developmental disabilities as well as the participants who were aged and disabled. We excluded the MR/DD sample from the frame prior to selecting the sample.

- The *Michigan* sample frame contained two files. One, of Michigan Choice participants, had 8,643 cases. The other, from the Michigan home health program, had 28,135 cases. The Michigan Choice file was inadvertently not used when drawing the sample. This means that the analysis had fewer waiver participants and more state plan personal care participants in the "developed" sample than planned. Because the analyses controls for whether an individual used these two types of

services, the omission of the Michigan HCBS waiver sample does not alter the analyses. This omission should also have little impact on the interpretation of the analyses, again because the variable will be used as a control for the regression analyses.

- In *Wisconsin*, five Family Care counties, Milwaukee, La Crosse, Fond du Lac, Portage, and Richland, all which had a capitated Medicaid long-term care demonstration in progress, were ineligible for the survey.

- Because the *Washington* State IRB required passive consent, the state sent MPR a file of 28,557 participants that had sample stratification variables such as age and gender but not personally identifying information. MPR selected a sample of 4,500 program participants and returned that file to the state. The state would only mail 3,000 letters, so MPR trimmed the sample to 3,000. The state linked the file to contact information and mailed 2,962 letters requesting permission to provide MPR with contact information for the survey. Program participants were to return a prepaid post card within two weeks if they did not want to participate in the survey. Of the 2,962 letters mailed, 510 were returned as non deliverable and 738 returned post cards indicating that they did not want to participate. Washington then provided contact information for the remaining 1,714 cases from which MPR selected a survey sample of 1,246. Washington State would not release social security numbers for program participants either. In Washington, only, we had to ask respondents for their social security numbers. Of the 601 survey respondents, 370 provided social security numbers. All but two could be matched to claims data.

In addition to a review of the eligibility requirements, we also classified the addresses into the following three address classes.[3]

1. Common street addresses (for which locating a phone number is typically easier than for other types of addresses)

2. P.O. Box, Rural Route, General delivery or other non-standard street addresses (for which phone number searches tend to be unsuccessful)

3. Duplicate/common street addresses.

To form this classification, we conducted an address parsing coupled with a phonic-based address duplicate detection procedure based on the Double-Take[4] software package. Any cases

---

[3]Address information was not provided by Washington to prepare these address classes.

[4]Double-Take, Version 2.005, 32-bit, Distributed by Peoplesmith Software, 50 Cole Parkway, Suite 34, Scituate, MA 02066-1337.

identified as address duplicates were placed into one address class (class 3) and the remaining cases were placed into either address class 1 or 2 based on whether the address was a standard street address, or a Post Office Box or other Box type address that would not identify the location of the residence. The benefit of separating out the duplicate addresses in this fashion was to allow the interviewer to contact a facility administrator/apartment manager to obtain contact information for multiple sample members at one time. We also conducted a visual review of the cases with common facility names to determine if the frame potentially included institutionalized persons, which would be determined to be ineligible during the interview. Table 1 gives a profile of each sampling frame.

B. SAMPLING DESIGN

Originally, the proposed sampling method was simple random sampling. Because high costs would be associated with in-person follow-up, we considered, but in the end rejected, the use of a geographically clustered sample design. To investigate whether to cluster the samples we determined the geographical dispersion of the cases in the frames by computing the person's distance from the center of the nearest large metropolitan area. To determine the distance, we obtained the longitude and latitude for each person's ZIP code and that for each of the centroids of the largest MSA counties (typically 4-15 in each state). We then used a trigonometric formula to convert the differences between the person's longitude and latitude points and that of the MSA counties to mileage-based distances. The average distances and frequencies by distance ranges are presented in Table 2.

TABLE 1

SUMMARY OF SAMPLING FRAME, PERSON COUNT AND CHARACTERISTICS

	AL	KY	MD	MI	WA	WI
Records received	5,728	12,897	3,343	28,135	28,562	8,861
Records eliminated	12	9	3	52	5	123[a]
Final Frame	5,716	12,888	3,340	28,083	28,557	8,738
Age						
0-17 years	259	648	58	155	0	107
18-24 years	116	405	50	1,669	210	167
25-34 years	235	546	120	2,927	681	263
35-44 years	337	723	173	4,055	1,664	602
45-54 years	467	1,095	234	4,774	3,139	857
55-64 years	682	1,838	383	4,635	3,828	1,002
65-74 years	869	2,670	687	4,471	5,709	1,756
75-84 years	1,384	3,143	1,000	3,704	7,219	2,247
85-94 years	1,139	1,658	566	1,513	4,844	1,591
95+ years	228	162	69	180	1,263	146
Address type class						
1. Standard street	4,134	5,033	2,069	22,048		7,347
2. P.O. Box address	777	1,406	81	1,459		441
3. Duplicate type	805	6,449	1,190	4,576		950

[a]The cases eliminated in WI were nursing home residents who were no longer eligible for HCBS services.

TABLE 2

DISTANCE OF PERSONS TO NEAREST METROPOLITAN AREA

	AL	KY	MD	MI	WA	WI
Average Distance	28.7	50.9	15.0	38.8	26.8	57.1
Frequency						
0-25 miles	2,706	3,198	2,908	17,255	19,390	4,089
26-50 miles	1,963	2,465	174	5,388	3,341	1,530
50-99 miles	1,045	6,610	231	2,204	4,934	1,290
100-149 miles		611	27	1,519	701	587
150+ miles	2	4		1,617	10	1,242
Unknown				100	181	
Total Persons	**5,716**	**12,888**	**3,340**	**28,083**	**28,557**	**8,738**

The results in Table 2 show that the average distances to the nearest city for considering the use of geographical clustering of the sample were sufficiently small for all but Wisconsin and Kentucky. For Wisconsin, because the majority (65 percent) of the cases were less than 50 miles from a major city, we decided to implement the original proposed simple random sampling methodology. On the other hand, Kentucky had a wide spread of cases and required more careful consideration; however, we decided that the best design for Kentucky was also the originally proposed methodology.

Our rationale for not geographically clustering the Kentucky sample stems from the unique characteristics of the population under study in this state. Specifically, we found that the population was small and the population to be highly concentrated in a few areas and very dispersed throughout the rest of the state. As an example, when we examined the population counts at the 5-digit ZIP code level, we found 70 percent of them to have less than 10 persons each, with a handful containing between 100-300 cases. We also found similar results at the county level with one county containing 10 percent of all the cases, and 20 percent of the counties having less than 20 cases each (many of these contain only 1 or 2 persons). This presented a problem for clustering the sample in that if we tried to keep the geographical land area of the interviewer areas/clusters to be relatively small to save travel time once in the area, we ended up having to select many areas to obtain a sufficient number of persons to meet the sampling and interviewing requirements. Because so many areas would be selected, they ended up basically covering the entire state, thus defeating the purpose for the clustering. In addition, because the in-person interviewing workload in this state would be small (less than 400 interviews), a sufficient workload could not exist in any one area to support hiring local staff. Based on these considerations, we felt that clustering the sample would not be sufficiently cost

effective to warrant the reduction in sampling precision that results from the clustering process. Therefore, we used a simple random sample in each state.

C. ALLOCATING SAMPLE TO STATES

The proposed sampling and interviewing process seeks to allocate the interviews proportionally among the developing and developed states (See Table 3). For each state, we selected a relatively large initial sample and divided the sample into random replicates or waves. We planned to release the waves in phases to ensure that each case receives the same level of effort during the interviewing process. To manage the waves, we made an initial large release to meet the interviewing requirements at an optimistic 90 percent response rate. Based on the findings from that release, we released additional waves as needed to obtain the desired number of completed interviews.

TABLE 3

INITIAL SAMPLE ALLOCATION AND FINAL SAMPLE BY STATE AND SAMPLE WAVE INFORMATION

	Developing Programs			Developed Programs				Developing Programs	Developed Programs
	AL	KY	MD	MI	WA	WI	Total		
Population	5,716	12,888	3,340	28,083	28,557	8,738	87,322	21,944	65,378
Target Allocation	625	1,410	365	1,031	1,048	321	4,800	2,400	2,400
Initial Sample	2,395	3,000	1,200	3,000	4,500	900	14,995	6,595	8,400
Number of Waves	240	100	50	100	100	45			
Average Cases Per Wave	10	30	24	30	45	20			
Final Sample	683	1,553	428	1,135	1,246	360	5,405	2,664	2,741

To select each sample, we utilized a sequential random sample selection procedure that sorts the beneficiaries in each the sampling stratum in a serpentine fashion based on a set of specified characteristics. This process, outlined by Chromy (1979),[5] imposes implicit stratification beyond

---

[5] Chromy, James R. (1979) "Sequential Sample Selection Methods," In Proceedings of the American Statistical Association Survey Research Section, pages 401-406.

the primary strata to ensure the sample is balanced on the implicit stratification variables. In this study, each state basically serves as the primary sampling strata. Within each state, we sorted the records using a serpentine methodology based on the age category (as presented in Table 1) and 3-digit ZIP code to ensure approximate proportional representation by these dimensions within each state.

The final sample included 5,405 persons. The distribution of the actual frame count, target allocation of the sample and the final sample by state is shown in Table 3.

III. DATA COLLECTION PROCEDURES

The telephone data collection was conducted at MPR's Plainsboro, New Jersey survey operations center. In total, 2,601 interviews were completed; 2,597 were usable for the analysis. Of the 2,601, 1,714 interviews were completed by telephone with beneficiaries and 744 interviews were completed by telephone with a proxy for the beneficiary. These interviews were conducted by telephone using MPR's Computer Assisted Telephone Interviewing system (CATI). Of the remaining 143 interviews, 142 interviews were completed in person with the beneficiary and one interview was completed in person with a proxy for the beneficiary. The in-person interviews were conducted using a hardcopy instrument. Trained telephone interviewers traveled to the six states to conduct the in-person interviews. The average interview length was 36 minutes.

A. INTERVIEWER TRAINING

MPR trained 40 telephone interviewers to administer the survey instrument. All but six of the interviewers trained had prior experience conducting telephone interviews. Study-specific training took twelve hours. Trainers explained the background and purpose of the study, reviewed the questionnaire, provided instructions for asking each question, and discussed methods for contacting respondents and gaining cooperation. In addition, we trained the interviewers on the challenges of interviewing people with disabilities. Interviewers had ample time for role playing, practice interviewing, and administrative procedures. After the main session, interviewers finished their training by completing practice interviews with a supervisor.

B. DATA COLLECTION SCHEDULE

Interviewing began in Alabama, Kentucky, Maryland, Michigan and Wisconsin on May 5, 2003 and began in Washington on September 29, 2003. A total of 2,705 cases were in the first sample release. On March 15, 2004 an additional 2,700 cases were released to interviewing across the six states. Interviewing ended on June 14, 2004. Table 4 shows the data collection progress by state and month.

TABLE 4

COMPLETED INTERVIEWS BY MONTH

Month, Year	Alabama	Kentucky	Maryland	Michigan	Washington	Wisconsin	Monthly Total	Cum Totals
May, 2003	40	120	28	88		38	314	314
June, 2003	46	126	22	97		20	311	625
July, 2003	20	49	12	24		7	112	737
August, 2003	6	2	2	14		0	24	761
September, 2003	1	0	1	6	10	2	20	781
October, 2003	0	0	0	0	144	0	144	925
November, 2003	0	1	2	2	60	0	65	990
December, 2003	14	29	6	41	22	6	118	1,108
January, 2004	8	28	6	8	37	4	91	1,199
February, 2004	12	11	2	12	14	1	52	1,251
March, 2004	38	53	45	73	104	35	348	1,599
April, 2004	95	160	34	122	87	20	518	2,117
May, 2004	37	71	34	92	90	34	358	2,475
June, 2004	9	34	19	25	33	6	126	2,601
Total	**326**	**684**	**213**	**604**	**601**	**173**	**2,601**	

C. RESPONDENT NOTIFICATION

In all states except Washington, sampled beneficiaries were notified by mail one week before an initial call was made to reassure them about the survey's authenticity and purpose. The advance letter was on CMS letterhead and explained the purpose of the study, confidentiality of responses, and voluntary participation (see Appendix A). The letter encouraged

respondents to call MPR's toll-free number for further information and to participate in the study.

An Institutional Review Board in Washington required passive consent prior to survey participation and would not share contact information with MPR until Medicaid recipients who did not wish to participate in the study had an opportunity to opt out. The Washington State Department of Social and Health Services, Aging and Disability Services Administration mailed an advance letter that explained the purpose of the study, confidentiality of responses, and voluntary participation to their program participants. As stated earlier, the mailing contained a postcard for participants to send back to the state if they did not wish to have their contact information shared with MPR. Those who did not return postcards and whose advance letters were not returned as undeliverable become eligible for the survey sample. Those selected received the same advance letter as program participants in other states.

D. USE OF PROXY RESPONDENTS

Despite their age and disabling conditions, 71 percent of the respondents were able to answer survey questions on their own. Twenty eight percent of the completed interviews were conducted by a proxy respondent. A proxy is defined as a person who completed an interview on behalf of the sample member. The proxy was recruited when interviewers learned that sample members were unable to complete the interview themselves due to a physical or mental condition such as hearing impairment, or dementia. Interviewers also recruited proxies to complete the interview for sample members having language barriers. Eligible proxies included individuals familiar with the health care experiences of the sample member. They were often the spouses, children, or other relatives and friends of the sample member. If family members or friends were not available, a volunteer or unpaid personal care or home helper may have been a proxy respondent. As a last resort, a paid personal care or home helper who was in frequent (at

least weekly) contact with the sample member may have been a proxy respondent. The single most common reason for using a proxy was because the sampled beneficiary was not cognitively or mentally able to complete the interview. Thirty percent of sample members under age 65 needed proxy respondent while 27 percent of sample members age 65 or older relied on proxy respondents. Elderly sample members were more likely than younger respondents to require in-person rather than telephone interviews (7 versus 3 percent).

E.   MONITORING INTERVIEWER PERFORMANCE

Both qualitative and quantitative indicators of interviewer performance were used to monitor data quality. Quantitative indicators, such as productivity and refusal rates were assessed from reports generated by the CATI system (see Appendix A). During the first week of the project, at least one completed interview was monitored for each telephone interviewer using MPR's central monitoring system. The system enables the supervisor to listen to interviews without the interviewer or the respondent being aware of it. The system also allows the supervisor to view the interviewer's CATI screen while the interview is in progress. Overall, approximately 7 percent of all interviews were monitored. For each monitored interview, the supervisor completed an on-line evaluation identifying specific errors. At the completion of the monitoring session, the supervisor reviewed any errors with the interviewers and made suggestions for improvement.

F.   OBTAINING CONTACT INFORMATION FOR SAMPLE MEMBERS

The state files from Alabama, Kentucky, Maryland, Michigan and Wisconsin contained a telephone number for 42 percent of the cases. To obtain telephone numbers and updated addresses for the remaining cases, MPR used Marketing Systems Group (MSG) who sent the file to Experian for NCOA (National Change Of Address) updates, then MSG used their database to

append new phone numbers or verify existing telephone numbers. This search yielded telephone

numbers for 65 percent of the cases, of which 48 percent did not have a prior telephone number.

The state file from Washington contained a phone number for 97 percent of the cases.

MPR sent this file to MSG to append new phone numbers or verify existing telephone numbers.

This search yielded matched telephone numbers for 56 percent of the cases. Telephone numbers

that were not verified were still used when possible.

Therefore, at the start of data collection 80 percent of the cases had telephone numbers. In

addition to the 20 percent of cases for which a telephone number was not initially located, 41

percent of the sample had an incorrect telephone number. MPR's locating department was able

to locate a telephone number for 63 percent of these cases and determined that twenty four

percent of these sampled beneficiaries were deceased. The following resources were used to

locate sample beneficiaries:

- *Directory Assistance.* The locating specialist asked the operator for the sampled respondent and others in the area with the same or similar last names. During the data collection period new on-line services allowed the locating specialist to perform their own directory assistance searches.

- *Advance Letter mailed "ADDRESS SERVICE REQUESTED."* The US Postal Service will return a letter with updated address information when it is available.

- *On-line database of addresses.* On-line databases were used to verify or update address information for sample beneficiaries. These databases were also used to look up cases by address, also called reverse address look-ups. Reverse address look-ups sometimes yielded a telephone number that was listed to someone other than the sample beneficiary.

- *Neighbors.* Reverse look-ups were used to obtain the names and telephone numbers of neighbors. Neighbors provided useful locating leads and took messages.

Our general approach to locating was to use the least expensive, automated sources first and

progress to the more expensive locating for cases that were not found.

G. SURVEY ELIGIBILITY

Five thousand four hundred and five (5,405) cases were released for interviewing. Thirty three percent (1,784 cases) were ineligible for survey participation. There were four reasons for ineligibility: the sample member was deceased (1,101 cases), the sample member was in a convalescent or nursing home or institution for more than 30 days (315 cases), the sample member either never received or no longer received home support services (343 cases) and the sample member no longer resided in the state where they were sampled or for Wisconsin, the county where they were sampled (25 cases). We did not conduct interviews with these cases.

IV. WEIGHTING AND NON-RESPONSE ADJUSTMENTS

We computed initial weights based on the selection probability and adjusted these weights for the proportion of the initial sample that was used in the survey. We then computed a final location and response-adjusted weight by running two consecutive logistic propensity models for each of the six states. A Chi-squared Automatic Interaction-Detection (CHAID) algorithm and logistic regression were used to identify factors associated with nonresponse and to develop the logistic models. The R-squares for the logistic models range from 0.03 to 0.09, and the Hosmer-Lemeshow goodness-of-fit statistics range from 0.42 to 0.99 for the 12 models. The design effects of unequal weighting are very close to 1 for all of the models.

The sampling weights are computed from the probability of selection with adjustments for the proportion of the initial sample released and for nonresponse. The non-response adjustment was done separately within each individual state. The non-response method used was logistic response propensity regression modeling in two stages: first for the ability to locate the person and then for response among the located person.

A. PREPARATION FOR WEIGHTING

Because of the difference between the number of total waves and the number of released waves, the initial weight was adjusted to account for the number of waves used and is:

$$(1) \quad Wgt\_input = Wgt\_sampling \times \frac{\#\,of\ total\ waves}{\#\,of\ released\ waves}$$

Here, $Wgt\_sampling$ is the initial sampling weight when the sample was selected in October 2002. The release-adjusted initial weights were then post-stratified so that the sum of

the post-stratified weights would equal the original sampling frame count in each state. We defined *Wgt _ pinput* as the post-stratified release-adjusted initial weight.

As indicated previously, the sampling frames contained demographic variables such as age and gender, county of residence, and an indicator of urban/rural status for all of the six states. Other information, such as phone number and address type, was available for some of the states. To improve the quality of non-response adjustment, we also obtained the *Rural-Urban continuum codes for Metro and Non-metro Counties,* developed by Department of Agriculture, from Area Resource File (ARF). These codes form a classification scheme that distinguishes metropolitan counties by size and non-metropolitan counties by degree of urbanization or proximity to metropolitan areas, based on the 2000 census population data. Each county and county equivalent is assigned one of the 12 urbanicity codes.

Because the number of levels in the urbanicity code, we grouped some levels together to ensure adequate counts in the final cells. Grouping was also done for other variables such as age and address type. The final set of proposed independent variables for each state are listed in Table 5.

TABLE 5

INDEPENDENT PREDICTOR VARIABLES BY STATE

	AL	KY	MD	MI	WA	WI
Age	5 levels	6 levels	4 levels	6 levels	6 levels	4 levels
Urbanicity	4 levels	4 levels	2 levels	4 levels	3 levels	3 levels
Urban Status	2 levels	2 levels	2 levels	2 levels	2 levels	2 levels
Address Type	3 levels	3 levels	2 levels	2 levels		2 levels
Gender	2 levels	2 levels	2 levels	2 levels	2 levels	2 levels
Phone Status		2 levels	2 levels	2 levels	2 levels	2 levels
SSN Available						2 levels
Wave Status		2 levels	2 levels	2 levels	2 levels	2 levels
Waiver Type	2 levels					

Because persons who can't be located cannot make a conscious decision about response, the nonresponse adjustment was divided into two stages: for the ability to locate a person and response among the located persons. Therefore, we first modeled the propensity to locate a sampled person and then we modeled the propensity of a person to respond conditional on its being located. Table 6 shows the number of respondents, the number of located cases and the total number of samples respectively for each state.

TABLE 6

SAMPLE SIZE FOR LOCATION MODEL AND RESPONSE MODEL

	AL	KY	MD	MI	WA	WI
Full Sample	683	1,553	428	1,135	1,246	360
Located Persons	642	1,440	392	1,023	1,147	329
Percent of Sample	94.0%	92.7%	91.6%	90.1%	92.1%	91.4%
Respondents	565	1,294	346	880	986	293
Percent of Located	88.0%	89.9%	88.3%	86.0%	86.0%	89.1%
Percent of Sample	82.7%	83.3%	80.8%	77.5%	79.1%	81.4%

B. LOCATION MODEL

For the location model, we defined a dependent variable, *Loct*, as 1 if the case is located and 0 otherwise. The procedure for the response model is analogous to this.

CHAID. To identify candidate independent variable and interactions for the modeling, we first ran a CHAID analysis to find possible significant predictors. CHAID iteratively segments a data set into mutually exclusive subgroups that share similar characteristics based on their effect on nominal or ordinal dependent variables. It automatically checks all variables in the data set and creates a hierarchy that shows all statistically significant subgroups. The algorithm finds splits in the population, which are as different as possible based on a chi-square statistic. It is a forward stepwise procedure, and it finds the most diverse split, and then works each of these

20

splits to find more diverse splits. Sample size limitations are set to avoid generating cells with small counts. It stops when splits no longer are significant; i.e., that group is homogeneous with respect to variables not yet used, or when the cells contain too few cases.

Because CHAID accepts multi-level nominal variables, we recoded our independent variables into 0/1 indicator variables so that the CHAID tree is easier to read and interpret. The following is one example of a classification tree (for Maryland). To avoid missing important predictors, we reran CHAID excluding the initial split variable (AGEC6 as in Figure 1). Generally, more variables appeared in the new tree. We combined the sets of variables identified to develop an initial set of predictors.

Logistic regression. As shown in Figure 1, AGEC6 and ADDRC1 were identified as the most significant main effects and the interaction of AGEC6 and ADDRC1 was also identified as a potential predictor. In most states, a large number of main effects and two and higher order interactions were identified by CHAID. To further reduce the set of predictors, we used the logistic regression procedure in SAS with both forward and backward step-wise selection to eliminate non-significant predictors. The predictors identified by backward and forward step-wise selection using SAS were entered into logistic model in SUDAAN to compute the design-based variances. We used the design-based variance estimates to identify the final model and to remove insignificant predictors. Table 7 shows the significant predictors in each of the six states.

From Table 6, we can see that age is consistently the most significant predictor. It is significant in all of the six states, either through a main effect or through the interaction with one or more other variables. The urban/rural code based on the *Rural-Urban continuum codes for Metro and Non-metro Counties* in the ARF data base was significant in five of the states. Other significant predictor variables were gender and address type.

21

FIGURE 1

CHAID CLASSIFICATION TREE FOR MARYLAND (LOCATION MODEL)
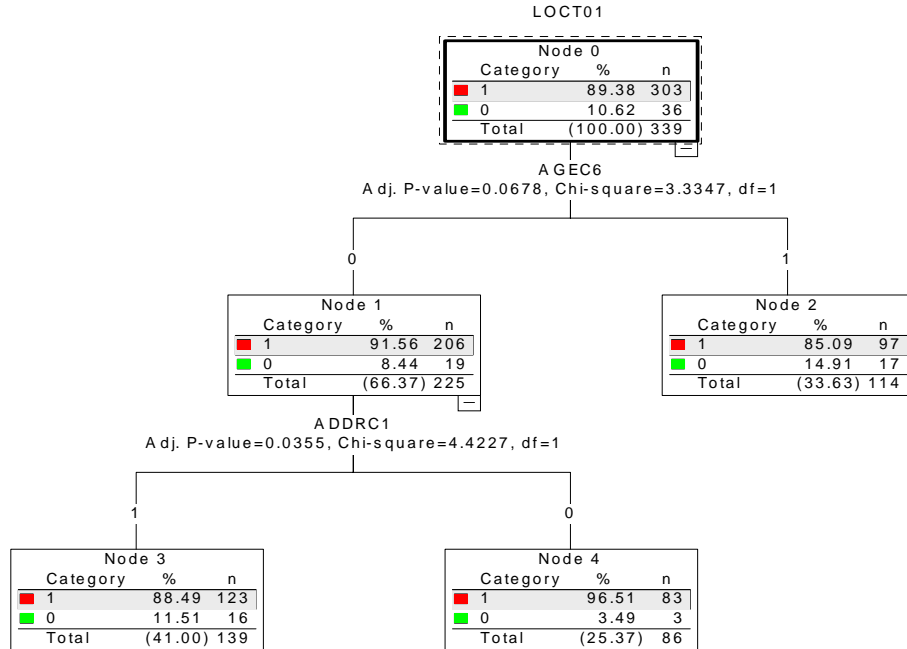
For the final location adjustment factor, we used the predicted propensity to be located (Exp_loct) computed in SUDAAN for each case. The final location-adjusted weight is defined as

$$
(2) \quad Wgt\_loct = \begin{cases} Wgtps\_pinput, \text{if deceased} \\ Wgtps\_pinput \times \dfrac{1}{Exp\_loct}, \text{if locatable} \\ 0, \text{otherwise} \end{cases}
$$

Because the locating procedures that were used are effective in identifying deceased persons, we excluded the deceased persons from the location adjustment (that is using the

TABLE 7

FINAL SIGNIFICANT VARIABLES IN THE LOCATION MODEL

	AL	KY	MD	MI	WA	WI
Age	Main	Interaction	Main	Interaction	Main	Main
Urbanicity	Interaction	Main	----	Main	Main	Main
MSA	Main	Main	----	----	----	----
Address Type	Main	Main	Interaction	----		Interaction
Gender	----	Main	Main	----	Main	Interaction
Missing Phone		Main	Main	Interaction	----	----
Missing SSN						----
Wave Status		Interaction	----	Main	Interaction	----
Waiver Type	Main					
Summary Statistics						
R-Square	0.0486	0.0478	0.0675	0.0584	0.0283	0.0940
Hosmer-Lemeshow						
Probability [a]	0.8402	0.8097	0.4231	0.9999	0.9899	0.6039
% Concordant	70.4	68.6	69.7	63.0	59.6	70.1
% Discordant	25.3	29.3	24.0	26.3	29.3	22.1

[a] Hosmer, David W. and Lemeshow, Stanley (2000) "Applied Logistic Regression" New York: *John Wiley & Sons*

locating procedures we "located" all deceased persons). Therefore, the weights for the deceased cases are not multiplied by the inverse of the expected probability.

Trimming. In many cases, one or more extreme weights can result from the nonresponse adjustment and potentially lead to large sampling variances. The purpose of trimming is to decrease the variance more than enough to compensate for the possible increase in bias. We use the "NAEP procedure" for trimming. The NAEP procedure has been reported in conjunction with the National Assessment of Educational Progress (NAEP) (Potter 1990)[6]. In the NAEP procedure, the trimming level is defined as

(3) $$Trim\_level = \sqrt{c \sum (Wgt\_loct)^2 / n}$$

---

[6]Potter, Frank J, (1990) "A Study of Procedures to Identify and Trim Extreme Sampling Weights." Proceedings of the American Statistical Association, Section on Survey Research Methods, 1990, pp. 225-230.

where c is a constant, and was given a value of 10 for this study (as in most other studies). Usually, if a weight is larger than $Trim\_level$, then it is given this value and the excess amount is evenly distributed to those weights that were not trimmed. Among all six states, trimming was needed only for weights for Michigan. Without loss of generality, we use Wgt_loct to denote the weight after trimming.

Post-stratification. The last step for the location model is the post-stratification so that the sum of the post-stratified weights after the location modeling would equal to the original sampling frame count for each state. We used Wgt_ploct to denote the weights after this post-stratification.

C. RESPONSE MODEL

The same procedures were used for the response model. The dependent variable $Resp$ was defined as 1 if the case is a respondent (including both cases with a completed interview and an ineligible case) and 0 otherwise. The dependent variable, $Resp$, only has values defined for located cases. Again, we first ran the CHAID algorithm to find possible predictors, and then we used SAS and SUDAAN to identify the significant predictors as main effects and interactions. Table 7 lists out the significant predictors for the response propensity model.

As seen in Table 8, most of the significant variables in the location model were significant again in the response model. Some variables that are significant in the location model as a main effect now are significant as an interaction in the response model, and vice versa.

TABLE 8

FINAL SIGNIFICANT VARIABLES IN THE RESPONSE MODEL

	AL	KY	MD	MI	WA	WI
Age	Main	Main	Interaction	Interaction	Main	Main
Urbanicity	Main	Main	----	Main	Main	Main
MSA	Main	Interaction	----	----	Main	Main
Address Type	Interaction	Interaction	Interaction	Interaction		----
Gender	----	Interaction	----	Interaction	Interaction	Interaction
Phone Status		----	Main	Interaction	----	----
SSN Status						----
Wave Status		Interaction	----	Interaction	Main	----
Waiver Type	Interaction					
Summary Statistics						
R-Square	0.0826	0.0556	0.0605	0.0637	0.0494	0.0712
Hosmer-Lemeshow						
Probability	0.8587	0.7345	0.9999	0.8523	0.994	0.9975
% Concordant	70.2	68.6	61.5	65.9	62.2	63.5
% Discordant	26.1	30.0	23.3	28.7	31.7	23.9

[a] Hosmer, David W. and Lemeshow, Stanley (2000) "Applied Logistic Regression" New York: *John Wiley & Sons*

For the response adjustment factor, we again used the predicted propensity to respond (Exp_ltnr) computed in SUDAAN for each case. The final response-adjusted weight is defined

(4)
$$Wgt\_ltnr = \begin{cases} Wgt\_ploct, \text{if deceased or non-locatable} \\ Wgt\_ploct \times \dfrac{1}{Exp\_ltnr}, \text{ if repond} \\ 0, \text{otherwise} \end{cases}$$

The weights were again review for extreme values and conducted as needed; trimming was needed only for Michigan. Finally the weights were post-stratified and the post-stratified weights are denoted by Wgt_pltnr.

25

APPENDIX A

ADVANCE LETTERS

ADVANCE LETTERS

Dear Medicaid Waiver Beneficiary:

You are one of many Americans receiving home and community based services under the Medicaid program. Medicaid is a federal and state program that helps pay medical costs for some people with low incomes and limited resources. The Centers for Medicare & Medicaid Services (CMS), formerly known as the Health Care Financing Administration, manages the federal part of the Medicaid program.

CMS is conducting a study about Medicaid home and community based services. The purpose of the study is to look at the way these Medicaid services affect the quality of your life, and to look at the quality of care you receive. The State of [insert state name] is participating in the study and you have been invited to participate as well. Your participation involves answering interview questions.

Mathematica Policy Research, a research firm, is working with CMS to collect data for this study. In a few weeks, a Mathematica interviewer will contact you to tell you more about the study and schedule a time to conduct the interview. You may do this by telephone or request that an interviewer visit your home at your convenience. The interview will take, at most, 40 minutes of your time.

If it will be difficult for you to participate in this interview, you may ask a relative, or friend who is familiar with your health care to answer questions for you. If this person is not available when you are initially contacted, an interviewer can contact you again at a more convenient time. You do not need to complete it all at once. No one will try to sell you anything or ask for a donation.

Your participation is voluntary, but very important. You won't lose any Medicaid benefits if you decide not to take part in the study. All information you provide will be kept confidential and your answers will not be shared with your doctor, health care providers or the Medicaid Program.

If you have any questions about the study or would , please feel free to call Carey Brown at MPR at 1-800-385-8046. These calls are free. Thank you in advance for your help.

Sincerely,

Susan Radke

Susan Radke
Project Officer

The valid OMB control number of this information is 0938-0826. Approval expires 06/30/2004.

ADVANCE LETTER FROM THE STATE OF WASHINGTON

Dear

You are being invited to take part in a study of clients who get personal care services from the Department of Social and Health Services. Mathematica Policy Research is doing this study for the U.S. Department of Health and Human Services (HHS). HHS is the federal agency that helps pay for the Medicaid program. The study will try to find out if our clients get the care they need. The researchers want to know about the care clients receive and if they have problems getting care.

Mathematica is a research company in New Jersey. The study team would like to talk to you about your health and the personal care services you get in the community. Some questions ask what you think about the care you receive. The researchers also want to get information from the Aging and Disability Service Administration about your care and what it costs.

This study is voluntary but very important. You won't lose any benefits if you decide not to take part, skip questions, or leave the study. Your Medicaid benefits won't change, no matter what you decide.

All study information will be kept confidential. The researchers won't tell anyone at DSHS or your care provider how you answered the study questions. This is research. **No one will try to sell you anything or ask for money.**

In 2 weeks, we plan to give your name and address to Mathematica. Then, an interviewer will call to ask if you would like to take part. If you are willing to be called about the study, you don't have to do anything. **If you don't want your name given to the study team, please fill out and return the postcard that came with this letter within 2 weeks.** You won't be contacted about this study again.

If you would like to talk about this study with someone from the research team, you can call **1-800-385-8046**. Thank you for taking the time to think about participation in this important study. We hope it will help us improve community-based care services for our clients.

Sincerely,

Penny Black, Director
Home and Community Services
Aging and Disability Service Administration

APPENDIX B

FINAL SURVEY STATUS REPORT

HCBS Standard Status Report - Produced on June 21, 2004

Major Category / Sub Category / Status			June 20, 2004			Cumulative			Calls
			N Cases	% Column	% Sub Category	N Cases	% Column	% Sub Category	Mean
FINAL	1.1 Final Complete	010 CATI complete	0	0	0	1711	31.66	65.78	8.1
		011 CATI proxy complete	0	0	0	740	13.69	28.45	9.6
		020 Field Callin complete	0	0	0	2	0.04	0.08	13.0
		021 Field Callin proxy complete	0	0	0	4	0.07	0.15	4.8
		040 Hardcopy complete	0	0	0	143	2.65	5.50	8.3
		041 Hardcopy complete - Proxy	0	0	0	1	0.02	0.04	5.0
		subtotal	0	0	0	2601	48.12	100.00	8.5
	1.2 Final Refusal	200 Refusal by known respondent	0	0	0	124	2.29	55.61	13.7
		210 Refusal by gatekeeper	0	0	0	35	0.65	15.70	21.2
		220 Refusal by unknown person	0	0	0	10	0.19	4.48	23.0
		230 Mechanical answering device	0	0	0	18	0.33	8.07	14.8
		250 Refusal-partial (started, not complete)	0	0	0	36	0.67	16.14	22.8
		subtotal	0	0	0	223	4.13	100.00	16.8
	1.3 Final (presumed) Eligible	300 Duplicate sample	0	0	0	7	0.13	0.98	3.0
		330 Effort ended-case retired	0	0	0	277	5.12	38.69	15.7
		590 Final unlocatable by phone center	0	0	0	432	7.99	60.34	8.4
		subtotal	0	0	0	716	13.25	100.00	11.2
	1.4 Final Ineligible	400 Language barrier (non Spanish)	0	0	0	56	1.04	3.00	17.3
		410 Physical/cognitive barrier	0	0	0	14	0.26	0.75	10.5
		420 Institutionalized	0	0	0	3	0.06	0.16	18.0
		424 Nursing Home	0	0	0	312	5.77	16.74	6.3
		430 Unavailable during field period	0	0	0	3	0.06	0.16	21.0
		440 Deceased	0	0	0	1101	20.37	59.07	4.5
		450 Moved out of fielding area	0	0	0	25	0.46	1.34	5.9
		460 Does not meet survey criteria	0	0	0	334	6.18	17.92	8.8
		461 Ineligible - never received benefits	0	0	0	2	0.04	0.11	12.0
		462 Ineligible - no longer receiving benefits	0	0	0	3	0.06	0.16	4.3
		463 Ineligible - undetermined benefits status	0	0	0	3	0.06	0.16	9.0
		470 No proxy available	0	0	0	8	0.15	0.43	15.8
		subtotal	0	0	0	1864	34.49	100.00	6.1
INTERIM	2.2 Locating Issues	530 Wrong number/no such person	0	0	0	1	0.02	100.00	6.0
		subtotal	0	0	0	1	0.02	100.00	6.0
TOTAL			0	0	0	5405	100.00	100.00	8.4

Major Category / Sub Category / Status			AL		KY		MD		MI	
			N	%	N	%	N	%	N	%
FINAL	1.1 Final Complete	010 CATI complete	190	27.82	412	26.53	140	32.71	412	36.30
		011 CATI proxy complete	110	16.11	234	15.07	49	11.45	174	15.33
		020 Field Callin complete	0	0	0	0	0	0	1	0.09
		021 Field Callin proxy complete	0	0	2	0.13	0	0	0	0
		040 Hardcopy complete	26	3.81	36	2.32	23	5.37	17	1.50
		041 Hardcopy complete - Proxy	0	0	0	0	1	0.23	0	0
		subtotal	326	47.73	684	44.04	213	49.77	604	53.22
	1.2 Final Refusal	200 Refusal by known respondent	14	2.05	19	1.22	16	3.74	27	2.38
		210 Refusal by gatekeeper	0	0	6	0.39	3	0.70	12	1.06
		220 Refusal by unknown person	0	0	2	0.13	1	0.23	6	0.53
		230 Mechanical answering device	4	0.59	4	0.26	1	0.23	7	0.62
		250 Refusal-partial (started, not complete)	6	0.88	7	0.45	5	1.17	10	0.88
		subtotal	24	3.51	38	2.45	26	6.07	62	5.46
	1.3 Final (presumed) Eligible	300 Duplicate sample	0	0	7	0.45	0	0	0	0
		330 Effort ended-case retired	47	6.88	94	6.05	10	2.34	46	4.05
		590 Final unlocatable by phone center	41	6.00	113	7.28	36	8.41	112	9.87
		subtotal	88	12.88	214	13.78	46	10.75	158	13.92
	1.4 Final Ineligible	400 Language barrier (non Spanish)	0	0	0	0	5	1.17	19	1.67
		410 Physical/cognitive barrier	2	0.29	5	0.32	0	0	3	0.26
		420 Institutionalized	0	0	2	0.13	0	0	1	0.09
		424 Nursing Home	55	8.05	101	6.50	25	5.84	37	3.26
		430 Unavailable during field period	0	0	2	0.13	0	0	1	0.09
		440 Deceased	155	22.69	369	23.76	89	20.79	143	12.60
		450 Moved out of fielding area	4	0.59	4	0.26	3	0.70	9	0.79
		460 Does not meet survey criteria	29	4.25	130	8.37	18	4.21	95	8.37
		461 Ineligible - never received benefits	0	0	0	0	0	0	1	0.09
		462 Ineligible - no longer receiving benefits	0	0	2	0.13	1	0.23	0	0
		463 Ineligible - undetermined benefits status	0	0	1	0.06	0	0	0	0
		470 No proxy available	0	0	1	0.06	2	0.47	2	0.18
		subtotal	245	35.87	617	39.73	143	33.41	311	27.40
INTERIM	2.2 Locating Issues	530 Wrong number/no such person	0	0	0	0	0	0	0	0
		subtotal	0	0	0	0	0	0	0	0
TOTAL			683	100.00	1553	100.00	428	100.00	1135	100.00

Major Category / Sub Category / Status			WA		WI		TOTAL	
			N	%	N	%	N	%
FINAL	1.1 Final Complete	010 CATI complete	432	34.67	125	34.72	1711	31.66
		011 CATI proxy complete	135	10.83	38	10.56	740	13.69
		020 Field Callin complete	1	0.08	0	0	2	0.04
		021 Field Callin proxy complete	2	0.16	0	0	4	0.07
		040 Hardcopy complete	31	2.49	10	2.78	143	2.65
		041 Hardcopy complete - Proxy	0	0	0	0	1	0.02
		subtotal	601	48.23	173	48.06	2601	48.12
	1.2 Final Refusal	200 Refusal by known respondent	34	2.73	14	3.89	124	2.29
		210 Refusal by gatekeeper	12	0.96	2	0.56	35	0.65
		220 Refusal by unknown person	1	0.08	0	0	10	0.19
		230 Mechanical answering device	2	0.16	0	0	18	0.33
		250 Refusal-partial (started, not complete)	6	0.48	2	0.56	36	0.67
		subtotal	55	4.41	18	5.00	223	4.13
	1.3 Final (presumed) Eligible	300 Duplicate sample	0	0	0	0	7	0.13
		330 Effort ended-case retired	66	5.30	14	3.89	277	5.12
		590 Final unlocatable by phone center	99	7.95	31	8.61	432	7.99
		subtotal	165	13.24	45	12.50	716	13.25
	1.4 Final Ineligible	400 Language barrier (non Spanish)	30	2.41	2	0.56	56	1.04
		410 Physical/cognitive barrier	3	0.24	1	0.28	14	0.26
		420 Institutionalized	0	0	0	0	3	0.06
		424 Nursing Home	65	5.22	29	8.06	312	5.77
		430 Unavailable during field period	0	0	0	0	3	0.06
		440 Deceased	267	21.43	78	21.67	1101	20.37
		450 Moved out of fielding area	5	0.40	0	0	25	0.46
		460 Does not meet survey criteria	50	4.01	12	3.33	334	6.18
		461 Ineligible - never received benefits	1	0.08	0	0	2	0.04
		462 Ineligible - no longer receiving benefits	0	0	0	0	3	0.06
		463 Ineligible - undetermined benefits status	1	0.08	1	0.28	3	0.06
		470 No proxy available	2	0.16	1	0.28	8	0.15
		subtotal	424	34.03	124	34.44	1864	34.49
INTERIM	2.2 Locating Issues	530 Wrong number/no such person	1	0.08	0	0	1	0.02
		subtotal	1	0.08	0	0	1	0.02
TOTAL			1246	100.00	360	100.00	5405	100.00

Major Category / Sub Category / Status			UNDER 65		65 OR OLDER		UNKNOWN		TOTAL	
			N	%	N	%	N	%	N	%
FINAL	1.1 Final Complete	010 CATI complete	779	37.83	892	28.17	40	22.35	1711	31.66
		011 CATI proxy complete	351	17.05	365	11.53	24	13.41	740	13.69
		020 Field Callin complete	2	0.10	0	0	0	0	2	0.04
		021 Field Callin proxy complete	1	0.05	3	0.09	0	0	4	0.07
		040 Hardcopy complete	39	1.89	98	3.09	6	3.35	143	2.65
		041 Hardcopy complete - Proxy	0	0	1	0.03	0	0	1	0.02
		subtotal	1172	56.92	1359	42.91	70	39.11	2601	48.12
	1.2 Final Refusal	200 Refusal by known respondent	54	2.62	67	2.12	3	1.68	124	2.29
		210 Refusal by gatekeeper	23	1.12	11	0.35	1	0.56	35	0.65
		220 Refusal by unknown person	6	0.29	4	0.13	0	0	10	0.19
		230 Mechanical answering device	8	0.39	9	0.28	1	0.56	18	0.33
		250 Refusal-partial (started, not complete)	7	0.34	27	0.85	2	1.12	36	0.67
		subtotal	98	4.76	118	3.73	7	3.91	223	4.13
	1.3 Final (presumed) Eligible	300 Duplicate sample	3	0.15	2	0.06	2	1.12	7	0.13
		330 Effort ended-case retired	124	6.02	142	4.48	11	6.15	277	5.12
		590 Final unlocatable by phone center	206	10.00	213	6.73	13	7.26	432	7.99
		subtotal	333	16.17	357	11.27	26	14.53	716	13.25
	1.4 Final Ineligible	400 Language barrier (non Spanish)	6	0.29	49	1.55	1	0.56	56	1.04
		410 Physical/cognitive barrier	3	0.15	11	0.35	0	0	14	0.26
		420 Institutionalized	0	0	1	0.03	2	1.12	3	0.06
		424 Nursing Home	40	1.94	257	8.11	15	8.38	312	5.77
		430 Unavailable during field period	1	0.05	2	0.06	0	0	3	0.06
		440 Deceased	199	9.66	854	26.97	48	26.82	1101	20.37
		450 Moved out of fielding area	13	0.63	12	0.38	0	0	25	0.46
		460 Does not meet survey criteria	188	9.13	137	4.33	9	5.03	334	6.18
		461 Ineligible - never received benefits	1	0.05	1	0.03	0	0	2	0.04
		462 Ineligible - no longer receiving benefits	1	0.05	2	0.06	0	0	3	0.06
		463 Ineligible - undetermined benefits status	0	0	2	0.06	1	0.56	3	0.06
		470 No proxy available	3	0.15	5	0.16	0	0	8	0.15
		subtotal	455	22.10	1333	42.09	76	42.46	1864	34.49
INTERIM	2.2 Locating Issues	530 Wrong number/no such person	1	0.05	0	0	0	0	1	0.02
		subtotal	1	0.05	0	0	0	0	1	0.02
TOTAL			2059	100.00	3167	100.00	179	100.00	5405	100.00

HCBS Status By Age Group (Alabama) - Produced on June 21, 2004

		Major Category / Sub Category / Status	UNDER 65		65 OR OLDER		TOTAL	
			N	%	N	%	N	%
FINAL	1.1 Final Complete	010 CATI complete	79	37.26	111	23.57	190	27.82
		011 CATI proxy complete	42	19.81	68	14.44	110	16.11
		040 Hardcopy complete	3	1.42	23	4.88	26	3.81
		subtotal	124	58.49	202	42.89	326	47.73
	1.2 Final Refusal	200 Refusal by known respondent	6	2.83	8	1.70	14	2.05
		230 Mechanical answering device	0	0	4	0.85	4	0.59
		250 Refusal-partial (started, not complete)	0	0	6	1.27	6	0.88
		subtotal	6	2.83	18	3.82	24	3.51
	1.3 Final (presumed) Eligible	330 Effort ended-case retired	15	7.08	32	6.79	47	6.88
		590 Final unlocatable by phone center	19	8.96	22	4.67	41	6.00
		subtotal	34	16.04	54	11.46	88	12.88
	1.4 Final Ineligible	410 Physical/cognitive barrier	0	0	2	0.42	2	0.29
		424 Nursing Home	9	4.25	46	9.77	55	8.05
		440 Deceased	21	9.91	134	28.45	155	22.69
		450 Moved out of fielding area	1	0.47	3	0.64	4	0.59
		460 Does not meet survey criteria	17	8.02	12	2.55	29	4.25
		subtotal	48	22.64	197	41.83	245	35.87
TOTAL			212	100.00	471	100.00	683	100.00

HCBS Status By Age Group (Kentucky) - Produced on June 21, 2004

Major Category / Sub Category / Status			UNDER 65		65 OR OLDER		UNKNOWN		TOTAL	
			N	%	N	%	N	%	N	%
FINAL	1.1 Final Complete	010 CATI complete	148	28.46	233	26.27	31	21.23	412	26.53
		011 CATI proxy complete	107	20.58	105	11.84	22	15.07	234	15.07
		021 Field Callin proxy complete	1	0.19	1	0.11	0	0	2	0.13
		040 Hardcopy complete	6	1.15	25	2.82	5	3.42	36	2.32
		subtotal	262	50.38	364	41.04	58	39.73	684	44.04
	1.2 Final Refusal	200 Refusal by known respondent	7	1.35	11	1.24	1	0.68	19	1.22
		210 Refusal by gatekeeper	2	0.38	4	0.45	0	0	6	0.39
		220 Refusal by unknown person	1	0.19	1	0.11	0	0	2	0.13
		230 Mechanical answering device	2	0.38	1	0.11	1	0.68	4	0.26
		250 Refusal-partial (started, not complete)	1	0.19	4	0.45	2	1.37	7	0.45
		subtotal	13	2.50	21	2.37	4	2.74	38	2.45
	1.3 Final (presumed) Eligible	300 Duplicate sample	3	0.58	2	0.23	2	1.37	7	0.45
		330 Effort ended-case retired	39	7.50	46	5.19	9	6.16	94	6.05
		590 Final unlocatable by phone center	51	9.81	51	5.75	11	7.53	113	7.28
		subtotal	93	17.88	99	11.16	22	15.07	214	13.78
	1.4 Final Ineligible	410 Physical/cognitive barrier	1	0.19	4	0.45	0	0	5	0.32
		420 Institutionalized	0	0	0	0	2	1.37	2	0.13
		424 Nursing Home	10	1.92	80	9.02	11	7.53	101	6.50
		430 Unavailable during field period	1	0.19	1	0.11	0	0	2	0.13
		440 Deceased	65	12.50	262	29.54	42	28.77	369	23.76
		450 Moved out of fielding area	2	0.38	2	0.23	0	0	4	0.26
		460 Does not meet survey criteria	72	13.85	51	5.75	7	4.79	130	8.37
		462 Ineligible - no longer receiving benefits	1	0.19	1	0.11	0	0	2	0.13
		463 Ineligible - undetermined benefits status	0	0	1	0.11	0	0	1	0.06
		470 No proxy available	0	0	1	0.11	0	0	1	0.06
		subtotal	152	29.23	403	45.43	62	42.47	617	39.73
TOTAL			520	100.00	887	100.00	146	100.00	1553	100.00

HCBS Status By Age Group (Maryland) - Produced on June 21, 2004

Major Category / Sub Category / Status			UNDER 65		65 OR OLDER		TOTAL	
			N	%	N	%	N	%
FINAL	1.1 Final Complete	010 CATI complete	44	37.93	96	30.77	140	32.71
		011 CATI proxy complete	20	17.24	29	9.29	49	11.45
		040 Hardcopy complete	7	6.03	16	5.13	23	5.37
		041 Hardcopy complete - Proxy	0	0	1	0.32	1	0.23
		subtotal	71	61.21	142	45.51	213	49.77
	1.2 Final Refusal	200 Refusal by known respondent	5	4.31	11	3.53	16	3.74
		210 Refusal by gatekeeper	1	0.86	2	0.64	3	0.70
		220 Refusal by unknown person	0	0	1	0.32	1	0.23
		230 Mechanical answering device	0	0	1	0.32	1	0.23
		250 Refusal-partial (started, not complete)	1	0.86	4	1.28	5	1.17
		subtotal	7	6.03	19	6.09	26	6.07
	1.3 Final (presumed) Eligible	330 Effort ended-case retired	4	3.45	6	1.92	10	2.34
		590 Final unlocatable by phone center	13	11.21	23	7.37	36	8.41
		subtotal	17	14.66	29	9.29	46	10.75
	1.4 Final Ineligible	400 Language barrier (non Spanish)	0	0	5	1.60	5	1.17
		424 Nursing Home	3	2.59	22	7.05	25	5.84
		440 Deceased	13	11.21	76	24.36	89	20.79
		450 Moved out of fielding area	0	0	3	0.96	3	0.70
		460 Does not meet survey criteria	5	4.31	13	4.17	18	4.21
		462 Ineligible - no longer receiving benefits	0	0	1	0.32	1	0.23
		470 No proxy available	0	0	2	0.64	2	0.47
		subtotal	21	18.10	122	39.10	143	33.41
TOTAL			116	100.00	312	100.00	428	100.00

HCBS Status By Age Group (Michigan) - Produced on June 21, 2004

Major Category / Sub Category / Status			UNDER 65		65 OR OLDER		TOTAL	
			N	%	N	%	N	%
FINAL	1.1 Final Complete	010 CATI complete	257	36.98	155	35.23	412	36.30
		011 CATI proxy complete	141	20.29	33	7.50	174	15.33
		020 Field Callin complete	1	0.14	0	0	1	0.09
		040 Hardcopy complete	10	1.44	7	1.59	17	1.50
		subtotal	409	58.85	195	44.32	604	53.22
	1.2 Final Refusal	200 Refusal by known respondent	15	2.16	12	2.73	27	2.38
		210 Refusal by gatekeeper	11	1.58	1	0.23	12	1.06
		220 Refusal by unknown person	4	0.58	2	0.45	6	0.53
		230 Mechanical answering device	5	0.72	2	0.45	7	0.62
		250 Refusal-partial (started, not complete)	3	0.43	7	1.59	10	0.88
		subtotal	38	5.47	24	5.45	62	5.46
	1.3 Final (presumed) Eligible	330 Effort ended-case retired	34	4.89	12	2.73	46	4.05
		590 Final unlocatable by phone center	80	11.51	32	7.27	112	9.87
		subtotal	114	16.40	44	10.00	158	13.92
	1.4 Final Ineligible	400 Language barrier (non Spanish)	2	0.29	17	3.86	19	1.67
		410 Physical/cognitive barrier	2	0.29	1	0.23	3	0.26
		420 Institutionalized	0	0	1	0.23	1	0.09
		424 Nursing Home	6	0.86	31	7.05	37	3.26
		430 Unavailable during field period	0	0	1	0.23	1	0.09
		440 Deceased	48	6.91	95	21.59	143	12.60
		450 Moved out of fielding area	8	1.15	1	0.23	9	0.79
		460 Does not meet survey criteria	65	9.35	30	6.82	95	8.37
		461 Ineligible - never received benefits	1	0.14	0	0	1	0.09
		470 No proxy available	2	0.29	0	0	2	0.18
		subtotal	134	19.28	177	40.23	311	27.40
TOTAL			695	100.00	440	100.00	1135	100.00

HCBS Status By Age Group (Wisconsin) - Produced on June 21, 2004

Major Category / Sub Category / Status			UNDER 65		65 OR OLDER		UNKNOWN		TOTAL	
			N	%	N	%	N	%	N	%
FINAL	1.1 Final Complete	010 CATI complete	52	46.43	64	29.77	9	27.27	125	34.72
		011 CATI proxy complete	12	10.71	24	11.16	2	6.06	38	10.56
		040 Hardcopy complete	6	5.36	3	1.40	1	3.03	10	2.78
		subtotal	70	62.50	91	42.33	12	36.36	173	48.06
	1.2 Final Refusal	200 Refusal by known respondent	6	5.36	6	2.79	2	6.06	14	3.89
		210 Refusal by gatekeeper	1	0.89	0	0	1	3.03	2	0.56
		250 Refusal-partial (started, not complete)	0	0	2	0.93	0	0	2	0.56
		subtotal	7	6.25	8	3.72	3	9.09	18	5.00
	1.3 Final (presumed) Eligible	330 Effort ended-case retired	7	6.25	5	2.33	2	6.06	14	3.89
		590 Final unlocatable by phone center	8	7.14	21	9.77	2	6.06	31	8.61
		subtotal	15	13.39	26	12.09	4	12.12	45	12.50
	1.4 Final Ineligible	400 Language barrier (non Spanish)	1	0.89	0	0	1	3.03	2	0.56
		410 Physical/cognitive barrier	0	0	1	0.47	0	0	1	0.28
		424 Nursing Home	3	2.68	22	10.23	4	12.12	29	8.06
		440 Deceased	13	11.61	59	27.44	6	18.18	78	21.67
		460 Does not meet survey criteria	3	2.68	7	3.26	2	6.06	12	3.33
		463 Ineligible - undetermined benefits status	0	0	0	0	1	3.03	1	0.28
		470 No proxy available	0	0	1	0.47	0	0	1	0.28
		subtotal	20	17.86	90	41.86	14	42.42	124	34.44
TOTAL			112	100.00	215	100.00	33	100.00	360	100.00

APPENDIX C

QUESTIONNAIRE

MATHEMATICA
Policy Research, Inc.

Medicaid Home & Community Based Waiver Program Study

Aged/Disabled Questionnaire

May 2003

INTRODUCTION

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

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

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

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

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

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

  <d> DON'T KNOW ⎤
  <r> REFUSED _____⎦ ➡ **goto A2**

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

  MM/DD/YY

  <d> DON'T KNOW
  <r> REFUSED

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

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

  <d> DON'T KNOW
  <r> REFUSED

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

(A3-A3a-j - ADAPTED FROM NHIS)

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

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

> **INTERVIEWER: 1. IF SAMPLE MEMBER RECEIVES ANY HELP ON AN ON GOING BASIS, CODE <1>**
>
> **2. IF SAMPLE MEMBER EATS MEALS IN A CONGREGATE SETTING, CODE <1>**

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

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

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

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

<d> DON'T KNOW
<r> REFUSED

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

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

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

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

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

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

<d> DON'T KNOW
<r> REFUSED

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

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

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

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

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

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

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

A3La.   From an agency or organization?

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

A3Lb.   Someone you or your family hired directly?

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

        <1> YES ➜ **goto B1**
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

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

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

        <d> DON'T KNOW
        <r> REFUSED

A4a.　　Please describe this help or care to me.

ENTER TEXT AND END WITH //

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

CODE ALL THAT APPLY

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

  <d>　DON'T KNOW
  <r>　REFUSED

B.   MARITAL STATUS AND LIVING ARRANGEMENTS

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

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

        <d> DON'T KNOW
        <r> REFUSED

B2.   Do you live . . .

        **INTERVIEWER: CONFIRM WITH SAMPLE MEMBER IF KNOWN FROM
                        SCREENER.**

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

        <d> DON'T KNOW
        <r> REFUSED

B2a.   Is your apartment in an assisted living facility?

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

        <1> YES ➡ **goto B2c**
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

       PROBE: Do not include yourself.

       PROBE: Most or all of the time.

       <   > NUMBER OF PEOPLE

       <0> LIVES ALONE ⌐

                             → **ALL goto B3a**

       <d> DON'T KNOW

       <r> REFUSED ⌐

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

       PROBE: Please include yourself in that number.

       PROBE: Your best estimate is fine.

       <2-100> NUMBER OF PEOPLE

       <d> DON'T KNOW
       <r> REFUSED

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

       <1> OWN
       <2> SHARE

       <d> DON'T KNOW ⌐
       <r> REFUSED ⌐ → **goto proxy decision**

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

       INTERVIEWER: CODE ALL THAT APPLY

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

       <d> DON'T KNOW
       <r> REFUSED

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

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

                    <d> DON'T KNOW ⌐
                                  ➜ **goto B3d**
                    <r> REFUSED ⌐

B3c.   Why would you like to live somewhere else?

                    INTERVIEWER: CODE ALL THAT APPLY

                    PROBE: Any other reasons?

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

                     <d>DON'T KNOW
                     <r> REFUSED

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

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

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

                    <d> DON'T KNOW
                    <r> REFUSED

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

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

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

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

        <d> DON'T KNOW
        <r> REFUSED

C. HEALTH

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

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

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

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

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

<d> DON'T KNOW
<r> REFUSED

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

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

<d> DON'T KNOW
<r> REFUSED

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

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

<d> DON'T KNOW
<r> REFUSED

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

                <1> YES
                <0> NO

                <d> DON'T KNOW
                <r> REFUSED

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

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

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

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

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

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

                <d> DON'T KNOW
                <r> REFUSED

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

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

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

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

<1> YES
<0> NO ➜ **goto dd1**

<d> DON'T KNOW
<r> REFUSED

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

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

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

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

<1-15> NUMBER OF UNPAID HELPERS

<d> DON'T KNOW
<r> REFUSED

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

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

      <1> YES
      <0> NO

      <d> DON'T KNOW
      <r> REFUSED

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

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

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

      PROGRAMMER: D4 $\leq$ D2

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

      <d> DON'T KNOW
      <r> REFUSED

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

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

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

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

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

        INTERVIEWER: CODE ALL THAT APPLY

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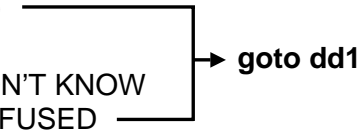   <17>   NON RELATIVE

         <d>   DON'T KNOW
         <r>   REFUSED

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

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

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

  <1> YES
  <0> NO ⟶
            goto dd1
  <d> DON'T KNOW
  <r> REFUSED ⟶

D7. How is this person related to you?

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

  <d> DON'T KNOW
  <r> REFUSED

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

REINFORCEMENT PROBE:

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

FATIGUE PROBE:

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

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

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

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

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

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

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

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

   <d> DON'T KNOW ⎤
                              ⎦➡ **goto D16**
   <r> REFUSED ⎯⎯⎯⎤

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

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

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

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

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

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

    <1> YES
    <0> NO

    <d> DON'T KNOW
    <r> REFUSED

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

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

    PROGRAMMER: D9a $\leq$ D8a

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

    <d> DON'T KNOW
    <r> REFUSED

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

        <1> YES ➜ **goto D11**
        <0> NO

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

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

        <1> YES
        <0> NO ➜ **goto D12**

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

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

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

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

     <d> DON'T KNOW
     <r> REFUSED

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

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

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

        ENTER TEXT

        <00> MORE THAN TWO AND ALL HELP EQUALLY

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

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

        <d> DON'T KNOW
        <r> REFUSED

UNMET NEED

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

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

   <1> YES
   <0> NO

   <d> DON'T KNOW
   <r> REFUSED

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

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

   <1> YES
   <0> NO

   <d> DON'T KNOW
   <r> REFUSED

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

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

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

   <1> YES
   <0> NO

   <d> DON'T KNOW
   <r> REFUSED

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

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

   <1> YES
   <0> NO

   <d> DON'T KNOW
   <r> REFUSED

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

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

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

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

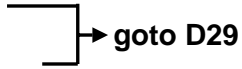D27.   In the past month, was there any time when you didn't buy or obtain medicine that you thought you needed?

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

          <1> YES
          <0> NO ➡ **goto D29**

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

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

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

          <d> DON'T KNOW
          <r> REFUSED

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

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

        PROGRAMMER: SET UP CODE ALL THAT APPLY MENU

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

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

        <d> DON'T KNOW
        <r> REFUSED

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

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

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

　　　<1> YES
　　　<0> NO

　　　<d> DON'T KNOW
　　　<r> REFUSED

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

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

　　　PROBE:　At least one meal a day

　　　<1> YES
　　　<0> NO

　　　<d> DON'T KNOW　**→ goto D32**
　　　<r> REFUSED

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

　　　PROBE:　At least one meal a day.

　　　<1> YES
　　　<0> NO

　　　<d> DON'T KNOW
　　　<r> REFUSED

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

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

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

    <d> DON'T KNOW
    <r> REFUSED

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

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

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

    <1> YES
    <0> NO

    <d> DON'T KNOW
    <r> REFUSED

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

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

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

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

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

PROBE: Your best estimate is fine.

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

<d> DON'T KNOW
<r> REFUSED

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

PROBE: Your best guess is fine.

<1-20> NUMBER

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

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

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

        <d> DON'T KNOW
        <r> REFUSED

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

INTERVIEWER: CODE ALL THAT APPLY

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

        <1> SAMPLE MEMBER
        <2> SAMPLE MEMBER'S FAMILY/FRIEND/NEIGHBOR/PROXY RESPONDENT
        <3> AGENCY
        <4> CASEWORKER/STATE/COUNTY
        <5> OTHER (SPECIFY AND END WITH //) [specify]
        <6> NEVER NEEDED TO REPLACE ➜ **goto E3**

        <d> DON'T KNOW
        <r> REFUSED

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

INTERVIEWER: CODE ALL THAT APPLY

        <1> FOUND REPLACEMENT RIGHT AWAY
        <2> RELIED ON FAMILY/FRIENDS/NEIGHBORS
        <3> DONE WITHOUT
        <4> SOUGHT TEMPORARY PLACEMENT IN FACILITY
        <5> USED TEMPORARY **PAID** HELP
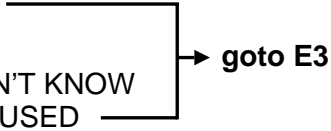   <6> OTHER (SPECIFY AND END WITH //) [specify]

        <d> DON'T KNOW
        <r> REFUSED

E2d.   Have you ever had a problem or difficulty finding a replacement?

      PROBE: Whatever you considered a problem or difficulty.

      <1> YES
      <0> NO

      <d> DON'T KNOW   → **goto E3**
      <r> REFUSED

E2e.   What were the problems or difficulties you experienced?

      INTERVIEWER: CODE ALL THAT APPLY

       <1> AIDE DIDN'T WANT TO WORK THE HOURS SM NEEDED
       <2> AIDE/HELPER NOT WILLING TO PROVIDE KIND OF HELP I NEEDED
       <3> INSUFFICIENT PAY/HELPER/AIDE WANTED MORE MONEY
       <4> HELPER/AIDE NEEDED MORE HOURS
       <5> GENDER OF POTENTIAL HELPER/AIDE
       <6> NEIGHBORHOOD SM LIVES IN/HARD TO GET PEOPLE TO WORK THERE
       <7> TRANSPORTATION
       <8> RACE/ETHNICITY OF POTENTIAL HELPER/AIDE
       <9> DIDN'T LIKE/TRUST ANY OF THE PEOPLE WHO
           WANTED TO WORK FOR ME
      <10> OTHER (SPECIFY AND END WITH //) [specify]

      <d> DON'T KNOW
      <r> REFUSED

      PROGRAMMER: IF D12 = <2>, goto E5, ELSE ASK E3

E3.   Thinking about last week, how many days, Monday through Friday, did ([FILL
      NAME(S) FROM D13]/your **paid** helper(s)) help you or care for you?

      <0-5> DAYS

      <d> DON'T KNOW
      <r> REFUSED

E3a.   Thinking about last week, did you get **paid** help on Saturday or Sunday?

   PROBE: Was that just Saturday or Sunday or both days?

   <1> SATURDAY ONLY
   <2> SUNDAY ONLY
   <3> BOTH SATURDAY AND SUNDAY
   <0> NEITHER

   <d> DON'T KNOW
   <r> REFUSED

E4a.   Thinking about Monday to Sunday last week, about how many hours would you say
   ([NAME(S) FROM D13]/your **paid** helper(s)) spent helping you with [FILL ITEMS
   CODED YES HELPED IN A3a-j AND/OR ITEMS CODED <1> to <11> in A4a]?

   PROBE: Your best estimate is fine.

   **INTERVIEWER: HELP SAMPLE MEMBER COMPUTE HOURS. IF HELP LIVES
               IN, PROBE FOR HOURS ON DUTY/SHIFT HOURS.**

   <2-168> HOURS PER WEEK ➡ **goto E7**

   <d> DON'T KNOW
   <r> REFUSED

E4b.   Perhaps you could estimate? Was it . . .

   PROBE: Your best estimate is fine.

   <1> 2-4 hours,
   <2> 5-10 hours,
   <3> 11-20 hours,
   <4> 21-40 hours,
   <5> 41-60 hours,
   <6> 61-80 hours,
   <7> 81-120 hours,
   <8> 121 or more?

   <d> DON'T KNOW
   <r> REFUSED

E5.	In general, would you say the number of hours of **paid** help that you get from your helpers, weekly are . . .

<1>	far too few,
<2>	not quite enough,
<3>	just about right,
<4>	a little more than you need, or
<5>	much more than you need?

<d>	DON'T KNOW
<r>	REFUSED

E6.	Is there someone else who helps you when your usual **paid** helper(s) (doesn't/don't) show up?

PROBE:	[FILL NAME(S) FROM D13.]

<1>	YES
<0>	NO
<n>	PAID WORKER ALWAYS SHOWS UP ➜ **goto ee1**

<d>	DON'T KNOW
<r>	REFUSED

E7.	Who helps you when ([FILL NAME(S) FROM D13]/your **paid** helpers) (is/are) not available?

INTERVIEWER: CODE ALL THAT APPLY

<1>	DAUGHTER/SISTER
<2>	SON/BROTHER
<3>	DAUGHTER IN-LAW/SISTER IN-LAW
<4>	SON-IN-LAW/BROTHER-IN-LAW
<5>	MOTHER
<6>	FATHER
<7>	OTHER FEMALE RELATIVE
<8>	OTHER MALE RELATIVE
<9>	NEIGHBORS OR FRIENDS/OTHER NON-RELATIVE
<10>	VOLUNTEER FROM AGENCY OR ORGANIZATION
<11>	**PAID** SUBSTITUTE
<12>	OTHER (SPECIFY AND END WITH //)
<0>	NO ONE

<d>	DON'T KNOW
<r>	REFUSED

ee1.　　**INTERVIEWER:　DOES THE SAMPLE MEMBER SEEM FATIGUED, CONFUSED OR NEED REINFORCEMENT?**

REINFORCEMENT PROBE:

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

FATIGUE PROBE:

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

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

F. SOCIAL/RECREATIONAL ACTIVITIES, EDUCATION AND EMPLOYMENT

F1.   Next, I have some questions about activities outside the home.

In the last week, please tell me on how many days you went out, either alone or with someone? Would you say . . .

PROBE: That is, since [FILL DAY OF WEEK] last week.

<0> never, ➡ **goto tF3**
<1> on one or two days,
<2> on three or four days,
<3> on five or six days, or
<4> every day?

<d> DON'T KNOW
<r> REFUSED

F2.   Thinking about your most recent outing, did you . . .

INTERVIEWER: CODE ALL THAT APPLY

<1> visit or meet friends or relatives,
<2> go shopping,
<3> go to see a doctor or other health care provider,
<4> go for a walk, including a trip in a wheelchair,
<5> eat out,
<6> go to a movie, play, concert or other entertainment, or
<7> do something else?

<d> DON'T KNOW
<r> REFUSED

PROGRAMMER (tF3):   IF SAMPLE MEMBER IS AGE 65 OR OLDER, goto SECTION G, ELSE ASK F3

F3.   The following questions are about education and employment.

In the last 6 months, that is, since [FILL MONTH], have you attended any school or participated in any training programs or taken any classes? Please include regular high school, GED classes, vocational or trade school, or other types of school as well as training programs to learn job skills.

PROBE: That is, since [FILL MONTH, YEAR].

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

F4.   In the last 6 months, that is, since [FILL MONTH], have you done any work for pay . . .

PROBE: That is, since [FILL MONTH, YEAR].

PROBE: Include any work you might have done in your own business where you got a regular paycheck.

<1> YES ➜ **goto Module G**
<0> NO

<d> DON'T KNOW
<r> REFUSED

F4a.   In the last six months, did you do any **unpaid** work?

PROBE: That is, since [FILL MONTH, YEAR].

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

F5.   Would you like to work at a **paid** job?

        <1> YES
        <0> NO ➔ **goto Module G**

        <d> DON'T KNOW
        <r> REFUSED

F6.   Why didn't you work at a paid job in the last six months? Was it because you couldn't
        get the help you needed with personal care, or transportation, or is there some other
        reason that you didn't work at a paid job in the last six months?

        INTERVIEWER: CODE ALL THAT APPLY

        <1> PERSONAL CARE,
        <2> TRANSPORTATION, OR
        <3> ANOTHER REASON? (SPECIFY)

        <d> DON'T KNOW
        <r> REFUSED

G.   SATISFACTION WITH LIFE (TO BE ASKED OF SAMPLE MEMBER ONLY)

G1aint.   **INTERVIEWER: ARE YOU SPEAKING WITH SM?**

                          <1> YES ➜ **goto G1**
                          <0> NO ➜ **goto G1bint**

G1bint.   **ASK TO SPEAK WITH SAMPLE MEMBER--EXPLAIN THESE QUESTIONS ARE ABOUT FEELINGS THAT MANY PEOPLE CAN ANSWER EVEN THOUGH THEY MAY NOT BE ABLE TO ANSWER FACTUAL QUESTIONS.**

                          <1> SAMPLE MEMBER UNABLE TO ANSWER FOR SELF ➜ **goto H1a**
                          <2> PROXY AGREED AND SAMPLE MEMBER AVAILABLE ➜ **goto G1**
                          <3> SAMPLE MEMBER LIVES ELSEWHERE
                                 OR UNAVAILABLE **PROGRAMMER: SET CASE FOR CALL BACK FOR MODULE G AND goto tH1**
                          <r> PROXY REFUSED ➜ **goto H1A**

G1.   These next few questions are about how you feel and how things have been with you in the past month.

      How much of the time during the past month did you feel full of energy? Was it . . .

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

      <1> most or all of the time,
      <2> some of the time, or
      <3> hardly ever?

      <d> DON'T KNOW
      <r> REFUSED

G2.   How much of the time (during the past month) have you felt so down in the dumps nothing could cheer you up? Was it . . .

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

      <1> most or all of the time,
      <2> some of the time, or
      <3> hardly ever?

      <d> DON'T KNOW
      <r> REFUSED

G3.   How much of the time (during the past month) have you felt calm and peaceful? Was it . . .

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

          <1> most or all of the time,
          <2> some of the time, or
          <3> hardly ever?

          <d> DON'T KNOW
          <r>   REFUSED

G4.   How much of the time (during the past month) did you feel worn out? Was it . . .

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

          <1> most or all of the time,
          <2> some of the time, or
          <3> hardly ever?

          <d> DON'T KNOW
          <r> REFUSED

G5.   How much of the time (during the past month) have you been a happy person? Was it . . .

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

          <1> most or all of the time,
          <2> some of the time, or
          <3> hardly ever?

          <d> DON'T KNOW
          <r> REFUSED

G6.   How much of the time (during the past month) did you feel that you were being pushed around in life? Was it . . .

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

          <1> most or all of the time,
          <2> some of the time, or
          <3> hardly ever?

          <d> DON'T KNOW
          <r> REFUSED

G7.   **INTERVIEWER: IN YOUR OPINION IS SM ABLE TO CONTINUE WITH THE QUESTIONS?**

          <1> YES
          <0> NO

G7a.   WAS THE INTERVIEW BEING CONDUCTED WITH . . .

          <1> PROXY, OR
          <2> SM?

H.   SATISFACTION WITH CARE (TO BE ASKED OF SAMPLE MEMBER OR INFORMAL CAREGIVER)

tH1.   PROGRAMMER: IF G1 = <3> SET CASE FOR CALL BACK FOR MODULE H AND goto K1, ELSE goto H1

H1.   **INTERVIEWER: ARE YOU SPEAKING WITH SAMPLE MEMBER OR PROXY RESPONDENT?**

<1> THE SAMPLE MEMBER ➜ **goto H1b**
<2> PROXY ➜ **goto H1a**

H1a.   **INTERVIEWER: IS PROXY A PAID CAREGIVER NAMED IN D13 (PROGRAMMER [FILL NAMES FROM D13]) AND/OR IDENTIFIED IN SCREENER?**

<1> PROXY IS A PAID CAREGIVER ➜ **goto K1**
<2> PROXY IS UNPAID CAREGIVER ➜ **goto H1b**

H1b.   Our next questions are about how satisfied you are with the help you receive and how much control you feel you have over day-to-day decisions.

For this series of questions, please think of the help and care you receive from ([FILL NAME(S) IN D13]/your **paid** helper(s)).

Please tell me how happy overall you are with the **paid** care and help you receive? Would you say . . .

<1> very happy,
<2> somewhat happy,
<3> somewhat unhappy, or
<4> very unhappy?

<d> DON'T KNOW
<r> REFUSED

H2.   How much control do you feel you have over your life? Would you say you have . . .

        <1> a lot of control,
        <2> some control,
        <3> a little control, or
        <4> no control?

        <d> DON'T KNOW
        <r> REFUSED

H3.   When you have had a problem with a **paid** helper, has it ever been difficult to get it
        resolved or fixed?

        PROBE: Whatever you consider a problem.

        <1> YES
        <0> NO
        <7> NEVER HAD A PROBLEM

        <d> DON'T KNOW
        <r> REFUSED

**tH4.   PROGRAMMER: IF SAMPLE MEMBER IN GROUP, FOSTER HOME OR
                    ASSISTED LIVING ARRANGEMENT (B2 = <4>, <5>, <9> OR
                    B2a = <1>) OR IF MORE THAN ONE NAME IN D13, goto H6,
                    ELSE ASK H4**

H4.   Who makes sure [FILL NAME IN D13] comes when scheduled and does the job the
        way it should be done? Is it you, a care manager (service coordinator), a supervisor,
        a family member or friend or someone else?

        <1> SAMPLE MEMBER
        <2> CARE MANAGER (SERVICE COORDINATOR)
        <3> FAMILY MEMBER/FRIEND/NEIGHBOR
        <4> AGENCY/SUPERVISOR
        <5> OTHER (SPECIFY AND END WITH //) [specify]
        <0> NO ONE

        <d> DON'T KNOW
        <r> REFUSED

H5.   Who signs your main helper's time sheet?

        <1> SAMPLE MEMBER
        <2> CARE MANAGER (SERVICE COORDINATOR)
        <3> FAMILY MEMBER/FRIEND/NEIGHBOR
        <4> AGENCY/SUPERVISOR
        <5> OTHER (SPECIFY AND END WITH //) [specify]
        <0> NO ONE

        <d> DON'T KNOW
        <r> REFUSED

H6.   In general, how well do you and ([FILL NAME(S) IN D13]/your **paid** helper(s)) get
        along? Would you say you get along . . .

        <1> very well,
        <2> well,
        <3> not very well, or
        <4> not at all well?

        <d> DON'T KNOW
        <r> REFUSED

H7.   In general, do you have any trouble communicating with ([FILL NAME(S) IN D13]/any
        of your **paid** helpers))?

        <1> YES, HAVE TROUBLE COMMUNICATING
        <0> NO, DO NOT HAVE ANY TROUBLE ➜ **goto H9**

        <d> DON'T KNOW
        <r> REFUSED

H8.   Is this because of . . .

        <1> language difficulties,
        <2> hearing or speech problems, or
        <3> something else? (SPECIFY)

        <d> DON'T KNOW
        <r> REFUSED

H9.   In the past month, how often have you had problems with ([FILL NAME(S) IN D13]/any of your **paid** helpers) ignoring you? Would you say . . .

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

        <0> never,
        <1> seldom,
        <2> sometimes,
        <3> often, or
        <4> very often?

        <d> DON'T KNOW
        <r> REFUSED

H10.   How often, if at all, in the past month, did ([FILL NAME(S) IN D13]/any of your **paid** helpers) get impatient with you or rush you? Would you say . . .

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

        <0> never,
        <1> seldom,
        <2> sometimes,
        <3> often, or
        <4> very often?

        <d> DON'T KNOW
        <r> REFUSED

tH10a.   IF C6 = <0>, ASK tH11, ELSE goto tH10a

H10a.   When you need help with bladder or bowel care, (do/does) ([FILL NAME(S) IN D13]/your **paid** helper(s)) assist you quickly enough? Would you say . . .
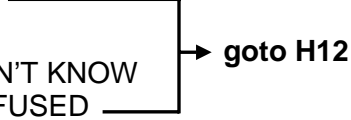
        <1> always,
        <2> almost always,
        <3> seldom, or
        <4> never?

        <d> DON'T KNOW
        <r> REFUSED

tH11.   PROGRAMMER: IF E2a = 1 OR 3, ASK H11, ELSE goto H12

H11.   Have you or a family member **ever** complained to a care manager (service coordinator) or someone at the agency employing them that your **paid** helpers ignored, or were impatient with you?

  <1> YES
  <0> NO
          goto H12
  <d> DON'T KNOW
  <r> REFUSED

H11a. Did the care manager (service coordinator) or someone at the agency resolve the problem?

  <1> YES
  <0> NO

  <d> DON'T KNOW
  <r> REFUSED

H12.   How often, if at all, did ([FILL NAME(S) IN D13]/one of your **paid** helper(s)) treat you badly in the past month? Would you say . . .

  <0> never,
  <1> seldom,
  <2> sometimes,
  <3> often, or
  <4> very often?

  <d> DON'T KNOW
  <r> REFUSED

H13.   In general, do you think ([FILL NAME(S) IN D13]/your **paid** helper(s)) (is/are) competent and well-trained?

  <1> YES
  <2> SOME HELPERS ARE, SOME ARE NOT
  <0> NO
  <3> SOMETIMES/IT DEPENDS

  <d> DON'T KNOW
  <r> REFUSED

H14.   Do you think ([FILL NAME(S) IN D13]/your **paid** helper(s)) (is/are) respectful of you
        and the way you like things done . . .

        <1> YES
        <2> SOMETIMES/DEPENDS
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

tH14a.   **PROGRAMMER: IF SAMPLE MEMBER IN GROUP, FOSTER HOME OR
                         ASSISTED LIVING ARRANGEMENT (B2=<4>, <5> OR <9> OR
                         B2a=<1>), goto H15, ELSE ASK H14a**

H14a.   Do you often have the following problems with your paid helper(s).

        INTERVIEWER: CODE ALL THAT APPLY

        <1> helpers do not show up on days they are scheduled or at all?
        <2> helpers show up late?
        <3> helpers do not work as hard as they should?

        <d> DON'T KNOW
        <r> REFUSED

tH14b.   **PROGRAMMER: IF <1>, <2>, OR <3> CODED IN H14a, ASK H14b, ELSE goto
                         H15**

H14b.   When these things happen, how much of a problem overall is it for you? Would you
        say is it . . .

        <1> a big problem,
        <2> a little problem, or
        <3> no problem at all?

        <d> DON'T KNOW
        <r> REFUSED

hh1.   **INTERVIEWER: DOES THE SAMPLE MEMBER SEEM FATIGUED, CONFUSED
            OR NEED REINFORCEMENT?**

REINFORCEMENT PROBE:

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

FATIGUE PROBE:

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

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

I. CONSUMER DIRECTION (NOT ASKED OF SAMPLE MEMBERS IN ASSISTED LIVING ENVIRONMENT)

tI1. **PROGRAMMER: IF SAMPLE MEMBER LIVES IN OWN HOME (B2 = <1>, <2>) OR HOME OF RELATIVE (B2 = <3> AND B2a = <0>), goto tI2, ELSE goto Section K**

tI2. **PROGRAMMER: IF SAMPLE MEMBER'S PAID HELP CHANGES FROM WEEK TO WEEK (D12 = <2>),OR MORE THAN ONE NAME IN D13, goto I5, ELSE ASK I1**

I1.   Now I'd like to ask you about how you selected [FILL NAME FROM D13].

Were you given a list of agencies or individuals to choose from when selecting [FILL NAME FROM D13]?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

I2.   Who chose [FILL NAME FROM D13]?

<1> CHOSEN BY AGENCY
<2> CHOSEN BY SAMPLE MEMBER
<3> CHOSEN BY SAMPLE MEMBER'S FAMILY/FRIENDS/
       NEIGHBORS/PROXY RESPONDENT

<d> DON'T KNOW
<r> REFUSED

I3.   Did you or a family member know [FILL NAME FROM D13] before (he/she) became your (main) **paid** helper?

<1> YES ➜ **goto I3a**
<0> NO ➜ **goto I4**

<d> DON'T KNOW
<r> REFUSED

I3a.   How did you know [FILL NAME FROM D13] before (he/she) became your (main)
        paid helper?

        <1> HELPER IS FAMILY MEMBER
        <2> HELPER IS FRIEND OR NEIGHBOR
        <3> HELPER REFERRED BY FAMILY MEMBER OR FRIEND
        <4> HELPER WAS A SUBSTITUTE IN THE PAST/
             WORKED FOR ME PREVIOUSLY
        <5> OTHER (SPECIFY AND END WITH //)

        <d> DON'T KNOW
        <r> REFUSED

I4.   Did you or a family member have the opportunity to interview [FILL NAME FROM
        D13] before (he/she) became your **paid** helper?

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

I5.   How much choice do you have in deciding what tasks ([FILL NAMES FROM
        D13]/your **paid** helpers) assist(s) you with or (do/does) for you? Would you say you
        have . . .

        <1> total choice, ➜ **goto I6**
        <2> some choice, or
        <3> no choice?

        <d> DON'T KNOW
        <r> REFUSED

I5a.   How happy are you with the amount of choice you have in deciding what tasks
        ([FILL NAMES FROM D13]/your **paid** helpers) will (do/does) for you? Would you say
        you are . . .

        <1> very happy,
        <2> happy,
        <3> somewhat happy, or
        <4> not happy at all?

        <d> DON'T KNOW
        <r> REFUSED

I6. How much choice do you have over what time and which days ([FILL NAMES FROM D13]/your **paid** helpers) come(s)? Would you say you have . . .

<1> total choice, ➞ **goto Section J**
<2> some choice, or
<3> no choice?

<d> DON'T KNOW
<r> REFUSED

I6a. How happy are you with the amount of choice you have over scheduling ([FILL NAMES FROM D13]/your **paid** helpers)? Would you say you are . . .

<1> very happy,
<2> happy,
<3> somewhat happy, or
<4> not happy at all?

<d> DON'T KNOW
<r> REFUSED

J.   CASE MANAGEMENT

J1.   Now I'd like to ask you some questions about how your overall care is managed.

Is there someone who you think of as the one who is in charge of your overall care, (including your home care)? This person would also coordinate your personal or social services.

<1> YES
<0> NO ➞ **goto Section K**

<d> DON'T KNOW
<r> REFUSED

J2.   Who is in charge of your overall care, including your home care?

INTERVIEWER: CODE ALL THAT APPLY

<1> DOCTOR
<2> CARE MANAGER (SERVICE COORDINATOR)
<3> OTHER PROVIDER
<4> FAMILY MEMBER
<5> FRIEND
<6> SAMPLE MEMBER ➞ **IF ONLY <6> SKIP TO J4**
<7> OTHER (SPECIFY AND END WITH //) [specify]

<d> DON'T KNOW
<r> REFUSED

J3.   During the last six months, that is, since [FILL MONTH] about how often did you see or talk to the [FILL FROM J2] ([the person/people] who helps you coordinate your personal or social services)?

INTERVIEWER: USE AS PROMPT

<1> DAILY
<2> SEVERAL TIMES A WEEK
<3> ONCE A WEEK
<4> ONCE A MONTH
<5> ONCE EVERY TWO OR THREE MONTHS
<6> ONCE IN THE LAST SIX MONTHS
<7> NOT AT ALL

<d> DON'T KNOW
<r> REFUSED

J4.   How do you feel about the amount of care coordination you receive? Would you say . . .

         <1> you need a lot more,
         <2> you need a little more,
         <3> the amount of care coordination you receive is about right, or
         <4> you receive too much care coordination?

         <d> DON'T KNOW
         <r> REFUSED

K. DEMOGRAPHICS

K1.   I just have a few general questions about you and your helper(s) and then we'll be done.

What is the highest grade or level of school that you have completed?

<1> 8TH GRADE OR LESS
<2> SOME HIGH SCHOOL, BUT DID NOT GRADUATE
<3> HIGH SCHOOL GRADUATE OR GED
<4> SOME COLLEGE OR 2 YEAR DEGREE
<5> 4-YEAR COLLEGE GRADUATE
<6> MORE THAN 4 YEAR COLLEGE DEGREE
<7> OTHER (SPECIFY AND END WITH //)

<d> DON'T KNOW
<r> REFUSED

K2.   Do you consider yourself to be of Hispanic or Latino origin, such as Mexican, Mexican-American, Puerto Rican, Cuban or other Spanish background?

<1> YES
<0> NO

<d> DON'T KNOW
<r> REFUSED

K3.   What race do you consider yourself to be? Are you . . .

INTERVIEWER: CODE ONE OR MORE.

INTERVIEWER: IF SAMPLE MEMBER SAYS MULTI-RACIAL ASK HIM/HER TO PICK CATEGORIES THAT BEST DESCRIBE HIS/HER RACIAL OR ETHNIC BACKGROUND.

<1> American Indian Or Alaska Native
<2> Asian (E.G., Indian, Chinese, Japanese, Korean, Vietnamese)
<3> Black Or African American
<4> Native Hawaiian Or Other Pacific Islander
<5> White, Or
<6> Something Else (Specify And End With //)

<d> Don't Know
<R> Refused

INTERVIEWER: ASK ONLY IF NECESSARY, OTHERWISE CHECK APPROPRIATE CATEGORY.

K4.   Are you male or female?

        <1> MALE
        <2> FEMALE

        <d> DON'T KNOW
        <r> REFUSED

tH15.   PROGRAMMER: ASK H15 ABOUT (FIRST) MAIN PAID HELPER (AND H16 ABOUT SECOND MAIN HELPER). IF NO MAIN PAID HELPER(S), goto hh1

H15.   Is [FILL NAME (1) FROM D13] of Hispanic or Latino origin, such as Mexican, Mexican-American, Puerto Rican, Cuban or other Spanish background?

        <1> YES
        <0> NO

        <d> DON'T KNOW
        <r> REFUSED

H15a.   What race is he or she?

        INTERVIEWER: CODE ONE OR MORE

        INTERVIEWER: IF SAMPLE MEMBER SAYS MULTI-RACIAL ASK HIM/HER TO PICK CATEGORIES THAT BEST DESCRIBE HIS/HER RACIAL OR ETHNIC BACKGROUND.

        <1> American Indian Or Alaska Native
        <2> Asian (E.G., Indian, Chinese, Japanese, Korean, Vietnamese)
        <3> Black Or African American
        <4> Native Hawaiian Or Other Pacific Islander
        <5> White, Or
        <6> Something Else (Specify And End With //) [Specify]

        <D> Don't Know
        <R> Refused

tH16. **PROGRAMMER: CHECK D13. IF NO SECOND MAIN PAID HELPER, goto hh1, ELSE ASK H16**

H16.   Is [FILL NAME (2) FROM D13] of Hispanic or Latino origin, such as Mexican, Mexican-American, Puerto Rican, Cuban or other Spanish background?

    <1> YES
    <0> NO

    <d> DON'T KNOW
    <r> REFUSED

H16a.   What race is he or she?

    INTERVIEWER: CODE ONE OR MORE

    INTERVIEWER: IF SAMPLE MEMBER SAYS MULTI-RACIAL ASK HIM/HER TO PICK CATEGORIES THAT BEST DESCRIBE HIS/HER RACIAL OR ETHNIC BACKGROUND.

    <1> American Indian Or Alaska Native
    <2> Asian (E.G., Indian, Chinese, Japanese, Korean, Vietnamese)
    <3> Black Or African American
    <4> Native Hawaiian Or Other Pacific Islander
    <5> White, Or
    <6> Something Else (Specify And End With //) [Specify]

    <D> Don't Know
    <R> Refused

K5.   And in the past year, approximately how much was your personal income from all sources before taxes were deducted? Please include income from wages before tax, Social Security Supplemental Security Income, rents, interest and dividends. Please stop me when I get to the appropriate category . . .

      PROBE: Other studies have shown that income can affect how people use services so this is important information.

      PROBE: Your best estimate is fine.
               All information is kept confidential and only used for this study.

      INTERVIEWER: ACCEPT $ AMOUNT IF SAMPLE MEMBER ONLY KNOWS NET.

      INTERVIEWER: READ 1 - 9 SLOWLY

      <1> less than $5,000,
      <2> $5,000 or more but less than $10,000,
      <3> $10,000 or more but less than $15,000,
      <4> $15,000 or more but less than $20,000,
      <5> $20,000 or more but less than $25,000,
      <6> $25,000 or more but less than $30,000,
      <7> $30,000 or more but less than $40,000, or
      <8> $40,000 or more?

      <d> DON'T KNOW
      <r> REFUSED

K5a.   **INTERVIEWER: IS THE AMOUNT IN K5 BEFORE OR AFTER TAXES?**

      <1> BEFORE TAXES (GROSS)
      <2> AFTER TAXES (NET)

L.   DISRUPTIVE BEHAVIORS

L1.   INTERVIEWER: ARE YOU SPEAKING WITH:

        <1> THE SAMPLE MEMBER
        <2> A PROXY ➜ **goto L3**

L2.   INTERVIEWER: THANK RESPONDENT AND ASK TO SPEAK TO CONTACT PERSON IDENTIFIED IN SCREENER QUESTION ? AS PERSON WHO KNOWS MOST ABOUT SAMPLE MEMBER'S CARE AND/OR HELPS (HIM/HER) THE MOST.

L3.   Sometimes people who depend on others for help behave in ways that make it difficult to care for them.

        Does [FILL SAMPLE MEMBER] sometimes wander away, behave offensively to others, or behave in a way likely to cause injury to (him/her)self or others?

        <1> YES
        <0> NO ➜ **goto thnx**

        <d> DON'T KNOW
        <r> REFUSED

L4.   How often must someone supervise [FILL SAMPLE MEMBER] because of this behavior? Is it . . .

        <1> not at all,
        <2> weekly or less often,
        <3> several times a week,
        <4> daily, or
        <5> 24 hours a day?

        <d> DON'T KNOW
        <r> REFUSED

thnx.   Thank you very much for your time. Those are all the questions I have. Your opinions and the experiences you have shared are very important to this research.