

**The Home and Community-Based Service
(HCBS) Experience Survey**

Part A

Justification and Supporting Statement

CMS- 10389

OMB CONTROL NUMBER

0938-NEW

SEPTEMBER 19, 2012

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Supporting Statement – Part A

Supporting Statement for Paperwork Reduction Act Submissions

A. Background

The Center for Medicaid and CHIP Services (CMCS) is responsible for the oversight of and payment for Medicaid home and community-based services (HCBS), which enable chronically ill and disabled Medicaid beneficiaries to receive care at home instead of being institutionalized. The number of older adults and people with disabilities who receive Medicaid-funded HCBS has increased appreciably in the last decade. HCBS programs serve beneficiaries with a broad range of severe physical, mental, and developmental conditions, through a wide array of providers. These long-term care services complement acute-care services, to maintain individual health and quality of life and enable this population to live in the community rather than an institution. Data have illustrated the health disparities experienced by people with disabilities; however, relatively little is known about their specific experiences with HCBS programs. As the primary funder of HCBS, CMS is seeking a mechanism to measure HCBS experience and outcomes. HCBS outcome measures based on individual experience are critical on several fronts, including public reporting, quality improvement and furthering comparative effectiveness research.

To calculate such measures, CMCS perceives the need for an experience-of-care survey aimed specifically at assessing HCBS programs. CMCS has made available to states an existing survey of its own design for several years, which it wishes to replace with a new survey, designed to align with the Agency for Healthcare Research and Quality's (AHRQ) Consumer Assessment of Healthcare Providers and Systems (CAHPS®) project. CAHPS is a family of surveys assessing patient experience with a variety of healthcare settings and services. CAHPS tools provide a standard methodology for benchmarking the performance of health care providers, using data obtained from patients and other consumers. CMS's goal is to test a new HCBS Experience Survey that can be adopted as a member of the CAHPS family of instruments, because the CAHPS imprimatur and standards will substantially improve the acceptability and the value of the HCBS survey to CMS, state Medicaid agencies, and HCBS providers. Accordingly, CMCS is proposing to field test a new HCBS experience-of-care survey that will conform to CAHPS principles and standards

The goal of this survey is to provide standard performance metrics for HCBS programs that are applicable to all populations served by these programs, including people with physical disabilities, cognitive disabilities, intellectual impairments, and/or disabilities due to mental illness. The assessment will enable HCBS programs to identify areas in which quality can be improved and provide CMCS, state Medicaid programs, consumers and their families, consumer advocacy organizations, and other stakeholders with comparisons across HCBS programs. This survey is intended to gather direct feedback from participants in Medicaid HCBS programs, operated by

individual states, about their experiences with services and supports. It is these programs, rather than the providers that deliver individual services, that are the intended unit of analysis. While several other participant surveys have been developed and tested and are in current use with HCBS recipients in various states, none have the ability to provide comparable information on program participants across the spectrum of disability and federally-funded services.

Survey responses will be compiled to develop quality measures at the program level. The goal for these measures is to enable the federal and state governments to expand quality improvement to encompass individual quality of life and outcome measures, across HCBS populations. Such measures will support exploration of the impact of program services, benchmarking, and identification of best practices. In addition, triangulation of new individual-level measures with systems-level measures derived from extant administrative data will provide a more comprehensive assessment of HCBS quality. CMS is seeking such measures for the purposes of quality improvement, public reporting and national comparisons. CMS anticipates that survey use will be optional for states operating HCBS programs.

B. Justification

1. *Need and Legal Basis*

Section 2701 under Subtitle I (Improving the Quality of Medicaid for Patients and Providers) of the Affordable Care Act requires the Secretary of Health and Human Services to develop an initial core set of health care quality measures for adults eligible for benefits under Medicaid (see Attachment A). The Secretary must also establish a Medicaid Quality Measurement Program for Adult Quality Measures (AQMP) after the release of the recommended core set. The law specifies contracts and grants should be in a similar manner to CHIPRA.

The Quality Measurement activity is the core element in implementation of this section of statute. CMS will work in collaboration with the Agency for Healthcare Research and Quality (AHRQ) through an Intra-Agency Agreement to identify an initial core set of standardized quality measures for adults enrolled in the Medicaid Program.

CMS will subsequently develop an Adult Quality Measures Program. CMS will utilize contractual and grant mechanisms for the development, testing, validation and management of quality measures for adult Medicaid populations. CMS will report state-specific quality of care measures applied under Medicaid. CMS' intent is to eventually include measures from the Home and Community-Based Services experience of care survey in the Adult Quality Measures Program.

2. *Information Users*

This study is a one-time pilot field test involving individuals who receive HCBS from Medicaid programs. The field test to be conducted under this request will be done for the following purposes:

- a) To assess survey methodology – to determine how well a face-to-face survey and telephone survey performs with individuals who receive HCBS services.
- b) Psychometric Analysis – to provide information for the revision and shortening of the survey based on the assessment of the reliability and construct validity of survey items and composites.
- c) Case mix adjustment analysis – Assess the variables that may be considered as case mix adjusters.
- d) Response bias analysis – to determine if there are differences between respondents and non-respondents on select demographic and program-related characteristics.

These preliminary research activities are not required by regulation, and will not be used by CMS to regulate or sanction its customers. They will be entirely voluntary and the confidentiality of respondents and their responses will be preserved.

The information collected will be used to revise and test the survey instrument described in the Background. Attachment B includes two versions of the survey (Spanish and English) and Attachment C has the introductory information. The end result will be an improvement in information collection instruments and in the quality of data collected, a reduction or minimization of respondent burden, increased agency efficiency, and improved responsiveness to the public. Following the field test, CMS will seek approval from the CAHPS consortium for the HCBS Experience Survey to be a new addition to the CAHPS® family of surveys.

3. *Use of Information Technology*

Testing will be done in both face-to-face and telephone survey modes, which are suggested for other CAHPS® surveys with similar populations. Many respondents are expected to have significant chronic conditions, have significant cognitive limitations, or have limited or no familiarity with electronic information technology. The use of automated, electronic, mechanical, or other technological collection techniques or other forms of information technology will likely increase—rather than decrease—the burden on potential respondents. In addition, these technologies would likely decrease response rates. Experience with a similar, previous CAHPS survey, the CAHPS survey for long stay nursing home residents, shows that face-to-face data collection works well for respondents, vendors, and service organizations. To understand if telephone mode is feasible, we are including a mode study. In this case, we want to test the feasibility of conducting the survey over the phone, similar to the majority of CAHPS surveys that offer this mode.

4. *Duplication of Efforts*

Some Medicaid waiver programs already carry out their own consumer experience of services surveys. These diverse surveys do not allow for comparisons across HCBS programs in different states and are not typically tested for validity or reliability. In some cases the data

are collected from HCBS staff, thus potentially biasing the results. Making comparative performance information available to the Medicaid HCBS programs can help programs determine and focus their quality improvement efforts and can create incentives for HCBS programs to improve the services they provide. In addition, for states that have multiple waiver programs serving similar populations, public reporting can help consumers and the state make comparisons across HCBS programs within a single state.

5. *Small Businesses*

This request does not involve small businesses.

6. *Less Frequent Collection*

This is a one-time pilot field test data collection.

7. *Special Circumstances*

This request is consistent with the general information collection guidelines of 5 CFR 1320.5(d)(2). No special circumstances apply.

This pilot field test is designed to assess a draft survey instrument, not to generalize the results to a population. The data will be used only to assess the quality of the items in the instrument. It will not be used to describe or regulate agencies or to set policy.

Field test respondents will be informed that their responses are private under the provisions of the Privacy Act prior to data collection, and that their individual responses will not be shared with direct services providers or other program staff. However, all participants will be notified that suspected abuse, neglect, or exploitation will be reported to Adult Protection or a comparable entity, and respondents will be informed of this requirement prior to the interview.

8. *Federal Register/Outside Consultation*

Similar to other CAHPS[®] survey development efforts, CMS is working with a variety of outside organizations and persons to develop the HCBS experience survey. Truven Health Analytics is being funded to perform primary survey development, with subcontracting support from The American Institutes for Research and the RAND Corporation.

In addition, the survey team has hosted three technical expert panel meetings to date on survey content and implementation issues; the first was held in Baltimore, MD on June 15, 2010 and the second two via conference calls on January 25, 2011 and April 24, 2012. Expert panel members at these meetings included representatives of the following agencies of state and federal governments, professional, nonprofit and private sector organizations:

Disability Rights Network of Pennsylvania
ADAPT
RAND Corporation
West Virginia Bureau for Medical Services
Florida Agency for Person with Disabilities
Self-Advocates Becoming Enabled (SABE)
National Alliance on Mental Illness (NAMI)
AARP
National Association of State Mental Health Program Directors (NASMHPD)
National Association of State Directors of Developmental Disability Services (NASDDDS)
George Mason University
Baruch College, City University of New York
Texas Department of Aging and Disability Services
University of Massachusetts Medical School
National Association of State Units on Aging and Disability (NASUAD)
National Association of State Medicaid Directors (NASMD)
Colorado Department of Healthcare Policy
National Association of State Head Injury Administrators (NASHIA)

In addition to formal Expert Panel meetings, the development team seeks feedback informally from members of this advisory group, on a periodic basis.

9. *Payments/Gifts to Respondents*

No payments or gifts will be given to respondents.

10. *Confidentiality*

Individuals and organizations will be assured of the privacy of their replies under Section 934(c) of the Public Health Service Act, 42 USC 299c-3(c). They will be told the purposes for which the information is collected and that, in accordance with this statute, any identifiable information about them will not be used or disclosed for any other purpose.

Individuals and organizations contacted will be further assured of the privacy of their replies under 42 U.S.C. 1306, and 20 CFR 401 and 4225 U.S.C.552a (Privacy Act of 1974), and OMB Circular No.A-130. In instances where respondent identity is needed, the information collection will fully comply with all respects of the Privacy Act.

AIR will obtain HIPAA waiver from the AIR Institutional Review Board to enable state Medicaid agencies to share contact information as part of the sample.

Some states have mandatory reporting laws for vulnerable adults, including elders and

persons with disabilities, which require reporting of suspected abuse and neglect. Interviewer staff will comply with all relevant state statutes with regards to mandatory reporting. In addition, all suspected abuse and neglect will be reported in states without mandatory reporting regulations.

11. Sensitive Questions

There is a series of nine questions that ask if the respondent has been harmed in any way (e.g., hit/hurt, verbally abused, victim of theft). The purpose of these items is to assess whether such events are occurring and if respondents receive assistance and support from their HCBS program in addressing them. This information will help state Medicaid programs determine if adequate protections from harm are in place, a statutory requirement for some Medicaid HCBS programs. Prior to this series of questions, all respondents will be reassured that these are asked of all respondents. They will also be informed of any relevant statutes regarding the interviewer’s mandatory reporting responsibilities, as defined by each State and by AIR and the survey vendor’s IRBs.

12. Burden Estimates (Hours & Wages)

The estimated annual hour burden is as follows:

Survey administration time is estimated at 30 minutes, based on the written length of the survey and CMS’s experience with previous CAHPS® surveys of comparable length that were fielded with a similar, although not identical, population.

The Bureau of Labor Statistics reported the average hourly wage for private, non-farm workers in the United States was \$23.29 in February 2012. An estimate of \$23.50 per hour allows for inflation and represents a conservative estimate of the wages of the respondents, the majority of whom are likely not employed as a result of their age and/or disability.

Table 1. Estimated Annualized Burden Hours

| Form Name | Number of Respondents | Number of responses per respondent | Hours per response | Total Burden hours |
|---------------------|-----------------------|------------------------------------|--------------------|--------------------|
| Face-to-face survey | 15,620 | 1 | .5 | 7,810 |
| Telephone survey | 2,380 | 1 | .5 | 1,190 |
| Total | 18,000 | 1 | .5 | 9,000 |

Table 2. Estimated Annualized Cost Burden

| Form Name | Number of Respondents | Total Burden hours | Average Hourly Wage Rate* | Total Cost Burden |
|---------------------|-----------------------|--------------------|---------------------------|-------------------|
| Face-to-face survey | 15,620 | 7,810 | \$23.50 | \$183,535 |
| Telephone survey | 2,380 | 1,190 | \$23.50 | \$27,965 |
| Total | 18,000 | 9,000 | \$23.50 | \$211,500 |

*Based upon the average non-farm, private wages reported U.S. Department of Labor, Bureau of Labor Statistics for February 2012. (<http://www.bls.gov/news.release/empsit.nr0.htm>, Last viewed February 21, 2012.)

13. Capital Costs

Capital and maintenance costs include the purchase of equipment, computers or computer software or services, or storage facilities for records, as a result of complying with this data collection. There are no direct costs to respondents other than their time to participate in the study.

14. Cost to Federal Government

The total cost for the contracted service will be \$450,000 for the field test for labor hours, materials and supplies, overhead, and general and administrative costs and fees. The annual cost for CMS staff to oversee the project is \$2,282.84, including benefits, for a total 5-year project cost of \$11, 412. In addition, approximately \$900,000 in contracted costs will be incurred for development of the survey, training of vendors, conducting the survey, and analyzing the data.

15. Changes to Burden

This is a new collection of information.

16. Publication/Tabulation Dates

The purposes of this survey effort are to revise and shorten the HCBS experience survey, to assess the effectiveness of a face-to-face survey and telephone survey with this population, and to assess case mix adjustment approaches, as necessary. The data will be used internally by the design team in order to achieve these goals. States that participate in the field test will receive summary data for their programs; some may chose to make these data public independent of the field test.

Data collection for the field test is scheduled to begin in Fall 2012 by a CMS-selected vendor. Sampling and data collection will be conducted by the survey vendor working with the state programs.

As part of voluntary state participation, we will provide reports to each state presenting each program's performance. The survey vendor will adjust the data for mode of survey

administration, patient mix, and non-response, if necessary. We intend to present data from the project at one or more professional conferences. As time allows, we plan to write an article for a health services research journal. Potential journals include *The Gerontologist*, *Health Services Research*, and *Medical Care*.

We plan to use the following analytical techniques:

- Psychometric analysis using classical test theory to address item functioning, identification of composites, evaluation of the measurement properties of the final composite scales, and evaluation of individual and inter-unit reliability.
- Non-response analysis
- Investigation of potential case-mix adjusters.
- Methodological experiments to compare the modes of face-to-face and telephone administration.
- Comparison of Spanish and English surveys.

These are the standard analytic tasks for the development of CAHPS surveys and will use the same methods that have been used for other CAHPS surveys.

We expect to report data out at the end of 2012 and to publish articles in 2013.

17. Expiration Date

This collection does not lend itself to the displaying of an expiration date.

18. Certification Statement

We are not asking for any exceptions to the Certification for Paperwork Reduction Act Submissions (Item 19 on OMB Form 83-1).