National Indian Health Board



September 20, 2013

Martique Jones,
Deputy Director, Regulations Development Group
Office of Strategic Operations and Regulatory Affairs
Centers for Medicare and Medicaid Services
Room C4–26–05
7500 Security Boulevard
Baltimore, Maryland 21244–1850

Re: Comments on CMS-10493, Agency Information Collection Activities: Proposed Collection; Comment Request

Dear Ms. Jones,

I write on behalf of the National Indian Health Board¹ (NIHB) regarding the request for comments on CMS-10493 under the Paperwork Reduction Act of 1995 (PRA), published in Vol 78 of the Federal Register Number 140, on Monday, July 22, 2013 (FR Doc No: 2013-17476).

The notice describes the Nationwide Consumer Assessment of Healthcare Providers and Systems (DCAHPS) Survey for Adults in Medicaid and invites comments on (1) the necessity and utility of the proposed information collection for the proper performance of the agency's functions: (2) the accuracy of the estimated burden; (3) ways to enhance the quality, utility and clarity of the information to be collected; and (4) the use of automated collection techniques or other forms of

¹ Established 40 years ago, NIHB is an inter-Tribal organization that advocates on behalf of Tribal governments for the provision of quality health care to all American Indians and Alaska Natives. NIHB is governed by a Board of Directors consisting of a representative from each of the twelve Indian Health Service ("IHS") Areas. Each Area Health Board elects a representative to sit on the NIHB Board of Directors. In areas where there is no Area Health Board, Tribal governments choose a representative who communicates policy information and concerns of the Tribes in that area with NIHB. Whether Tribes operate their entire health care program through contracts or compacts with IHS under Public Law 93-638, the Indian Self-Determination and Education Assistance Act ("ISDEAA"), or continue to also rely on IHS for delivery of some, or even most, of their health care, NIHB is their advocate.



information technology to minimize the information collection burden. Our comments relate to items (1) and (3).

(1) The necessity and utility of the proposed information collection for the proper performance of the agency's functions

We agree with the intended goal of the DCAHPS Survey for Adults in Medicaid:

". . . to attain national and state-by-state estimates of adult Medicaid beneficiaries' access and experience and satisfaction with care across different financing and delivery models (e.g., managed care and fee-for-service) and population groups (e.g., beneficiaries with physical, mental or both physical and mental disabilities, dually eligible beneficiaries, all other beneficiaries."

We also agree with the stated intention that this survey will provide baseline information on

"...the experiences of low-income adults during the early stages of implementation of the Affordable Care Act provision that permits states to expand eligibility to adults with income below 138 percent of the federal poverty level who were not previously eligible."

We note that the survey includes a question to identify American Indians and Alaska Natives, as well as other ethnic groups, and we think this will be helpful to identify issues of access to care for AI/ANs who are enrolled in Medicaid, including Medicaid Expansion in states where it is available.

(3) Ways to enhance the quality, utility and clarity of the information to be collected

It appears that the survey is intended to compare the access to care and quality of care for fee-for-service and managed care plans. It is important to note that there are certain protections in the law that prohibit AI/AN from being automatically enrolled in Medicaid managed care plans. Most Tribes are located in remote, rural areas where there is not a strong managed care presence. Furthermore, there are several barriers that prohibit or discourage I/T/U from becoming providers in managed care networks. As a result of the circumstances, most AI/AN who are Medicaid recipients are in fee-for-service Medicaid programs. While this works well to assure that the I/T/U is compensated for the services that they provide to Medicaid enrollees, it may create problems accessing specialty medical care in some geographic areas where the number of specialists is limited and they are primarily accessed through managed care networks. This survey should be able to help assess the prevalence of problems with access to specialty medical care, if there is a sufficient sample of AI/AN included in the survey.

Conversely, when states receive a waiver or State Plan Amendment that allows them to enroll AI/AN in managed care plans, it is important to measure the outcomes in terms of access to primary care. We are particularly concerned about new proposals in which State Medicaid Programs would purchase health plans on the individual Exchange/Marketplace for the Medicaid Expansion population and/or some portion of the traditional Medicaid population. Federal regulations have failed to assure that the I/T/U will be in the networks of Qualified Health Plans (QHPs) and Multi State Plans (MSPs) offered on the individual Exchanges/Marketplaces. If State Medicaid programs are allowed to purchase closed panel HMO plans, then the I/T/U cannot get paid for the services that they provide to Medicaid beneficiaries. Unfortunately, the proposed questions do not collect data on whether Indian health providers are continuing to serve as providers of primary care, dental care, and mental health services for AI/AN enrolled in Medicaid (with or without payment from Medicaid). We therefore offer some recommendations below about how to revise the questions to capture this essential information.

It appears that the data collection plan includes a mailed written survey and a telephone survey. It is expected that there will be 510,000 respondents annually. If 1.5 percent of the respondents were AI/AN, there would be 7,650 AI/AN respondents, which would be a good size sample to draw conclusions about the AI/AN experience in Medicaid as long as there is a good representation for at least these four groups of interest:

- 1) I/T/U user enrolled in fee-for-service Medicaid
- 2) AI/AN who does not use I/T/U and is enrolled in fee-for-service Medicaid
- 3) I/T/U user enrolled in Medicaid managed care plan
- 4) AI/AN who is not an I/T/U user and is enrolled in Medicaid managed care plan

However, we are concerned that there will not be a high enough response rate from AI/AN. Some of the factors that could contribute to a low response rate for AI/AN above and beyond that of other Medicaid recipients include [low education levels, low literacy levels, the questionnaire is too long (52 questions), the questions are too complex, there is a high degree of distrust about information collection, and there is no incentive to complete the questionnaire. In addition, there is distrust of surveys not understood to be in the interest of AIAN., Furthermore, it may be difficult to reach people in a telephone survey, particularly if they do not have a telephone. In the US Census, AIAN households are more likely than households generally not to have telephones. AI/AN are not likely to respond to surveys if they are not approached in a culturally appropriate way or do not trust the person who is conducting the survey..

The U.S. Census Bureau and other researchers have learned that the best way to achieve a high response rate to surveys in AI/AN communities is to have people hired by the Tribe conduct the interviews in person. Tribes know who is acceptable and trustworthy in a community. The local tribal elders and other tribal leaders need to be approached respectfully and have the survey explained so they can promote cooperation with the survey. Tribes also know how to structure incentives to increase participation (such as entering respondents' names in a drawing for a prize).

Our suggestion is that a portion of the annual funding for the DCAHPS Survey for Adults in Medicaid be designated for grants or contracts to Tribes, Tribal Organizations and/or the I/T/U to conduct the data collection in person in AI/AN communities.

We also recommend that the survey in AI/AN communities be enhanced changing the wording slightly on some questions and/or answers to questions that will make the data more useful for analysis. For example, in addition to asking about their ancestral origins, it would also be appropriate to ask if they were a member or descendant of a member of an Indian tribe or Alaska Native Corporation. We recommend the following approach for collecting data for Federal statistics and program administrative reporting:

Question 1: Please indicate all of the following that apply to you:

- a. **American Indian or Alaskan Native.** I am a person having origins in any of the original peoples of North, Central, or South America.²
- b. Asian. I am a person having origins in any of the countries of Asia;
- c. Black. I am a person having origins in any of the black racial groups of Africa.
- d. **Pacific Islander or Native Hawaiian.** I am a person having origins in Hawaii, the Philippines or other Pacific Island.
- e. **White.** I am a person having origins in any of the original peoples of Europe, North Africa, or the Middle East.

For those who check 'a. AI/AN', <u>regardless of any other race or ethnicity [Hispanic]</u> they check ask:

Question 2: Are you a member of a federally recognized Indian tribe or a shareholder in an Alaska Native Regional or Village Corporation?

- a. Yes
- b. No
- c. Don't Know

<u>Regardless of response to Question 2, ('Yes', 'No', or 'Don't Know') ask;</u>

Question 3: Are you eligible to receive medical or dental care Indian Health Service, Tribal or Urban Indian health programs, at no cost?

- a. Yes
- b. No
- c. Don't Know

² Derived from U.S. Census definition. http://www.census.gov/prod/cen2010/briefs/c2010br-10.pdf

For those who check 'Yes' to Question 3:

Question 3: If so, have you received medical or dental care from an Indian Health Service, Tribal or Urban Indian health program in the past [time period covered by the Consumer Assessment survey]?

- a. Yes
- b. No
- c. Don't Know

Another place where we feel the questionnaire could be enhances is to add a response to Question 14e3 (What kind of place do you go to most often—a clinic, doctor's office, emergency room, or some other place?) to include an Indian health facility. A third example relates to the section of questions (15-23) about having a "personal doctor." In most I/T/U facilities, people may see various providers including doctors, nurse practitioners, physician assistants, and community health aides. Instead of using term "personal doctor," it might be more useful to use the concept regular source of health care, such as I/T/U facility. These changes can be made without reducing the integrity of data set, and will assure that people provide more accurate information.

Thank you for considering these suggestions. The TTAG would be happy to assist CMS in planning this important research activity in Tribal areas. Please contact Jennifer Cooper via jcooper@nihb.org if you have any questions.

Sincerely,

Cathy Abramson

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Chair, NIHB

cc: Dr. Yvette Roubideaux, Director, Indian Health Service

Kitty Marx, Director, CMS Tribal Affairs Group

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