

**Field Test of the  
“Assessment of Health Plans and Providers by  
People with Activity Limitations” (AHPPPAL)  
Survey**

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by**

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- Field test: Inland Empire Health Plan, Partnership Health Plan of California, and the California Department of Health Care Services

The AHPPAL builds upon more than 10 years of work by the federal Agency for Healthcare Research and Quality (AHRQ)'s CAHPS® Development Team, particularly upon the Medicaid CAHPS® questionnaires and the CAHPS® Clinician and Group Survey questionnaire. Our research protocol was modeled on the CAHPS® development processes in order to assure a high degree of scientific rigor and to enhance its evaluation for adoption by federal agencies.

Major funding for work prior to this field test was supported by the US Department of Education/National Institute for Disability Rehabilitation and Research, # H133A040016. The further analyses described in this report will also be funded by NIDRR under the same grant.

The English and Spanish versions of the AHPPAL are placed in the public domain.

## Executive Summary

### Project Overview

This project is part of a larger study to develop organizational performance measures for the care provided to people with activity limitations arising from chronic illness or long-term disability. The approach is to develop, test, and implement performance measures that are especially relevant to people with disabilities through the extension of CAHPS<sup>®</sup> and HEDIS<sup>®</sup>, which are widely used measurement processes in the commercial and public sectors.

This particular project extended the CAHPS. CAHPS uses survey data to collect information on quality that is not captured in administrative data, especially information about access to services and quality of care processes. However, few CAHPS<sup>®</sup> measures address the needs of people with disabilities.

More payers, providers, and people with disabilities are demanding these types of measures. For example, CMS recently started signing Special Needs Plans (SNP) contracts with niche health systems to provide specialized services to Medicare adults with chronic care needs or disabilities, institutionalized beneficiaries, or dual eligibles. As of August 2008, there are over 880,000 beneficiaries (including 92,000 Californians) enrolled in SNPs for dual-eligibles; at least some of these SNPs are known to target people with disabilities. In addition, 232,383 Medicare beneficiaries in the country were enrolled in 131 SNPs for people with chronic or disabling conditions, including 38 contracts in California. Only one of those SNPs, however, specifically services people with disabilities. Regardless of the type of SNP, CMS, states, the SNP medical directors and people with disabilities desire statistically reliable, valid and relevant indicators to measure organizational performance. Some measures for populations with disabilities have been suggested by expert panels, but none have yet been field tested.

This study, funded by the California HealthCare Foundation, conducted a field test of the “*Assessment of Health Plans and Providers by People with Activity Limitations*” (AHPPPAL, pronounced “apple”). The majority of the items are from three CAHPS item banks: the Health Plan Adult Medicaid 4.0 core and supplement questions, and the Clinician and Group Practice Survey. New content and items were developed from the needs expressed by focus groups of Medicaid beneficiaries with disabilities and from several panels of technical experts conducted during 2005-2007. The AHPPPAL includes 6 new and 11 modified questions for people with mobility impairments; 2 new questions about medical supplies; 5 new content areas (reproductive health; care coordination services; functional abilities incorporating the American Community Survey; National Core Indicators for everyday life; and ease of communicating when the respondent has a speech impairment). In addition, there are 16 modifications to existing CAHPS questions, as well as revised instructions to complete the CAHPS survey, that were changed after our cognitive testing.

This study had five tasks :

1. Translate into Spanish and cognitively test (in Spanish) a version of the Medicaid CAHPS that includes additional content areas identified by people with disabilities.
2. Measure the effect of “modality of administration” on global ratings by fielding the survey via mail with telephone follow-up.
3. Determine which question responses should be composited to create statistically valid comparisons between health plans or provider groups.
4. Adjust the comparative measures using an appropriate case-mix adjuster.
5. Test the survey in a fee-for-service program.

The survey was tested in English and Spanish at three Medicaid health delivery systems in California: one HMO in a voluntary enrollment county, one HMO in a mandatory enrollment county, and one in a home and community-based care program for adults with developmental disabilities who would otherwise receive care in nursing homes or acute care facilities.

The survey was fielded in November and early December, 2007. We followed the CAHPS and National Committee for Quality Assurance (NCQA) survey protocols as closely as possible. However, some operational delays encountered at the start of the project required us to compress the timeframe for the questionnaire. Thus, the AHPPPAL was mailed to the sample, followed by a phone call a week later, a post-card reminder, and repeated phone-calls.

The 1,086 completed surveys comprised an unweighted response rate of 46% and a weighted response rate of 42%. These rates are 5% more than the response rates to the state-sponsored Medicaid CAHPS in prior years. About 60% of surveys were completed by phone, with the balance by mail.

### **Key Findings: Survey Questions and Administration**

Key findings from the field test about the survey instrument and administration of the survey include:

- Factor analysis of summary comparative measures shows that the constructs by people with disabilities of major content areas (e.g., “access to care”) do not composite in the same way as for people without disabilities who respond to CAHPS. This finding suggests that it is inappropriate to compare responses of disabled beneficiaries to beneficiaries with other Medicaid entitlements, even when they are answering the same CAHPS questions.
- Existing case-mix adjusters in the CAHPS Reporting Tool Kit provide limited explanatory power in global ratings by people with disabilities. We are developing a new case-mix adjuster that directly captures an index functional ability and complexity.
- Of the 75 new and revised questions which were tested, most questions have excellent psychometric properties and were completed appropriately rather

- than skipped. In the final AHPPPAL, 8 questions are dropped from the tested instrument, 2 questions are rephrased.
- Only 11% of people in the sampling frame refused to participate in the study. Among those who responded, 0.03% had participation barriers that prevented them from completing the survey. The length of the survey (115 questions) is acceptable.
  - About 40% of responses were completed by a proxy. Global ratings by proxies were not statistically significantly different from global ratings by self-respondents, when controlling for telephone/paper administration and language.
  - People and proxies responding by telephone are significantly more likely to rate health plans and physicians one point higher than when responding by mail.
  - We suggest 275 completed surveys per site when there are 4 comparison sites. This assumes that at least 40% of respondents have experience with specific benefit areas (mental health, medical equipment, physical therapy).
  - Inaccurate contact information for Medicaid beneficiaries can be a major problem in fielding surveys: among those who did not respond, 49% could be not located, and 28% had correct information but could not be contacted.
  - 33% of respondents did not understand the question designating race.

### **Key Findings: Beneficiary Experiences**

Analysis of the weighted responses to questions about key issues identified by consumers with disabilities and in Healthy People 2010 showed that, overall, most people rate their care highly:

- On a low-to-high scale of 0-10, the mean ratings are: 8.07 for their Medi-Cal benefit plans; 8.36 for their personal physicians; 8.23 for their specialists; and 7.05 for counseling services.
- 87% of respondents said that their personal doctors “usually” or “always” explain things in a way that is easy to understand, listen carefully to them, and show respect for what beneficiaries have to say.
- 67% of respondents receive advice on exercise and 63% receive advice on nutrition.
- Nearly 80% of respondents said:
  - Their personal doctors spend enough time with them (79%).
  - Their personal doctors seem informed and up-to-date about care received from specialists (77%).
  - Their personal doctors take the beneficiary’s preferences into account when deciding among different treatment choices (79%).
  - Were able to schedule urgent and routine appointments as soon as they thought they needed (78%).
  - Found it easy to get medical supplies, if they needed them (80%).
- 95% of people had no trouble moving around inside their personal physician’s office. However:

- 20% of the respondents were “never” or “sometimes” unable to get onto the examination table when they needed to.
- 80% of people who saw specialists said their specialists usually or always seemed to know important information about the beneficiary’s medical history.

Analysis of the weighted responses identified the following important opportunities for health plans and programs to improve public health goals expressed in Healthy People 2010:

- Reproductive health: 61% of respondents reported that they are sexually active or want to be sexually active.
  - Of them, 72% of them reported getting *no* information on preventing sexually transmitted diseases.
  - Nearly 80% of these respondents of child-bearing or -fathering age did *not* receive family planning counseling.
- Mental and emotional health: 41% of respondents reported their current mental health as “poor” or “fair”.
  - Of them, 40% reported *no* screening for current anxiety.
  - Of them, 45% reported *no* screening for depression.
  - Less than half of people who said they needed counseling “usually” or “always” received it.
- Equipment repairs: 50% of people needing mobility or breathing equipment repairs found it difficult to get it done.
- Transportation: 50% of people asking the health plan for help arranging transportation had trouble getting it,
  - 50% of people who got plan-arranged transportation had trouble getting the vehicle on-time.
- Alternative formats: A small percentage yet large number of people may need printed materials in alternative formats because of functional illiteracy. They should be asked if they want it in some other way.

#### **Recommendations for Medicaid CAHPS and Medicare (M-CAHPS) Sponsors**

- Revise the CAHPS instructions and impaired mobility questions.
- Include the American Community Survey questions on functional ability.
- Include questions about quality of life from the National Core Indicators.
- Add questions on building barriers, reproductive health, and need for information in listening format.
- Allow proxy respondents.
- Revise methods to compute composite measures and to adjust them for case mix, when respondents indicate they have a disability.
- Comparative analyses using conventional race categories as a controlling variable should be interpreted very carefully, or ignored.
- Consider the AHPPAL for beneficiary evaluation of Home and Community Based Waiver programs.

## **Next Steps**

Further data analysis is underway to determine the best statistical method for computing and reporting measures. A User's Guide and Technical Manual will be released in December, 2008. A version of the AHPPPAL for proxy respondents will also be developed and cognitively tested.

## Introduction

The impetus for this project arises from a body of work by the principal investigator since 1999 to close the gap in access to quality health services for adults of working age with disabilities. The primary strategy is to develop, test, and disseminate organizational performance measures that are especially relevant to people with disabilities through the extension of existing measurement processes used in the commercial and public sectors, i.e., HEDIS<sup>®\*</sup> and CAHPS<sup>®†</sup>.

HEDIS measures mostly rely on administrative data, using service counts from claims and encounters and, occasionally, from medical chart review. CAHPS uses survey data to report complementary information on quality that are not captured in administrative data, especially about access to care and the quality of care processes. Originally, HEDIS and CAHPS were developed to allow employers and the Medicare/Medicaid programs measure outcomes between different HMOs and fee-for-service plans. In response to requests from health plans and Blue Cross/Blue Shield, recent research has developed comparative performance measures *between* physician group practices. Starting in 2004, “thought leader” group practices began to use CAHPS results to identify areas for clinical process improvement *within* practices.

However, HEDIS<sup>®</sup> and CAHPS measures are geared towards the 85% of the population without disabilities – people who are relatively healthy and do not place long-term demands on the health system. Consequently, there are few formal processes to collect and report quality measures of health systems and provider groups that are focused on the remaining 15% of the population. This is especially troubling because people with disabilities, as a group, need more care more often, and frequently have more than one type of disability that impacts how they interface with health care providers. Recognizing this gap, the National Institute for Disability and Rehabilitation Research (NIDRR) awarded a 5-year federal grant in 2003 to Susan Palsbo (this project’s principal investigator) to develop such measures.<sup>‡</sup> With actionable measures, health plans and provider groups will be able to improve business and clinical processes, become more disability competent, and ultimately improve outcomes.

Since the time Dr. Palsbo was awarded her NIDRR grant, Congress passed the Medicare Advantage Act. Under this Act, CMS enters into contracts with focused health systems known as Special Needs Plans (SNPs). SNPs provide specialized services to Medicare adults with chronic care needs arising from age, specific chronic conditions such as diabetes, or from disability. Additionally, some states allow their Medicaid contractors to enroll dual-eligibles in SNPs and then integrate the funding streams and benefits. Most people with disabilities in SNPs are enrolled in these dual-eligible, integrated care programs.

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\* For information on HEDIS, visit [www.ncqa.com](http://www.ncqa.com)

† For information on CAHPS, visit [www.cahps.ahrq.gov](http://www.cahps.ahrq.gov)

‡ US Department of Education, Grant #H133A040016.

CMS, the states, and SNP medical directors desire statistically reliable, valid and relevant indicators to measure access and care quality. Some measures particularly relevant to people with disabilities have been suggested by various expert panels over the prior 10 years, but none have yet been field tested.

This CHCF-funded study had five tasks:

1. Translate into Spanish and cognitively test (in Spanish) a version of the Medicaid CAHPS that includes additional content areas identified by people with disabilities.
2. Measure the effect of “modality of administration” on global ratings by fielding the survey via mail with telephone follow-up.
3. Determine which question responses should be composited to create statistically valid comparisons between health plans or provider groups.
4. Adjust the comparative measures using an appropriate case-mix adjuster
5. Test the survey in a fee-for-service program.

In addition, this study extended research on AHRQ’s set of supplemental questions addressing the needs of adults with mobility impairments (PWMI), released in 2007. This project continued that work by cognitively testing the questions with people representing more diverse disabilities than in the original cognitive test.

## **Methods**

### **Content Areas and Question Selection**

The content of the AHPPPAL was informed by several advisory panels and focus group work convened before this grant. People with disabilities told us that many of the current topic areas in the CAHPS surveys were relevant, but did not go into enough detail or provide information on attributes that are particularly important to people with disabilities. For example, there are several CAHPS questions on transportation services, but they ask about how well health plans help people get transportation and not whether the arranged transportation arrives on time or is wheel-chair accessible.

Table 1 shows the new questions we tested that were ultimately adopted in the final AHPPPAL. The new content areas are:

- availability of American Sign Language interpreters when needed
- difficulty speaking with a personal doctor when the beneficiary has impaired speech
- physical barriers in the doctor’s office and exam room
- availability of written information in alternative formats
- medical supply benefit management
- pain management
- fatigue management
- reproductive health
- attributes of provided transportation

- health care transitions (leaving the hospital)
- care coordination by case managers
- National Core Indicators on the quality of life
- American Community Survey questions on functional ability
- learning disabilities

## **Translation and Cognitive Testing**

The second step of the study was to translate the questions into Spanish. This work was conducted by American Institutes for Research (AIR), funded under a separate California HealthCare Foundation grant. Two native Spanish-speaking health services researchers independently translated the questions into Spanish. A third native-speaking health services researcher reconciled the different translations.

Preliminary cognitive testing was conducted in English by Dr. Palsbo in northern Virginia in 2006, followed by more in-depth cognitive testing conducted by AIR in Spanish in Berkeley and Salinas, California in September, 2007. Cognitive testing resulted in some further adjustments to specific words or phrases; these, in turn, led to parallel adjustments in the original English. Based on results from the cognitive interviews and upon conferring with project team members, 36 items in the original English version of the survey were revised to clarify the meaning of the item and 16 were deleted. Detailed information is provided in AIR's final report to CHCF.\*

To our knowledge, this is the first time that many of the existing CAHPS questions have been cognitively tested on a population of adults across the spectrum of disability or with proxy respondents. Our findings led us to revise the CAHPS instructions to survey recipients, questions about years of education, most of the mental health service questions, and reasons for using a proxy respondent. Table 1 shows which existing questions were modified as a result of cognitive testing.

## **Survey Sample and Procedures**

All aspects of fielding the survey were conducted by Mathematica Policy Research, Inc. (MPR), a company with extensive experience in surveying people with disabilities for federal and state agencies. Much of the information in this section is drawn from their report.

The survey operations followed the CAHPS Survey Protocol as closely as time allowed. Since this was a research study, the project was reviewed and approved by the Institutional Review Boards of George Mason University and the California Health and Human Services Agency Committee for the Protection of Human Subjects.

There were three participating study sites:

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\* A copy is available by emailing Sue Palsbo at spalsbo@gmu.edu or calling 541-505-7591.

- Partnership Health Plan (PHP), an HMO located between Sacramento and San Francisco Bay, with 86,000 Medi-Cal beneficiaries
- Inland Empire Health Plan (IEHP), an HMO located in southern California in San Bernardino, with 284,000 Medi-Cal beneficiaries
- The State of California's Acute Facility/Nursing Home (AF/NH) Waiver, a statewide fee-for-service program that provides in-home care for 318 beneficiaries with developmental disabilities who would otherwise be institutionalized.

MPR provided PHP, IEHP, and the AF/NH Waiver program with detailed instructions for generating their sample frame files. The instructions included information about preferred file format, data elements, contact information for questions, delivery instructions, and the timeline for submission.

Beneficiaries had to meet four criteria to be in the sampling frame:

1. Continuous enrollment in the health plan's Medi-Cal product line from August 1, 2006, to July 31, 2007 (did not apply to the AF/NH Waiver).
2. Primary Medi-Cal Aid Code of "60" on July 31, 2007, i.e., individuals classified as participants in the Supplemental Security Income and State Supplementary Payment (SSI/SSP) Program available to California's aged, blind, and disabled. An unknown number of dual-eligibles were included.
3. Language flag of "English," "Spanish," or "no valid data reported" or "NA".
4. Between the ages of 18 and 64 on July 31, 2007.

MPR examined the sample frame files received from PHP, IEHP, and the AF/NH Waiver program to ensure the inclusion of only study-eligible participants. Individuals under age 18 or over age 64 and individuals with a language code other than English, Spanish, or unknown were excluded from the sample frame files. The final sample frame consisted of 10,571 individuals. Their demographic characteristics are shown in Table 2.

To compare enrollees between plans, MPR allocated the sample so that the effective sample size for each plan was as close to equal as possible. (Because of the small number of enrollees in the AF/NH Waiver program, everyone in that program was surveyed.) To compare English speakers with Spanish speakers, MPR allocated the sample to achieve approximately equal effective sample sizes for the two groups. More detailed information on sampling is available in MPR's technical report.\*

MPR followed the CAHPS Survey Protocol to select the sample of individual enrollees to be surveyed. That protocol uses a two-stage procedure because the frame could have more than one enrollee per household and the survey protocol

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\* A copy of this report is available by emailing Sue Palsbo at spalsbo@gmu.edu or calling 541-505-7591.

stipulated interviews with only one enrollee per household.\* In the first stage, where there were multiple survey-eligible enrollees at the same address covered under the same subscriber identification number, MPR selected one enrollee at random. MPR selected the second-stage sample from the group of those enrollees in the frame who either (1) were the only survey-eligible enrollee in their household or (2) were sampled as part of the first stage. MPR then assigned each enrollee remaining in the frame a measure of size (MOSi) equal to the number of survey-eligible adults in their household. MPR then selected the sample of enrollees within stratum using probability proportional to size (PPS) methods. Table 3 presents the characteristics of the final sample, which consisted of 2,537 beneficiaries.

The AHPPAL survey was fielded over a seven-week period from November 5, 2007, through December 12, 2007, as follows:

Mail Survey Sent to Entire Sample	n = 2,527	11/05/07
Reminder Letter Sent to Non-Responders	n = 2,513	11/12/07
Telephone Follow-up with Non-Responders	n = 2,229	11/19/07
Postcard Sent to Non-Responders	n = 1,936	12/07/07
End of Data Collection		12/21/07

The survey materials included an initial survey packet, a reminder letter, and a reminder postcard in English and Spanish, all written at a 5<sup>th</sup> to 6<sup>th</sup> Flesch-Kincaid grade level. Following the CAHPS Survey Protocol, we included a cover letter printed on health plan letterhead. The personalized cover letter explained the purpose of the study, the length of the survey, and the sample member’s rights and provided a toll-free number to call for answers to inquiries. The letter included the California Relay number for use by deaf people or people who are hard of hearing. The letter included a text block in 16-point font, instructing people with visual impairments to call MPR’s toll-free line for a large-print survey or to complete the survey by telephone.

At the request of the California Health and Human Services Agency Committee for the Protection of Human Subjects, we included a sheet with “Frequently Asked Questions” about the risks and benefits of participation in the research study, the funding for the study, and how data would be used.

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\* The project team had several discussions about this “one enrollee per household” restriction. Our concern was the situation of congregate group housing for people with disabilities. It is not unusual for unrelated people with disabilities to share living quarters because the dwelling is building accessible, close to accessible transportation, or is an apartment within an assisted living facility. Thus, the one enrollee per household restriction could unnecessarily exclude a person in a small sampling cell who we would otherwise include. For example, if an English-speaking person was selected, his unrelated but co-habiting Spanish speaking friend was automatically excluded. In the end, we followed the CAHPS Survey Protocol, but we believe this restriction needs further evaluation.

The packet also included the survey instrument in English or Spanish, as well as a card in the alternate language expressing how to obtain a copy in the alternate language. The AHPPAL was printed as an 8x11 inch booklet format, 10 pages in length, double-sided, size 13 font. The cover of the AHPPAL booklet conformed to the CAHPS Survey Protocol, including a box on the confidentiality of responses and voluntary participation. The cover page also listed a toll-free number so that survey recipients could call to ask questions about the study or to complete the questionnaire by telephone.

A reminder letter was sent to 2,513 non-responders one week following the initial mailing. Telephone follow-up began the following week. To ensure that sample members completing the questionnaire by telephone understood the basic tenets of informed consent (confidentiality, voluntary nature of participation, and survey topics), the interviewer administered a cognitive screener developed by MPR. If the sample beneficiary failed to pass the screen, the interviewer sought a proxy.

If a telephone informant indicated that the sample member was too cognitively impaired to participate in the survey, the interviewer provided information about how the questionnaire was designed for a person with a disability and how MPR could accommodate him/her by, for example, rereading questions, using amplification devices, speaking slowly, and offering rest breaks. If the informant continued to indicate that the sample member was unable to participate, the interviewer sought a proxy. In these cases, the cognitive screener was not administered.

MPR implemented several strategies so that sample members with a wide range of disabilities could participate in the survey. The strategies included the following:

- Toll-free number
- California Relay for people with hearing impairments (no requests)
- Large, 16-point font for people with impaired vision (no requests)
- Proxy respondents (40% used this)
- Interviewing over several sessions (no requests).

Each telephone interviewer underwent eight hours of project-specific training, in addition to the standard eight hours of general interviewer training. More detailed information on the sampling, survey packets, and training of telephone interviewers is available in MPR's technical report.\*

## **Response Rates, Characteristics and Lessons Learned**

Table 4 presents unweighted and weighted response rates by race/ethnicity, age, language, and health plan.

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\* A copy of this report is available by emailing Sue Palsbo at [spalsbo@gmu.edu](mailto:spalsbo@gmu.edu), 541-505-7591.

- Number of completed surveys: 1,086
- 59.2% by telephone (n = 643)
- 40.8% by mail (n = 443)
- Unweighted response rate = 46.3%
- Weighted response rate = 41.7%
- People with higher weights were slightly less likely to respond. For example, the response rate among Spanish speakers (a group that was heavily sampled and had lower weights) was higher than that of the other groups sampled at a lower rate, which thus had higher weights.

Reasons for non-response	number	percent of non-respondents
Unable to locate	660	49.4%
Contact information verified, contact not made with sample member	373	28.0%
Refusals	270*	20.2%
Participation barrier, no proxy identified	29	2.2%
Other non-complete	4	<1.0%

\*48 were adamant refusers

- Non-response bias: non-respondents were more likely to be non-Hispanic, under age 50, English speaking, and in one of the two HMOs.
- Lessons learned:
  - Incorrect contact information is the primary reason for not being able to contact a sampled member.
  - Even when contact information is correct, about half of Medicaid beneficiaries with disability benefits and/or their proxies may not be able or willing to respond to research studies using CAHPS

## Data Cleaning

MPR cleaned the data to correct for navigation errors and to add in known age and gender information when the respondent skipped those questions. Details on data cleaning are provided in MPR's technical report.

## Findings: Survey Content and Item Properties

### New Content Areas

We included several new content areas and more in-depth questions on existing CAHPS content areas. These were:

- availability of American Sign Language (ASL) interpreters when needed
- difficulty speaking with a personal doctor when the beneficiary has impaired speech
- physical barriers in the doctor's office and exam room
- availability of written information in alternative formats
- medical supply benefit management
- pain management
- fatigue management
- reproductive health
- attributes of provided transportation
- health care transitions (leaving the hospital)
- care coordination by case managers
- National Core Indicators\* of everyday life
- American Community Survey† questions on functional ability
- learning disabilities

Analysis of field test results identified some problem questions:

American Sign Language. People did not have trouble answering the question on ASL, but the interpretation of the responses does not make the distinction between ASL provided by the doctor's office, ASL provided by a family member, or no need for ASL because the beneficiary lip reads or gets by with pen and paper.

- *This question is revised to specify if a person needs ASL to communicate with their personal doctor.*

Speech therapy. Very few people answered this question, which is part of the CAHPS-PWMI.

- *This question is dropped from the AHPPPAL.*

Pain and fatigue management. Most people who said their doctors talked with them about the effect of pain or fatigue on their life also said the doctor

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\* [www.hsri.org/nci](http://www.hsri.org/nci) *The National Core Indicators* is a collaboration among participating National Association of State Directors of Developmental Disability Services (NASDDDS) member state agencies and the Human Services Research Institute (HSRI), with the goal of developing a systematic approach to performance and outcome measurement.

† [www.census.gov/acs](http://www.census.gov/acs) The American Community Survey lets communities see how they are changing between each 10-year census.

talked with them about pain and fatigue management. The questions on frequency of pain and fatigue limitations added no information.

- *We recommend replacing the PWMI questions on understanding pain and fatigue with the new AHPPPAL questions on pain and fatigue management. While focus groups told us they wanted emphatic physicians, the desirable outcome is symptom management. The questions on severity of pain and fatigue are dropped because they did not add any explanatory power to the analysis.*

History of anxiety, depression or explosive anger. This is prevalent in the study population, but these conditions are usually episodic.

- *This question is revised to specify a current diagnosis, i.e. during the look-back period.*

The following new content questions tested well, because most people who screened into the content area went on to complete the follow-up questions:

- Interior and exterior building barriers (the definition of building barriers we offered was well understood).
- Impaired speech.
- Modified mental health services questions.
- New question on medical supplies.
- Reproductive health.
- Leaving the hospital.
- Care coordination.
- The National Core Indicators on quality of everyday life.
- History of learning disabilities, or of severe and persistent mental illness.
- The American Community Survey questions on functional ability.

### **Skipped Questions**

The AHPPPAL contains 30 yes/no questions that ask if certain events occurred, such as “In the last 12 months, did you visit your doctor for personal care?”. If the answer is “no”, the respondent is directed to skip over the next few questions that ask about experiences with that type of service.

People can skip questions *inappropriately* for several reasons: they misunderstand the instructions; they may be confused by the question; they may get bored or tired and abandon the questionnaire; or the question may touch on medically or culturally sensitive topics. The field-test results help us evaluate the reasons people did not provide any answer to particular questions.

## **Navigation Errors**

The most significant navigation error occurred on our revised instruction page. The field-tested AHPPPAL used the example of the first question in the survey, “Do you have a personal doctor?” and then directed the respondent to skip to question 32, which is the actual skip. Several respondents proceeded directly to question 32, rather than answering the first question in the survey. MPR attempted to contact people who made this apparent navigation error, but was unable to reach 9 of them.

There were no other significant navigation errors.

- *We added a box underneath the example that tells people the survey begins on the next page.*
- *We revised the example to direct people to question #3 instead of #32, so they will recognize an error right away.*

## **Abandonment**

The field-tested AHPPPAL had 110 questions. This compares to 39 questions for the Adult Medicaid Core, and 81 questions for the Medicare CAHPS (M-CAHPS). If the length was excessive, we would expect more missing responses near the end of the survey. However, this did not happen.

- *The number and relevance of the questions are acceptable for respondents.*

## **Confusing Questions or Confusing Response Options**

The CAHPS research team considers that a question with 10% or more skipped or listed responses should be dropped. The question that the most people had trouble answering was the standard CAHPS question, “What is your race?”. While only 4% skipped this question, 29% checked “other”. The vast majority of these wrote down a nationality such as Mexican, Salvadorian, Italian or even American. Many people who meet the conventional definition of Latino or Hispanic skipped that question. Unfortunately, the response options are dictated by the US Census Bureau and cannot be changed. However, we encourage individual states or health plans to devise their own list of racial, ethnic, and nationalities when using the CAHPS.

- *Comparative analyses using conventional race categories as a controlling variable should be interpreted very carefully, or ignored.*

## **Sensitive Questions**

Several content areas addressed areas that are medically or culturally sensitive. We thought the questions on mental health and reproductive health would be most sensitive.

Most people (98%) did not skip the mental health questions. However, 7% of respondents skipped the questions on reproductive health.

- *We recommend that the questions on reproductive health be retained, because we found a widespread interest and activity in sexual activity, with very little education in safe sexual practices or family planning. Responsible sexual behavior is a leading health indicator in Healthy People 2010.*

## Question Order

Usually, surveys order their questions so that most people will answer the first set of questions. The Medicaid CAHPS and Medicare M-CAHPS health plan instruments place questions about the need for emergency or urgent care, first, followed by questions about your personal doctor.

In contrast, the Clinician and Group CAHPS starts off with questions about the personal doctor. The field-tested AHPPAL followed the latter convention, starting off with questions about the personal physician and placed questions about access to care in the middle of the survey. Our reasoning was that we thought more people in Medi-Cal were likely to answer affirmatively that they had a personal physician, than the number of people who needed urgent care. This reasoning was borne out by the results: 92% of respondents had a personal doctor, 57% saw a specialist, and 55% needed care right away.

However, several potential users of the AHPPAL advised the AHPPAL template is more likely to be used if the question order is more similar to the Medicaid CAHPS and M-CAHPS.

- *The question order is revised to parallel the content in the existing Medicaid CAHPS. The next set of questions asks about clinical services, then benefit administration, and ends with functional and demographic information.*

## Scale Evaluation

Many questions in the AHPPAL and the CAHPS offer ordinal response scales, such as never/sometimes/usually/always, or a numerical scale of global performance ratings ranging from 0-10. The scales indicate the relative position of experiences, but not the magnitude of difference.

If everyone reports high values (the ceiling), or low values (the floor), there is a lack of variation. This hampers our ability to make distinctions between sites or between populations within a site, because most statistical procedures rely on scores being variable and evenly distributed across the entire scale. Often, statistical tests assume that scores are normally distributed in bell curve. In other words, most people would rate their physicians and health plans around 4-6 on an 11-point scale.

In the field test, most respondents gave their Medi-Cal physicians and health plans a score of 8 or 9. This complicates our ability to find significant differences between health delivery systems we tested, but does show that most beneficiaries believe they are getting high quality care. The fact that each Medi-Cal contractor participating in the study is meeting quality goals does not mean that the scale needs to be expanded.

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\* The participating sites have a local reputation for being thought leaders in quality care for Medi-Cal beneficiaries. Their willingness to participate in this study is one example of their commitment. Thus, it is not altogether surprising that most respondents rated their plans very highly.

- *The standard 4-point and 11-point CAHPS scales appear to be sufficient for people with disabilities.*

### **Look-back Period**

The Medicaid CAHPS and Medicare CAHPS use 6 month look-back periods. In contrast, the field-tested AHPPPAL survey used a 12 month look-back period. We selected 12 months because we wanted to be sure we captured enough people who answered the PWMI questions on durable medical equipment fulfillment and repair.

The AHPPPAL expanded the existing PWMI question on assistive mobility devices to include assistive breathing devices. When phrased this way, 40% of respondents needed or used assistive equipment, of which 17% tried to get new or replacement equipment and 14% tried to get their plan to pay for equipment repairs. It is reasonable to assume that a 6-month look-back period would result in percentages of 40%, 8%, and 7%, respectively. Thus, if we wanted 100 responses to these particular questions, we would seek 1500 completed responses per evaluation site for a 6-month look-back, and 750 completed responses for a 12-month look-back.

On the other hand, using a 6 month look-back instead of 12 months would increase the number of people eligible for sampling at each evaluation site. It would also make the referent period the same as for Medicaid beneficiaries without disabilities and for Medicare beneficiaries, enhancing direct comparisons of responses to the same questions contained in different surveys.

- *The final AHPPPAL is changed from a 12 month look-back to 6 months, acknowledging that there may not be enough respondents to some questions to allow comparability between evaluation sites.*

### **Findings: Modality of Administration**

CAHPS surveys are usually administered by mail, telephone, or a combination of the two. We used mail with telephone follow-up. Our preliminary analysis of the global rating questions shows that mean rating of telephone respondents was 0.36 points higher than paper respondents when controlling for use of proxy respondent and language. Thus, analysts need to subtract 0.36 from the global ratings, if the survey was completed by telephone. More information will be included in the forthcoming manual on reporting AHPPPAL measures.

### **Findings: Proxy Respondents**

The CAHPS Reporting Tool Kit directs analysts to omit global ratings provided by proxy respondents. The CAHPS surveys offer a standardized set of questions on why and how proxy respondents assisted in survey completion.

We were concerned that the directive to exclude proxy respondents results in excluding quality ratings from the very people we most want to hear from: people with disabilities.

The field-tested AHPPPAL offered an expanded set of reasons for using proxy respondents: visual limitations (written survey), manipulative limitations (written survey), hearing limitations (phone survey), cognitive limitations, and an open-ended response.

- 31% of the weighted respondents used proxies
- 71% of people in AF/NH Waiver used proxies
- reasons for using a proxy respondent:
  - 11%: Difficulty seeing questions
  - 20%: Difficulty with reading (*possible indication of illiteracy*)
  - 6%: Difficulty seeing where to write answers
  - 20%: Difficulty writing
  - 20%: Difficulty remembering
  - 23%: Proxy helps make health decisions
  - 3%: Translated into my language
  - 53%: Other reasons: mental retardation, paralysis, autism, things related to hearing or auditory processing (re: answering phone interviews)

We also compared the mean global ratings for proxy respondents to self-respondents. Our analysis shows that, controlling for differences in mode of administration and language, global ratings by proxies were not statistically significantly different from global ratings by self-respondents, with p-values 0.42 for the physician ratings, 0.49 for specialist ratings, and 0.62 for overall health plan ratings.

A 2007 study by Mathematica Policy Research\* found that when a proxy must be used, for example when the sample beneficiary has mental retardation or a severe learning disability, data quality is generally not compromised if proxy use is restricted to specific types of questions, such as factual information on how often services were received.

Additional analyses in the next few months will develop a proxy respondent version of the survey and devise comparative measures.

- *Including the voice of people who need assistance to complete the AHPPPAL (and the CAHPS) will not necessarily bias global ratings and may contribute important operational information.*

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\* Wright D, Sloan M, Barrett K, Livermore G. 2007. Quality of Self And Proxy Responses on a National Survey of Persons with Disabilities. Presented at the AAPOR Conference.

## Findings: Composite Measures

The CAHPS Reporting Tool Kit includes several statistical programs that help analysts convert survey responses into four composite measures:

- getting needed care
- getting care quickly
- how well doctors communicate
- health plan information and customer service

The Reporting Tool Kit then adjusts the responses using the question about the number of visits (AHPHPAL question #5), and directs analysts how to compute significant differences between analysis sites. Some states and employers compile the global and composite measures into comparative rankings of health plan performance.

Our focus groups of Medicaid beneficiaries with disabilities, as well as other advisory panels, place a high priority on accessibility, administration of specific benefits, self-direction, and care coordination as performance measures. Therefore, we used the data from the field test to composite various AHPHPAL questions into the following constructs:

1. Healthy living
2. Doctor-to-doctor communication
3. Case management services
4. Leaving the hospital
5. Shared decision-making
6. Accessibility
7. How well doctors communicate (the same as in CAHPS)
8. Getting care quickly
9. Pharmacy
10. Therapy
11. Equipment and supplies
12. Transportation services

A statistical procedure known as “construct validation” checks what underlying construct is being measured. We are especially interested in the coefficient of reproducibility (which indicates how well the data from the individual measures included in the scale can be reconstructed from the composite scale), internal validation (which checks the relation between the individual measures included in the scale and the composite scale, itself), and external validity (the relation between the composite scale and other indicators of the variable, drawn from encounter and claims data).

Our initial analyses using the field test data suggest that the coefficient of reproducibility is very low. In other words, each item in the AHPHPAL is asking

about qualitatively different attributes. We will continue to explore discriminant validity and the coefficient of reproducibility in the coming months.

- *There will likely be many more comparative measures on providing care to Medicaid beneficiaries with disabilities, than there are for other Medicaid populations.*
- *Few of these measures will be composites of multiple questions.*

### **Findings: Surveying Beneficiaries in a Home and Community-Based Waiver Program (Surveying fee-for-service)**

One of the field-test sites was the State of California's "In-Home Operations Program," which pays its physicians using fee-for-service. This program had the best response rate of the three study sites. We believe this happened because the beneficiaries had a personal Waiver Provider Case Manager who had regular contact with them. Thus, the contact information was current and complete.

Completion rates were high for most questions. We conclude that the AHPPPAL is suitable for use in fee-for-service programs and for home and community based waiver programs that serve people with disabilities.

### **Findings: Case Mix and Discriminant Validity**

The overall objective of this body of research is to develop quality measures that help everyone identify:

- good performers
- specific care processes that need improvement
- characteristics of underserved populations, and
- long-term program outcomes.

The comparative measures need to account for characteristics of respondents that can bias their ratings. For example, older people with disabilities tend to give slightly higher scores than younger people with disabilities. We do not want to penalize one program just because it enrolls mostly younger people.

The CAHPS Reporting Tool Kit suggests stratifying measures by the number of visits to physicians, as well as by a question asking about the presence of chronic conditions. But we already know that disabled Medi-Cal beneficiaries see their physicians frequently and have continuous care needs. Thus, the usual stratifiers did not help us discriminate between analysis sites.

We used the answers to the American Community Survey questions to develop a crude index of functional complexity or ability mix. This index gave least weight to sensory impairments, mid-weight to cognitive impairments and mental illness, and greatest weight to physical impairments since (in the Medicaid population) those are usually associated with complex medical needs. When we computed the mean functional mix, the AF/NH Waiver program had the most functional ability and IEHP

had the least ability. This relationship had face validity, since the AF/NH Waiver program has an eligibility screen based on activities of daily living and screens out anyone with severe and persistent mental illness. Of the two HMOs, IEHP is located in a county with voluntary managed care enrollment, while PHP is located in a county with mandatory managed care enrollment.

- *Our preliminary analysis convinces us that we need to adjust measures for the functional mix at each evaluation site. Over the next few months, we will continue to explore how to make this adjustment.*

We also want to generate model reports that look at ratings as reported by people with various types of activity limitations. An example would be ratings for a particular plan as reported by people with physical impairments, compared to the ratings reported by people with persistent mental illness.

## **Findings: Identifying People with Mobility Impairments**

CAHPS contains two screening questions for people to self-identify as having impaired mobility of the lower limb. These questions are:

IM20. A quarter mile is about 5 city blocks or 0.4 kilometers. In the last 12 months, were you able to walk that far?

IM21. In the last 12 months, did you have difficulty or need assistance to walk that far?

Many rehabilitation researchers have published studies on the social and cognitive acceptability of the term “walk” by people who use wheelchairs. Several studies of people with spinal cord injuries have concluded that the term “walk” offends wheelchair users; they prefer the term “wheel”.

The term “wheel” did not survive our cognitive testing in the group of people with disabilities, especially those with disabilities that do not include impaired mobility. Consequently, we retained the verb “walk.”

During cognitive testing, some people said the distance was weather-dependent. Many people had trouble estimating distance. In the field-test of the AHPPPAL, we tried a fixed time period of “10 minutes without stopping”, or roughly the time it takes a person to walk ¼-mile at a steady pace of 3 mph.

Of the 1086 respondents, only 19 people skipped over this question. The distribution of responses was: never-34%, sometimes-26%, usually-13%, always-27%.

- *We believe that the new phrasing is acceptable and less ambiguous to most people with disabilities.*
- *The final AHPPPAL is revised to refer to audio and audio-visual formats, rather than Braille.*

## Findings: Number of Responses Needed (Sample Size)

The field test data allow us to make preliminary estimates of the number of completed surveys needed to make valid comparisons between two or more group practices on a performance measure, or two or more Medi-Cal contractors. The more contractors or physician groups being analyzed, the fewer the number of completed surveys are needed. Similarly, the larger the difference we are concerned about, the fewer the number of responses needed (Table 5).

In other words, we are looking for the fewest number of completed surveys to detect a meaningful difference between the average rating for one site and the average across all sites.

Thus, the minimum number of surveys is an up-front policy decision, driven by how much of a difference the sponsor wants to detect and by the projected number of respondents to key questions. If the sponsor is only interested in identifying the very best and very worst health plans or group practices using the global ratings, and there are 5 sites being surveyed, then the sponsors need 28 completed surveys, per analytical site. If the sponsor wants to identify organizations that are “better than some but still need improvement”, then they need 110 respondents from each of the 5 sites.

In our field test, we had at least 184 unweighted responses from each study site (Table 4). We want to know if the average quality rating given by enrollees at one site (say, Site A) is significantly better or worse than the overall average across all 1086 respondents. Therefore, from looking at Table 5, we know that if the true average of the ratings for site A (that is, the average rating if we had gotten responses from *every* Medi-Cal beneficiary at site A) is different by 0.3 points or more on the 0-10 global rating scale from the true overall average, we will be able to discover that difference in 80 out of 100 random samples consisting of 184 respondents.

One thing to remember, however, is that AHPPPAL asks about some experiences that few beneficiaries use, such as experience with durable medical equipment. The field test suggests that 7% of respondents would have experience with getting equipment repaired over a 6-month period. If the survey sponsor is looking at 5 different sites, and wants to detect a difference of 0.3 from the overall average on the 4-point scale (e.g., How often was it easy to get equipment repaired? Never/Sometimes/Usually/Always), the sponsor would need to have the following number of completed surveys:

$$110 \text{ (from Table 5) } / 0.07 \text{ (\% of people with experience) } = 1571 \text{ completes}$$

However, if a Medical Director is less interested in that particular question and is more interested in mental health services, experiences with medical supplies and

equipment, and experiences with physical therapy, about 275 completed surveys are needed:

110 (from Table 5) / 0.4 (% of people with experience) = 275 completes

### **Implication: Prevalence of Illiteracy**

The field test results suggest that approximately 10% of the respondents in our sample are functionally illiterate. We computed this by first looking at the question about the need for information in alternative formats including large print, audio, Braille or computer disk. Nearly two-thirds (64%) of respondents answering “yes” to this question later reported that they are not blind or do not have serious difficulty seeing. Most of the mail respondents falling into this category used a proxy respondent “because I have difficulty reading.”

This quantitative finding is supported by qualitative research conducted by the principal investigator. During the focus groups conducted to identify potential content areas for the AHPPAL, she encountered at least one person in each group of 7-8 individuals who needed to have the informed consent read to them. Often, the illiterate individuals were age 50 or older, and it is likely that they did not benefit from the educational interventions that are available to students with disabilities, today. Other illiterate individuals may have a co-existing learning disability or intellectual disability that prevents their ability to process and organize visual information. When survey sponsors and health delivery systems are considering the needs of people with vision impairments, they should consider the needs of people who are illiterate.

- *The survey, recruitment materials and consumer information should be available in audio format.*

### **Utility of the AHPPAL Data**

Since our long-term objective is to develop comparative access and quality measures, we conducted a preliminary analysis of the data collected from the study. We gave each study site its results for each question, by language and by functional ability. Results were weighted to account for the over-sampling of Spanish speakers.

The combined information across all sites shows that most people rated their care highly:

- On a low-to-high scale of 0-10, the mean ratings are: 8.07 for their Medi-Cal benefit plans; 8.36 for their personal physicians; 8.23 for their specialists; and 7.05 for counseling services.
- 87% of respondents said that their personal doctors “usually” or “always” explain things in a way that is easy to understand, listen carefully to them, and show respect for what beneficiaries have to say.

- 67% of respondents receive advice on exercise and 63% receive advice on nutrition.
- Nearly 80% of respondents said:
  - Their personal doctors spend enough time with them (79%).
  - Their personal doctors seem informed and up-to-date about care received from specialists (77%).
  - Their personal doctors take the beneficiary's preferences into account when deciding among different treatment choices (79%).
  - Were able to schedule urgent and routine appointments as soon as they thought they needed (78%).
  - Found it easy to get medical supplies, if they needed them (80%).
- 95% of people had no trouble moving around inside their personal physician's office. However:
  - 20% of the respondents were "never" or "sometimes" unable to get onto the examination table when they needed to.
  - 12% of the respondents were "never" or "sometimes" weighed.
- 80% of people who saw specialists said their specialists usually or always seemed to know important information about the beneficiary's medical history.

Our analysis identified the following important opportunities for the three study sites to improve public health goals specified in Healthy People 2010:

- Reproductive health: 61% of respondents reported that they are sexually active or want to be sexually active.
  - Of them, 72% of them reported getting *no* information on preventing sexually transmitted diseases.
  - Nearly 80% of these respondents of child-bearing or -fathering age did *not* receive family planning counseling.
- Mental and emotional health: 41% of respondents reported their current mental health as "poor" or "fair".
  - Of them, 40% reported *no* screening for current anxiety.
  - Of them, 45% reported *no* screening for depression.
  - Less than half of people who said they needed counseling "usually" or "always" received it.
- Equipment repairs: 50% of people needing mobility or breathing equipment repairs found it difficult to get it done.
- Transportation: 50% of people asking the health plan for help arranging transportation had trouble getting it,
  - 50% of people who got plan-arranged transportation had trouble getting the vehicle on-time.

All sites were already aware of problems with equipment repairs and transportation, through their grievance and appeals process. The field-test data have helped them to quantify the magnitude of the problem.

The findings on reproductive health, need for mental and emotional health, and need for alternative formats were a major surprise to the study sites. One site selected 4 areas for improvement: Sexual/reproductive health, Mental health/depression, Navigating the provider office (getting into the office and in/around the exam room), and Physical Activity/Exercise. After sharing the survey results with the provider community in a provider newsletter, the site implemented multiple new procedures to help their physician panel provide more disability-appropriate care.

## Conclusions and Next Steps

The final AHPPPAL survey is at Appendix 1. The Spanish version is available from the author. Our major conclusions are:

- The AHPPPAL can be fielded to beneficiaries in any type of delivery system, including HMOs, HCBW programs, and fee-for-service clinics.
- The AHPPPAL can be fielded in its entirety or the questions marked as “NEW” can be added to the existing Medicaid CAHPS questions.
- Modifications should be made to many existing CAHPS questions, including CAHPS questions on mental health services and for people with impaired mobility, as well as the instructions to complete the CAHPS, to enhance clarity for respondents.
- Data from the survey can be used to assess overall Medicaid program outcomes as well as delivery of specific services to beneficiaries with disabilities.
- Comparative analyses using “race” as a controlling variable should be interpreted very carefully, or ignored.
- The standard 4-point and 11-point CAHPS scales appear to be sufficient for people with disabilities.
- A 6-month look-back period will make the time period the same as in the Medicaid and Medicare CAHPS surveys; however, the number of completed responses will have to increase in order to have enough respondents to questions on specific services that are infrequently used.
- Responses from proxies should be included in the overall analysis of data.
- Sponsors need to consider functional illiteracy when designing their plan to field the survey.

The next steps will be funded under federal grant # H133A040016, with a target complete date of December 31, 2007. These analyses and development projects are:

1. A version of the AHPPPAL for *proxy respondents*.
2. A *Reporting Manual* that will include instructions for:

- a. Composite measures
  - b. Adjusting composite and global measures for the demographic and functional mix of respondents at each analysis site
  - c. The number of responses necessary to detect differences between analysis sites
3. Suggested layouts for reporting comparative measures.
4. Instructions for comparing responses to certain AHPPPAL questions to responses to the same questions in the Medicaid CAHPS®.

**Table 1. Crosswalk Between the AHPPPAL and Existing CAHPS Questions**

*The foundation survey for the AHPPPAL is the Adult Medicaid Health Plan CAHPS and Adult Medicaid Supplement. Some additional questions come from the Clinician and Group Practice CAHPS. Numbers in the chart refer to the question number in the CAHPS.*

<p><i>Yellow filled questions are screener questions.</i></p>	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
Survey instructions	Modified				Existing CAHPS instructions failed cognitive testing.
<b>Your Health Care in the Last 6 Months</b>					
1. In the last 6 months, did you have an illness, injury, or condition that needed care right away in a clinic, emergency room, or doctor's office?			3		
2. In the last 6 months, when you needed care right away, how often did you get care as soon as you thought you needed?			4		
3. In the last 6 months, not counting the times you needed care right away, did you make any appointments for your health care at a doctor's office or clinic?			5		
4. In the last 6 months, not counting the times you needed care right away, how often did you get an appointment for your health care at a doctor's office or clinic as soon as you thought you needed?			6		
5. In the last 6 months, not counting the times you went to an emergency room, how many times did you go to a doctor's office or clinic to get health care for yourself?			7		This question is an important case-mix adjuster in Medicaid CAHPS but testing showed it is not important in the AHPPPAL. So, we could drop this question.

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
6. Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate all of your health care in the last 6 months?			8		
<b>Your Personal Doctor</b>					
7. A personal doctor is the one you would usually see if you need a checkup, want advice about a health problem, or get sick or hurt. Do you have a personal doctor?			9		
8. How many months or years have you been going to your personal doctor?				CC1	
9. In the last 6 months, did you visit your personal doctor for care?			10		
10. In the last 6 months, how often did your personal doctor explain things in a way that was easy to understand?			11		
11. In the last 6 months, how often did your personal doctor listen carefully to you?			6		
12. An interpreter is someone who repeats what one person says in a language used by another person. In the last 6 months, did you need an interpreter to help you speak with your personal doctor?	Modified			I 1	AHPPPAL references personal doc; Adult Supp references any doc or provider
13. In the last 6 months, when you needed an interpreter to help you speak with your personal doctor, how often did you get one?	Modified			I 2	AHPPPAL references personal doc; Adult Supp references any doc or provider
14. Do you use sign language to speak to hearing people?	NEW				
15. In the last 6 months, how often did you have a hard time speaking with your personal doctor because you use sign language?	NEW				
16. Do you have difficulty speaking or speak slowly because of a health condition?	NEW				

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
17. In the last 6 months, how often did you have a hard time speaking with your personal doctor because you have difficulty speaking or speak slowly?	NEW				
18. In the last 6 months, did you and your personal doctor talk about healthy eating habits?	Modified			HP 3	AHPPPAL simplified to a single-barreled question
19. In the last 6 months, did you and your personal doctor talk about the exercise or physical activity you get?				HP 4	
20. In the last 6 months, did you and your personal doctor talk about things in your life that worry you or cause you stress?				HP 5	
21. In the last 6 months, did your personal doctor ever ask you whether there was a period of time when you felt sad, empty or depressed?				HP 6	
22. In the last 6 months, how often did your personal doctor show respect for what you had to say?			13		
23. 17. In the last 6 months, how often did your personal doctor spend enough time with you?			14		
24. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care. In the last 6 months, did your personal doctor suggest you see a specialist for a particular problem?				PK1	
25. In the last 6 months, how often did your personal doctor seem informed and up-to-date about the care you got from specialists?				OHP 2	
26. Choices for your treatment or health care can include choices about medicine, surgery, therapy, or procedures. In the last 6 months, did your personal doctor tell you there was more than one choice for your treatment or health care?				H2	

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
27. In the last 6 months, how often did your personal doctor talk with you about the pros and cons of each choice for your treatment or health care?				H3	
28. In the last 6 months, when there was more than one choice for your treatment or health care, how often did your personal doctor ask which choice you thought was better for you?	Modified			H4	AHPPPAL response scale is modified to "how often"
29. In the last 6 months, did your personal doctor order a blood test, x-ray or other test for you?					21
30. In the last 6 months, when your personal doctor ordered a blood test, x-ray or other test for you, how often did you get those results?	Modified				22 AHPPPAL does not specify that followup was directly from doctor's office.
31. Using any number from 0 to 10, where 0 is the worst personal doctor and 10 is the best personal doctor possible, what number would you use to rate your personal doctor?			15		
<b>Your Personal Doctor's Office</b>					
Some places have barriers that prevent you from entering or moving around your doctor's office or clinic. Barriers include: the only entrance has stairs; the doorway is too narrow for a wheelchair; the door handles are hard to use.					
32. In the last 6 months, were there barriers that made it hard for you to <u>get into</u> your personal doctor's office?	NEW				Untested Impaired Mobility question.
33. In the last 6 months, were there barriers that made it hard for you to <u>move around inside</u> the exam rooms at your personal doctor's office?	NEW				Untested Impaired Mobility question.
34. In the last 6 months, when you visited your personal doctor's office, how often were you able to get on the examination table when you needed to?	Modified			IM 2	AHPPPAL modified in light of cognitive testing

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
35. In the last 6 months, when you visited your personal doctor, how often did someone weigh you?				IM 3	Outcome of concern is "never" being weighed.
36. In the last 6 months, when you visited your personal doctor's office, did you try to use the restroom?				IM 4	
37. In the last 6 months, how often was it easy to move around in this restroom?	Modified			IM 5	AHPPPAL simplified question to refer to restroom used
<b>Getting Health Care from Specialists</b>					
38. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care. In the last 6 months, did you try to make any appointments to see a specialist?			16		
39. In the last 6 months, how often was it easy to get appointments with specialists?			17		
40. In the last 6 months, how many specialists did you see? Please count the number of different specialists, not the number of visits.	Modified		18		AHPPPAL distinguishes between # of different specialists, not # of visits, because we believe this is a more direct measure of comorbidities and complexity
41. In the last 6 months, how often did the specialists you saw seem to know the important information about your medical history?				SC6	
42. We want to know your rating of the specialist you saw most often in the last 6 months. Using any number from 0 to 10, where 0 is the worst specialist possible and 10 is the best specialist possible, what number would you use to rate the specialist?			19		

Yellow filled questions are screener questions.	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
43. A personal doctor is the one you would usually see if you need a checkup, want advice about a health problem, or get sick or hurt. Was the specialist you saw most often in the last 6 months also your personal doctor?				UT 2	
<b>Care Coordination</b>					
44. A Waiver Provider Case Manager is a nurse or social worker who knows all of your health and social needs, who helps you follow your doctors' instructions, and who helps you get the medical care you need. In the last 6 months, did you have a Waiver Provider Case Manager?	NEW				
45. In the past 6 months, how often did your Waiver Provider Case Manager help you get the care, services and medicines that you needed?	NEW				
46. In the last 6 months, how often did the Waiver Provider Case Manager seem to know the important information about your medical history?	NEW				
47. In the last 6 months, how often did your Waiver Provider Case Manager take into account what you wanted to do?	NEW				
48. Think about your Waiver Provider Case Manager. Using any number from 0 to 10, 0 is the worst Waiver Provider Case Manager possible and 10 is the best Waiver Provider Case Manager possible, what number would you use to rate your Waiver Provider Case Manager ?	NEW				
49. In the last 6 months, did you have more than one health-related case manager, at the same time?	NEW				
50. In the last 6 months, how often did all of them seem to know important information about your health and healthcare?	NEW				

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
<b>Behavioral Health Care</b>					
51. In the last 6 months, did you need medicine for a mental or emotional condition?	Modified				AHPPPAL separates out the medicine from the counseling, since these benefits may be administered separately and since people may need one or both.
52. In the last 6 months, how often was it easy to get the medicine that you needed?	NEW				
53. In the last 6 months, did you need any counseling for a mental or emotional condition?	Modified			MH 2	AHPPPAL drops "through your health plan" because of other providers.  AHPPPAL specifies counseling, only
54. In the last 6 months, how often was it easy to get the counseling that you needed?	Modified			MH 3	
55. Using any number from 0 to 10, where 0 is the worst counseling possible and 10 is the best counseling possible, what number would you use to rate all the counseling you received in the last 6 months?	Modified			MH 4	
<b>Leaving the Hospital</b>					
56. In the last 6 months, did you stay overnight in a hospital?	Modified			CC 18	
57. During your most recent overnight hospital stay, did any doctors, nurses or other hospital staff talk with you about your preferences for where you would go when you left the hospital?	NEW				
58. Thinking about your most recent hospital stay, did you understand your instructions on how to take care of yourself after leaving there?	NEW				
59. Thinking about your most recent hospital stay, did your hospital doctor prescribe medicine to be taken after you left?	NEW				

	AHPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
60. Did you understand the reasons for taking your medicine after leaving there?	NEW				
<b>Pain and Fatigue</b>					
61. In the last 6 months, did you have pain for more than 14 days in a row that was not the result of surgery?	Modified			IM 6	AHPPAL modified after cognitive testing.
62. In the last 6 months, how often did pain limit your ability to do the things you needed to do?	NEW				
63. In the last 6 months, did you and any doctor talk about different things you can do to help with your pain?	NEW				
64. In the last 6 months, did you have fatigue that did not go away with rest, for more than 30 days in a row?	Modified			IM 9	
65. In the last 6 months, how often did fatigue limit your ability to do the things you needed to do?	NEW				
66. In the last 6 months, did you and any doctor talk about different things you can do to help with your fatigue?	NEW				
<b>Reproductive Health</b>					
67. Are you sexually active?	NEW				
68. Would you like to be sexually active?	NEW				
69. In the last 6 months, did any doctor or nurse talk with you about things you can do to prevent sexually transmitted diseases (STDs) such as herpes or AIDS?	NEW				
70. Are you at the age when you could father or give birth to a baby?	NEW				
71. In the last 6 months, did you and any doctor or nurse talk about birth control or planning for a baby?	NEW				
<b>Health Information</b>					
72. In the last 6 months, did you need health information in a listening format such as a tape recording or TV show?	NEW				

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
73. How often did you get the information in the way you needed?	NEW				
<b>Prescription Medicines</b>					
74. In the last 6 months, did you get any new prescription medicines or refill a prescription for medicine?				PM1	AHPPPAL tagged with "for medicine" to exclude glasses and hearing aids, etc.
75. In the last 6 months, how often was it easy to get the medicine your doctor prescribed?	Modified			PM3	Modified since health plan doesn't always fill the Rx.
<b>Therapy and Medical Supplies</b>					
76. In the last 6 months, did you need physical or occupational therapy?				IM 11	
77. In the last 6 months, how often was it easy to get physical or occupational therapy through your health plan?				IM 6	AHPPPAL says "physical or occupational" rather than "this kind of"
78. "Medical supplies" include things most people use only once, like needles for shots, bags to collect urine, or feeding tubes. In the last 6 months, did you need medical supplies at home?	NEW				
79. In the last 6 months, how often was it easy to get the medical supplies you needed?	NEW				
<b>Mobility and Breathing Equipment</b>					
Mobility equipment includes things like a wheelchair, or walker. Breathing equipment includes things like an oxygen tank or suction machine.					
80. In the last 6 months, did you need any mobility or breathing equipment?	Modified			IM 15, CC9	
81. In the last 6 months, did you try to have your health plan get or replace mobility or breathing equipment?				IM 18, CC10	

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
82. In the last 6 months, how often was it easy to get your health plan to get or replace mobility or breathing equipment?				IM 19	
83. In the last 6 months, did you try to get your health plan to pay for repairs to mobility or breathing equipment?				IM 16	
84. In the last 6 months, how often was it easy to get your health plan to pay for repairs to mobility or breathing equipment?				IM 17	
<b>Transportation in the Last 6 Months</b>					
Your health plan helps with transportation to and from clinics or doctors' offices. Your health plan can send a bus, taxi or van, or give you fare vouchers, bus passes or tickets.					
85. In the last 6 months, did you contact your health plan to get help with transportation?				T 1	AHPPPAL uses "contact" instead of "phoned"
86. In the last 6 months, when you contacted your health plan to get help with transportation, how often did you get it?				T 2	
87. In the last 6 months, when your health plan scheduled a taxi or medical van to take you to or from a medical appointment, how often did the vehicle arrive on time?	Modified			T3	T 3 asks, Did the transportation "meet your needs."
88. How often were you able to get into the vehicle you needed?	Modified			T3	T 3 asks, Did the transportation "meet your needs."
<b>Your Everyday Life</b>					
89. In the last 6 months, how often were you able to participate in community and family activities as much as you wanted to?	NEW				
90. In the last 6 months, how often did most people treat you with courtesy and respect?	NEW				

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
91. In the last 6 months, how often were you able to discuss your worries with people close to you?	NEW				
92. In the last 6 months, how often were you able to do things in private when you wanted to?	NEW				
93. In the last 6 months, how often did you feel safe?	NEW				
94. In the last 6 months, how often were you involved as much as you wanted in making choices about your meals?	NEW				
95. In the last 6 months, how often did you believe your life has purpose?	NEW				
<b>Your Health and Abilities</b>					
96. In general, how would you rate your overall physical health?		28		26	
97. In general, how would you rate your overall mental or emotional health?				MH 1	
98. Are you deaf or do you have serious difficulty hearing?	ACS				
99. Are you blind or do you have serious difficulty seeing, even when wearing glasses?	ACS				
100. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?	ACS				
101. Because of a physical, mental, or emotional condition, do you have difficulty dressing or bathing?	ACS			CC 15	
102. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?	Modified			CC 16	
103. Has a doctor or teacher ever told you that you have a learning problem?	NEW				

	AHPPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
104. Has a doctor ever told you that you have bipolar disorder or schizophrenia?	NEW				
105. In the last 6 months, has a doctor told you that you have anxiety, depression, or explosive anger?	NEW				
106. In the last 6 months, how often were you able to walk for 10 minutes without stopping?	Modified			IM 20	10 minutes is less ambiguous than distance.
107. In the last 6 months, how often did you need assistance or use equipment to walk that long without stopping?				IM 21	
108. What is your age?		33			
109. Are you male or female?		34		P 1	
110. How many years of school or special education did you complete?	Modified	35			
None	NEW				Added because of cognitive testing.
1-8 years					
9-6 years, did not graduate					
1 or more years of special education high school or GED	NEW				Added because of cognitive testing.
trade school or technical degree	NEW				Added because of cognitive testing.
some college or 2-year degree					
4-year college degree					
more than 4 years of college					
111. Are you of Hispanic or Latino origin or descent?		36			
112. What is your race?	Modified	37			AHPPPAL says "check all that apply" other surveys say "Please mark one or more".

	AHPPAL	CAHPS HP 4.0 Adult Medicaid	CAHPS HP 4.0 Adult Supplement	CAHPS Clinician & Group Adult Primary Care	Comment
<i>Yellow filled questions are screener questions.</i>					
113. What language do you mainly speak at home?				13	
114. Did someone help you complete this survey?		38			
115. How and why did that person help you?		39			
Read the questions to me Wrote down the answers I gave Answered the questions for me Translated the questions into my language Helped in some other way (please print)					These responses will be expanded during cognitive testing of the proxy respondent version.

**Table 2. Demographic Characteristics of the Sampling Frame**

	PLAN							
	All		AF/NH Waiver		IEHP		PHP	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
<b>All</b>	10,571	100.0	318	100.0	5,789	100.0	4,464	100.0
<b>Language</b>								
English	7,562	71.5	282	88.7	3,089	53.4	4,191	93.9
Spanish	815	7.7	36	11.3	506	8.7	273	6.1
Unknown	2,194	20.8	0	0.0	2,194	37.9	0	0.0
<b>Sex</b>								
Female	4,076	38.6	200	62.9	1,992	34.4	1,884	42.2
Male	6,495	61.4	118	37.1	3,797	65.6	2,580	57.8
<b>Age</b>								
18 to 29	2,736	25.9	147	46.2	1,442	24.9	1,147	25.7
30 to 49	4,274	40.4	135	42.5	2,424	41.9	1,715	38.4
50 to 64	3,561	33.7	36	11.3	1,923	33.2	1,602	35.9
<b>Race/Ethnicity</b>								
Hispanic	2,317	21.9	81	25.5	1,625	28.1	611	13.7
Black, non-Hispanic	2,435	23.0	37	11.6	1,181	20.4	1,217	27.3
White, non-Hispanic	4,322	40.9	159	50.0	2,187	37.8	1,976	44.3
Not reported	956	9.0	12	3.8	588	10.2	356	8.0
Other	541	5.1	29	9.1	208	3.6	304	6.8

**Table 3. Demographic Characteristics of the Sample**

	All		PLAN					
			AF/NH Waiver		IEHP		PHP	
	Number	Percent	Number	Percent	Number	Percent	Number	Percent
<b>All</b>	2,527	100.0	318	100.0	1,343	100.0	866	100.0
<b>Language</b>								
English	1,446	57.2	282	88.7	467	34.8	697	80.5
Spanish	511	20.2	36	11.3	306	22.8	169	19.5
Unknown	570	22.6	0	0.0	570	42.4	0	0.0
<b>Sex</b>								
Female	1,409	55.8	118	37.1	832	62.0	459	53.0
Male	1,118	44.2	200	62.9	511	38.1	407	47.0
<b>Age</b>								
18 to 29	673	26.6	147	46.2	327	24.4	199	23.0
30 to 49	960	38.0	135	42.5	512	38.1	313	36.1
50 to 64	894	35.4	36	11.3	504	37.5	354	40.9
<b>Race/Ethnicity</b>								
Hispanic	778	30.8	81	25.5	491	36.6	206	23.8
Black, non-Hispanic	480	19.0	37	11.6	238	17.7	205	23.7
White, non-Hispanic	939	37.2	159	50.0	437	32.5	343	39.6
Not reported	217	8.6	12	3.8	133	9.9	72	8.3
Other	113	4.5	29	9.1	44	3.3	40	4.6

**Table 4. Demographic Distribution of Weighted and Unweighted Respondents**

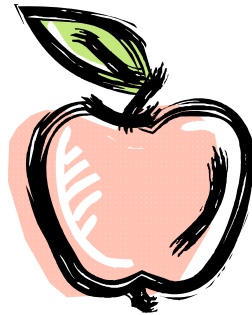
	Eligible Sample*	Completes	Response Rate	
			Unweighted	Weighted
<b>Total</b>	2,420	1,086	46.3	41.7
<b>Race/Ethnicity</b>				
Hispanic	747	375	51.6	47.0
Black, non-Hispanic	471	156	34.0	31.6
White, non-Hispanic	897	418	47.8	44.0
Not reported	203	93	48.0	46.3
Other	102	44	46.6	40.1
<b>Age</b>				
18 to 29	643	262	42.4	34.5
30 to 49	919	393	44.2	40.9
50 or 64	858	431	51.4	47.6
<b>Language</b>				
English	1,379	596	44.7	40.6
Spanish	486	273	57.8	57.6
Other	555	217	40.1	40.1
<b>Health Plan</b>				
IEHP	1,301	561	44.3	42.0
PHP	829	341	42.6	40.0
AF/NH Waiver	290	184	64.8	65.4

\*107 individuals in the sample were determined to be ineligible for study participation at the time of the interview.

**Table 5. Sample size required in each plan to detect the difference between the mean from one plan and the mean of other plans with 0.80 power at significance level of 0.05.**

Effect Size	2 plans or group practices	3 plans or group practices	4 plans or group practices	5 plans or group practices	10 plans or group practices	15 plans or group practices	20 plans or group practices
0.1 (i.e., a very small difference)	1570	1178	1047	982	873	841	827
0.2	393	295	262	246	219	211	207
0.3	175	131	117	110	97	94	92
0.4	99	74	66	62	55	53	52
0.5	63	48	42	40	35	34	34
0.6 (i.e., a big difference)	44	33	30	28	25	24	23

# Assessment of Health Plans and Providers by People with Activity Limitations



[English version]

*All information that would let someone identify you or your family will be kept private. <Name of fielding organization> will not share your personal information with anyone without your OK. You may choose to answer this survey or not. If you choose not to, this will not affect your <name of health insurer> benefits.*

*Your responses to this survey are completely private. Once you complete the survey, place it in the envelope that was provided, seal the envelope, and return the envelope to <Name of fielding organization>. It has already been addressed for you!*

*You may notice a number on the cover of this survey. This number is **only** used to let us know if you returned your survey so we don't have to send you reminders. If you want to know more about this study, please call <Name of fielding organization> toll-free at <Name of fielding organization> and ask for <pseudonym>.*

Omit this page when fielding the survey.

Several research papers about this instrument are being prepared for peer review during 2008. For questions about the use, analysis, or psychometric properties of the AHPPPAL, please contact Susan Palsbo, PhD, at 541-505-7591. For a copy in Spanish, contact Susan Palsbo, PhD, at 541-505-7591.

Funding for the development and validation of this instrument was provided by the US Department of Education/National Institute for Disability and Rehabilitation Research, # H133A040016. Additional funding was provided by the California HealthCare Foundation, # 07-1085.

This instrument is in the public domain.

## How to Answer the Questions in the Survey

Answer the questions by writing ✍ an “x” in the box (□) to the left of the answer you choose. For example, if you choose “yes”, it would be:

- Yes
- No

Sometimes you need to skip questions in the survey, depending on your answer. When this happens, you will see an arrow (→) to the right of the answer you choose, with a note that tells you what question to answer next, like this:

### 1. Do you have a personal doctor?

- Yes → **If Yes, go to Question 2**
- No → **If No, go to Question 3**

So, if you answer “Yes” for Question 1, you should go to Question 2. But if you answer “No”, for Question 1, you should skip over questions 2 and go directly to Question 3.

**Please turn to the next page to start the survey.**

## YOUR HEALTH CARE IN THE LAST 6 MONTHS

These questions ask about your own health care. Do not include care you got when you stayed overnight in a hospital. Do not include the times you went for dental care visits.

1. In the last 6 months, did you have an illness, injury, or condition that needed care right away in a clinic, emergency room, or doctor's office?

<sup>1</sup> Yes → If Yes, go to Question 2  
<sup>0</sup> No → If No, go to Question 3

2. In the last 6 months, when you needed care right away, how often did you get care as soon as you thought you needed?

<sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

3. In the last 6 months, not counting the times you needed care right away, did you make any appointments for your health care at a doctor's office or clinic?

<sup>1</sup> Yes → If Yes, go to Question 4  
<sup>0</sup> No → If No, go to Question 6

4. In the last 6 months, not counting the times you needed care right away, how often did you get an appointment for your health care at a doctor's office or clinic as soon as you thought you needed?

<sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

5. In the last 6 months, not counting the times you went to an emergency room, how many times did you go to a doctor's office or clinic to get health care for yourself?

<sup>0</sup> None  
<sup>1</sup> 1  
<sup>2</sup> 2  
<sup>3</sup> 3  
<sup>4</sup> 4  
<sup>5</sup> 5 to 9  
<sup>6</sup> 10 or more

6. Using any number from 0 to 10, where 0 is the worst health care possible and 10 is the best health care possible, what number would you use to rate all of your health care in the last 6 months?

<sup>0</sup> 0 Worst health care possible  
<sup>1</sup> 1  
<sup>2</sup> 2  
<sup>3</sup> 3  
<sup>4</sup> 4  
<sup>5</sup> 5  
<sup>6</sup> 6  
<sup>7</sup> 7  
<sup>8</sup> 8  
<sup>9</sup> 9  
<sup>10</sup> 10 Best health care possible

## YOUR PERSONAL DOCTOR

7. A personal doctor is the one you would usually see if you need a checkup, want advice about a health problem, or get sick or hurt.

Do you have a personal doctor?

- <sup>1</sup> Yes → If Yes, go to Question 2  
<sup>0</sup> No → If No, go to Question 32

8. How many months or years have you been going to your personal doctor?

- <sup>1</sup> Less than 6 months  
<sup>2</sup> At least 6 months but less than 1 year  
<sup>3</sup> At least 1 year but less than 2 years  
<sup>4</sup> At least 2 years but less than 5 years  
<sup>5</sup> 5 years or more

9. In the last 6 months, did you visit your personal doctor for care?

- <sup>1</sup> Yes → If Yes, go to Question 10  
<sup>0</sup> No → If No, go to Question 38

10. In the last 6 months, how often did your personal doctor explain things in a way that was easy to understand?

- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

11. In the last 6 months, how often did your personal doctor listen carefully to you?

- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

12. An interpreter is someone who repeats what one person says in a language used by another person.

In the last 6 months, did you need an interpreter to help you speak with your personal doctor?

- <sup>1</sup> Yes → If Yes, go to Question 13  
<sup>0</sup> No → If No, go to Question 14

13. In the last 6 months, when you needed an interpreter to help you speak with your personal doctor, how often did you get one?

- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

14. Do you use sign language to speak to hearing people?

- <sup>1</sup> Yes → If Yes, go to Question 15  
<sup>0</sup> No → If No, go to Question 16

15. In the last 6 months, how often did you have a hard time speaking with your personal doctor because you use sign language?

- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

16. Do you have difficulty speaking or do you speak slowly because of a health condition?
- <sup>1</sup> Yes → If Yes, go to Question 17  
<sup>0</sup> No → If No, go to Question 18
17. In the last 6 months, how often did you have a hard time speaking with your personal doctor because you have difficulty speaking or speak slowly?
- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always
18. In the last 6 months, did you and your personal doctor talk about healthy eating habits?
- <sup>1</sup> Yes  
<sup>0</sup> No
19. In the last 6 months, did you and your personal doctor talk about the exercise or physical activity you get?
- <sup>1</sup> Yes  
<sup>0</sup> No
20. In the last 6 months, did you and your personal doctor talk about things in your life that worry you or cause you stress?
- <sup>1</sup> Yes  
<sup>0</sup> No
21. In the last 6 months, did your personal doctor ask you whether there was a period of time when you felt sad, empty or depressed?
- <sup>1</sup> Yes  
<sup>0</sup> No
22. In the last 6 months, how often did your personal doctor show respect for what you had to say?
- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always
23. In the last 6 months, how often did your personal doctor spend enough time with you?
- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always
24. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care.
- In the last 6 months, did your personal doctor suggest you see a specialist for a particular problem?
- <sup>1</sup> Yes → If Yes, go to Question 25  
<sup>0</sup> No → If No, go to Question 26

25. In the last 6 months, how often did your personal doctor seem informed and up-to-date about the care you got from specialists?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

26. Choices for your treatment or health care can include choices about medicine, surgery, therapy, or procedures.

In the last 6 months, did your personal doctor tell you there was more than one choice for your treatment or health care?

- <sup>1</sup> Yes → If Yes, go to Question 27
- <sup>0</sup> No → If No, go to Question 29

27. In the last 6 months, how often did your personal doctor talk with you about the pros and cons of each choice for your treatment or health care?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

28. In the last 6 months, when there was more than one choice for your treatment or health care, how often did your personal doctor ask which choice you thought was better for you?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

29. In the last 6 months, did your personal doctor order a blood test, x-ray or other test for you?

- <sup>1</sup> Yes → If Yes, go to Question 30
- <sup>0</sup> No → If No, go to Question 31

30. In the last 6 months, when your personal doctor ordered a blood test, x-ray or other test for you, how often did you get those results?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

31. Using any number from 0 to 10, where 0 is the worst personal doctor and 10 is the best personal doctor possible, what number would you use to rate your personal doctor?

- <sup>0</sup> 0 Worst personal doctor possible
- <sup>1</sup> 1
- <sup>2</sup> 2
- <sup>3</sup> 3
- <sup>4</sup> 4
- <sup>5</sup> 5
- <sup>6</sup> 6
- <sup>7</sup> 7
- <sup>8</sup> 8
- <sup>9</sup> 9
- <sup>10</sup> 10 Best personal doctor possible

## YOUR PERSONAL DOCTOR'S OFFICE

Some places have barriers that prevent you from entering or moving around your doctor's office or clinic. Barriers include: the only entrance has stairs; the doorway is too narrow for a wheelchair; the door handles are hard to use.

32. In the last 6 months, were there barriers that made it hard for you to get into your personal doctor's office?

<sup>1</sup> Yes

<sup>0</sup> No

33. In the last 6 months, were there barriers that made it hard for you to move around inside the exam rooms at your personal doctor's office?

<sup>1</sup> Yes

<sup>0</sup> No

34. In the last 6 months, when you visited your personal doctor, how often were you able to get on the examination table when you needed to?

<sup>1</sup> Never

<sup>2</sup> Sometimes

<sup>3</sup> Usually

<sup>4</sup> Always

35. In the last 6 months, when you visited your personal doctor, did someone weigh you?

<sup>1</sup> Never

<sup>2</sup> Sometimes

<sup>3</sup> Usually

<sup>4</sup> Always

36. In the last 6 months, when you visited your personal doctor's office, did you try to use the restroom?

<sup>1</sup> Yes → If Yes, go to Question 37

<sup>0</sup> No → If No, go to Question 38

37. In the last 6 months, how often was it easy to move around in this restroom?

<sup>1</sup> Never

<sup>2</sup> Sometimes

<sup>3</sup> Usually

<sup>4</sup> Always

## GETTING HEALTH CARE FROM SPECIALISTS

When you answer the next questions, do not include dental visits or care you got when you stayed overnight in a hospital.

38. Specialists are doctors like surgeons, heart doctors, allergy doctors, skin doctors, and other doctors who specialize in one area of health care.

In the last 6 months, did you try to make any appointments to see a specialist?

<sup>1</sup> Yes → If Yes, go to Question 39

<sup>0</sup> No → If No, go to Question 40

39. In the last 6 months, how often was it easy to get appointments with specialists?

<sup>1</sup> Never

<sup>2</sup> Sometimes

<sup>3</sup> Usually

<sup>4</sup> Always

40. In the last 6 months, how many specialists did you see? Please count the number of different specialists, not the number of visits.

- <sup>0</sup> None →If None, go to Question 44
- <sup>1</sup> 1 specialist
- <sup>2</sup> 2
- <sup>3</sup> 3
- <sup>4</sup> 4
- <sup>5</sup> 5 or more specialists

41. In the last 6 months, how often did the specialists you saw seem to know the important information about your medical history?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

42. We want to know your rating of the specialist you saw most often in the last 6 months. Using any number from 0 to 10, where 0 is the worst specialist possible and 10 is the best specialist possible, what number would you use to rate the specialist?

- <sup>0</sup> 0 Worst specialist possible
- <sup>1</sup> 1
- <sup>2</sup> 2
- <sup>3</sup> 3
- <sup>4</sup> 4
- <sup>5</sup> 5
- <sup>6</sup> 6
- <sup>7</sup> 7
- <sup>8</sup> 8
- <sup>9</sup> 9
- <sup>10</sup> 10 Best specialist possible

43. A personal doctor is the one you would usually see if you need a checkup, want advice about a health problem, or get sick or hurt. Was the specialist you saw most often in the last 6 months also your personal doctor?

- <sup>1</sup> Yes
- <sup>0</sup> No – my personal doctor is not a specialist
- <sup>2</sup> No – I do not have a personal doctor

### CARE COORDINATION

44. A <site term for Case Manager> is a nurse or social worker who knows all of your health and social needs, who helps you follow your doctors' instructions, and who helps you get the medical care you need.

In the last 6 months, did you have a <site term for Case Manager>?

- <sup>1</sup> Yes →If Yes, go to Question 45
- <sup>0</sup> No → If No, go to Question 51

45. In the past 6 months, how often did your <site term for Case Manager> help you get the care, services and medicines that you needed?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

46. In the last 6 months, how often did the <site term for Case Manager> seem to know the important information about your medical history?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

47. In the last 6 months, how often did your <site term for Case Manager> take into account what you wanted to do?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

48. Think about your <site term for Case Manager>. Using any number from 0 to 10, 0 is the worst <site term for Case Manager> possible and 10 is the best <site term for Case Manager> possible, what number would you use to rate your <site term for Case Manager> ?

- <sup>0</sup> 0 Worst possible <site term for Case Manager>
- <sup>1</sup> 1
- <sup>2</sup> 2
- <sup>3</sup> 3
- <sup>4</sup> 4
- <sup>5</sup> 5
- <sup>6</sup> 6
- <sup>7</sup> 7
- <sup>8</sup> 8
- <sup>9</sup> 9
- <sup>10</sup> 10 Best possible <site term for Case Manager>

49. In the last 6 months, did you have more than one health-related case manager, at the same time?

- <sup>1</sup> Yes → If Yes, go to Question 50
- <sup>0</sup> No → If No, go to Question 51

50. In the last 6 months, how often did all of them seem to know important information about your health and healthcare?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

### BEHAVIORAL HEALTH CARE

51. In the last 6 months, did you need medicine for a mental or emotional condition?

- <sup>1</sup> Yes → If Yes, go to Question 52
- <sup>0</sup> No → If No, go to Question 53

52. In the last 6 months, how often was it easy to get the medicine that you needed?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

53. In the last 6 months, did you need any counseling for a mental or emotional condition?

- <sup>1</sup> Yes → If Yes, go to Question 54
- <sup>0</sup> No → If No, go to Question 56

54. In the last 6 months, how often was it easy to get the counseling that you needed?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

55. Using any number from 0 to 10, where 0 is the worst counseling possible and 10 is the best counseling possible, what number would you use to rate all the counseling you received in the last 6 months?

- <sup>0</sup> 0 Worst counseling possible
- <sup>1</sup> 1
- <sup>2</sup> 2
- <sup>3</sup> 3
- <sup>4</sup> 4
- <sup>5</sup> 5
- <sup>6</sup> 6
- <sup>7</sup> 7
- <sup>8</sup> 8
- <sup>9</sup> 9
- <sup>10</sup> 10 Best counseling possible

### LEAVING THE HOSPITAL

56. In the last 6 months, did you stay overnight in a hospital?

- <sup>1</sup> Yes → If Yes, go to Question 57
- <sup>0</sup> No → If No, go to Question 61

57. During your most recent overnight hospital stay, did any doctors, nurses or other hospital staff talk with you about your preferences for where you would go when you left the hospital?

- <sup>1</sup> Yes
- <sup>0</sup> No

58. Thinking about your most recent hospital stay, did you understand your instructions on how to take care of yourself after leaving there?

- <sup>1</sup> Yes
- <sup>0</sup> No

59. Thinking about your most recent hospital stay, did your hospital doctor prescribe medicine to be taken after you left?

- <sup>1</sup> Yes → If Yes, go to Question 60
- <sup>0</sup> No → If No, go to Question 61

60. Did you understand the reasons for taking your medicine after leaving there?

- <sup>1</sup> Yes
- <sup>0</sup> No

### PAIN and FATIGUE

61. In the last 6 months, did you have pain for more than 14 days in a row that was not the result of surgery?

- <sup>1</sup> Yes → If Yes, go to Question 62
- <sup>0</sup> No → If No, go to Question 64

## REPRODUCTIVE HEALTH

62. In the last 6 months, how often did pain limit your ability to do the things you needed to do?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

63. In the last 6 months, did you and any doctor talk about different things you can do to help with your pain?

- <sup>1</sup> Yes
- <sup>0</sup> No

64. In the last 6 months, did you have fatigue that did not go away with rest, for more than 30 days in a row?

- <sup>1</sup> Yes → If Yes, go to Question 65
- <sup>0</sup> No → If No, go to Question 67

65. In the last 6 months, how often did fatigue limit your ability to do the things you needed to do?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

66. In the last 6 months, did you and any doctor talk about different things you can do to help with your fatigue?

- <sup>1</sup> Yes
- <sup>0</sup> No

67. Are you sexually active?

- <sup>1</sup> Yes → If Yes, go to Question 69
- <sup>0</sup> No → If No, go to Question 68

68. Would you like to be sexually active?

- <sup>1</sup> Yes → If Yes, go to Question 69
- <sup>0</sup> No → If No, go to Question 72

69. In the last 6 months, did any doctor or nurse talk with you about things you can do to prevent sexually transmitted diseases (STDs) such as herpes or AIDS?

- <sup>1</sup> Yes
- <sup>0</sup> No

70. Are you at the age when you could father or give birth to a baby?

- <sup>1</sup> Yes → If Yes, go to Question 71
- <sup>0</sup> No → If No, go to Question 72

71. In the last 6 months, did you and any doctor or nurse talk about birth control or planning for a baby?

- <sup>1</sup> Yes
- <sup>0</sup> No

## HEALTH INFORMATION

72. In the last 6 months, did you need health information in a listening format, such as a tape recording or TV show?

<sup>1</sup> Yes → If Yes, go to Question 73

<sup>0</sup> No → If No, go to Question 74

73. How often did you get the information in the way you needed?

<sup>1</sup> Never

<sup>2</sup> Sometimes

<sup>3</sup> Usually

<sup>4</sup> Always

## PRESCRIPTION MEDICINES

74. In the last 6 months, did you get any new prescription medicines or refill a prescription for medicine?

<sup>1</sup> Yes → If Yes, go to Question 75

<sup>0</sup> No → If No, go to Question 76

75. In the last 6 months, how often was it easy to get the medicine your doctor prescribed?

<sup>1</sup> Never

<sup>2</sup> Sometimes

<sup>3</sup> Usually

<sup>4</sup> Always

## THERAPY and MEDICAL SUPPLIES

76. In the last 6 months, did you need physical or occupational therapy?

<sup>1</sup> Yes → If Yes, go to Question 77

<sup>0</sup> No → If No, go to Question 78

77. In the last 6 months, how often was it easy to get physical or occupational therapy through your health plan?

<sup>1</sup> Never

<sup>2</sup> Sometimes

<sup>3</sup> Usually

<sup>4</sup> Always

78. “Medical supplies” include things most people use only once, like needles for shots, bags to collect urine, or feeding tubes. In the last 6 months, did you need medical supplies at home?

<sup>1</sup> Yes → If Yes, go to Question 79

<sup>0</sup> No → If No, go to Question 80

79. In the last 6 months, how often was it easy to get the medical supplies you needed?

<sup>1</sup> Never

<sup>2</sup> Sometimes

<sup>3</sup> Usually

<sup>4</sup> Always

## MOBILITY and BREATHING EQUIPMENT

Mobility equipment includes things like a wheelchair or walker. Breathing equipment includes things like an oxygen tank or suction machine.

80. In the last 6 months, did you need any mobility or breathing equipment?

- <sup>1</sup> Yes → If Yes, go to Question 81  
<sup>2</sup> No → If No, go to Question 85

81. In the last 6 months, did you try to have your health plan get or replace mobility or breathing equipment?

- <sup>1</sup> Yes → If Yes, go to Question 82  
<sup>0</sup> No → If No, go to Question 83

82. In the last 6 months, how often was it easy to get your health plan to get or replace mobility or breathing equipment?

- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

83. In the last 6 months, did you try to get your health plan to pay for repairs to mobility or breathing equipment?

- <sup>1</sup> Yes → If Yes, go to Question 84  
<sup>0</sup> No → If No, go to Question 85

84. In the last 6 months, how often was it easy to get your health plan to pay for repairs to mobility or breathing equipment?

- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

## TRANSPORTATION

Your health plan helps with transportation to and from clinics or doctors' offices. Your health plan can send a bus, taxi or van, or give you fare vouchers, bus passes or tickets.

85. In the last 6 months, did you contact your health plan to get help with transportation?

- <sup>1</sup> Yes → If Yes, go to Question 86  
<sup>0</sup> No → If No, go to Question 89

86. In the last 6 months, when you contacted your health plan to get help with transportation, how often did you get it?

- <sup>1</sup> Never → If Never, go to Question 89  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

87. In the last 6 months, when your health plan scheduled a taxi or medical van to take you to or from a medical appointment, how often did the vehicle arrive on time?

- <sup>1</sup> Never  
<sup>2</sup> Sometimes  
<sup>3</sup> Usually  
<sup>4</sup> Always

**88. How often were you able to get into the vehicle you needed?**

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

**93. In the last 6 months, how often did you feel safe?**

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

### YOUR EVERYDAY LIFE

**89. In the last 6 months, how often were you able to participate in community and family activities as much as you wanted to?**

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

**90. In the last 6 months, how often did most people treat you with courtesy and respect?**

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

**91. In the last 6 months, how often were you able to discuss your worries with people close to you?**

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

**92. In the last 6 months, how often were you able to do things in private when you wanted to?**

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

**94. In the last 6 months, how often were you involved as much as you wanted in making choices about your meals?**

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

**95. In the last 12 months, how often did you believe your life has purpose?**

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

### YOUR HEALTH and ABILITIES

**96. In general, how would you rate your overall physical health?**

- <sup>1</sup> Excellent
- <sup>2</sup> Very good
- <sup>3</sup> Good
- <sup>4</sup> Fair
- <sup>5</sup> Poor

**97. In general, how would you rate your overall mental or emotional health?**

- <sup>1</sup> Excellent
- <sup>2</sup> Very good
- <sup>3</sup> Good
- <sup>4</sup> Fair
- <sup>5</sup> Poor

98. Are you deaf or do you have serious difficulty hearing?

- <sup>1</sup> Yes
- <sup>0</sup> No

99. Are you blind or do you have serious difficulty seeing, even when wearing glasses?

- <sup>1</sup> Yes
- <sup>0</sup> No

100. Because of a physical, mental, or emotional condition, do you have serious difficulty concentrating, remembering, or making decisions?

- <sup>1</sup> Yes
- <sup>0</sup> No

101. Because of a physical, mental, or emotional condition, do you have difficulty dressing or bathing?

- <sup>1</sup> Yes
- <sup>0</sup> No

102. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping?

- <sup>1</sup> Yes
- <sup>0</sup> No

103. Has a doctor or teacher ever told you that you have a learning problem?

- <sup>1</sup> Yes
- <sup>0</sup> No

104. Has a doctor ever told you that you have bipolar disorder or schizophrenia?

- <sup>1</sup> Yes
- <sup>0</sup> No
- <sup>2</sup> Not sure

105. In the last 6 months, has a doctor told you that you have anxiety, depression, or explosive anger?

- <sup>1</sup> Yes
- <sup>0</sup> No
- <sup>2</sup> Not sure

106. In the last 6 months, how often were you able to walk for 10 minutes without stopping?

- <sup>1</sup> Never → If Never, go to Question 108
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

107. In the last 6 months, how often did you need assistance or use equipment to walk that long without stopping?

- <sup>1</sup> Never
- <sup>2</sup> Sometimes
- <sup>3</sup> Usually
- <sup>4</sup> Always

## ABOUT YOU

### 108. What is your age?

- <sup>1</sup> 18 to 24 years old
- <sup>2</sup> 25 to 34 years old
- <sup>3</sup> 35 to 44 years old
- <sup>4</sup> 45 to 54 years old
- <sup>5</sup> 55 to 64 years old
- <sup>6</sup> 65 to 74 years old
- <sup>7</sup> 75 years or older

### 109. Are you male or female?

- <sup>1</sup> Male
- <sup>2</sup> Female

### 110. How many years of school or special education did you complete? *Mark all that apply.*

- <sup>0</sup> None
- <sup>1</sup> 1 to 8 years
- <sup>2</sup> 9 to 12 years but did not graduate
- <sup>3</sup> 1 or more years of special education
- <sup>4</sup> High school graduate or GED
- <sup>5</sup> Trade school or technical degree
- <sup>6</sup> Some college or 2-year degree
- <sup>7</sup> 4-year college degree
- <sup>8</sup> More than 4 years of college

### 111. Are you of Hispanic or Latino origin or descent?

- <sup>1</sup> Yes, Hispanic or Latino
- <sup>2</sup> No, not Hispanic or Latino

### 112. What is your race? *Mark all that apply.*

- <sup>1</sup> White
- <sup>2</sup> Black or African-American
- <sup>3</sup> Asian
- <sup>4</sup> Native Hawaiian or other Pacific Islander
- <sup>5</sup> American Indian or Alaska Native
- <sup>6</sup> Other (please print):  
\_\_\_\_\_

### 113. What language do you mainly speak at home?

- <sup>1</sup> English
- <sup>2</sup> Spanish
- <sup>3</sup> Some other language (please print): \_\_\_\_\_

### 114. Did someone help you complete this survey?

- <sup>1</sup> Yes → If Yes, go to Question 115
- <sup>0</sup> No → Thank you for completing this survey!

### 115. How did that person help you? *Mark all that apply.*

- <sup>1</sup> Read the questions to me (*omit for phone surveys*)
- <sup>2</sup> Wrote down the answers I gave (*omit for phone surveys*)
- <sup>5</sup> Answered the questions for me
- <sup>7</sup> Translated the questions into my language.
- <sup>8</sup> Helped in some other way  
(Please print). \_\_\_\_\_

***Thanks for completing this survey!***

