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July 5, 2011

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Department of Health and Human Services

Hubert H. Humphrey Building, Room 445-G

200 Independence Avenue, SW

Washington, DC 21244-1850

Re: **Medicaid Program; Methods for Assuring Access to Covered Medicaid Services**  
**CMS 2328-P**

Dear Dr. Berwick:

National Patient Advocate Foundation (NPAF) would like to thank you for the opportunity to comment on the afore-referenced proposed rule which solicits comments on the Centers for Medicare and Medicaid Services guidelines to frame alternative approaches for States to demonstrate consistency with the access to health care items and services that are within the scope of the covered benefits, as required by section 1902(a)(30)(A) of the Social Security Act. This section of the Act requires states to comply with Medicaid access requirements described, in relevant part, "as may be necessary to safeguard against unnecessary utilization of such care and services and to assure that payments are consistent with efficiency, economy, and quality of care and are sufficient to enlist enough providers so that care and services are available under the plan at least to the extent that such care and services are available to the general population in the geographic area."

NPAF is a non-profit organization dedicated to improving patient access to healthcare services through both federal and state policy reform. Its mission is to be the voice for patients who have sought care after a diagnosis of a chronic, debilitating or life-threatening illness. NPAF has a fifteen year history of serving as the trusted patient voice. The advocacy activities of NPAF are informed and influenced by the experience of patients who receive direct, sustained case management services from our companion organization, Patient Advocate Foundation (PAF). In 2010, PAF resolved 82,963 cases nationally and provided information to almost 4 million online contacts. Nine percent of these patients, or 7,549 of them were Medicaid beneficiaries. PAF's Patient Data Analysis Report (PDAR), which will be described in greater detail later, provides detailed analyses of these cases and informs the comments within this letter.

### **Importance of Methods for Assuring Access to Covered Medicaid Services**

This section of the law is important as it assures access to a program that touches the lives of many Americans. According to the Kaiser Family Foundation, over 69 million people were Medicaid beneficiaries during 2011.<sup>1</sup> However, that figure is only the tip of the iceberg in terms of the program's impact. Data on the nonelderly population in 2006, revealed at least 57% have participated in Medicaid sometime during the previous two decades or lived with someone who

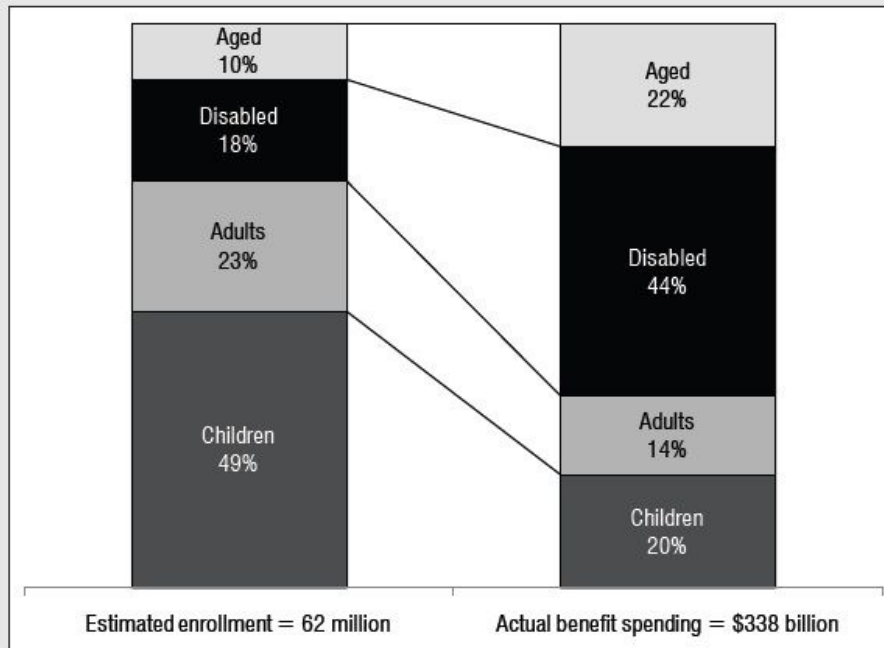
<sup>1</sup> "Medicare, Medicaid, and the Multiplier Effect," *Kaiser Family Foundation: Pulling It Together*, 10 June 2011.

participated in Medicaid during that period.<sup>2</sup> The report identifies the importance as well as unique features of the Medicaid program. The program covers the diverse health needs of enrollees; directly supports safety-net providers; covers long-term services and supports for low-income Medicare beneficiaries, and reduces uncompensated care.<sup>3</sup> Clearly, availability of appropriate Medicaid services affects the very fabric of the nation.

Recent federal budget realities concerning the Medicaid program are a likely harbinger of future state challenges to the Medicaid program in general and section 1902(a)(30)(A) in particular. The Congressional Budget Office estimates that for only the second time in the Medicaid's 46-year history, Medicaid spending will decline.<sup>4</sup> The recent Medicaid and CHIP Payment and Access Commission (MACPAC) report concludes that In 2010, Medicaid spending totaled \$406 billion, with a federal share of \$274 billion and a state share of \$132 billion. To accommodate the nearly \$90 billion in federal funding that ran out on June 30, states are cutting Medicaid payments to both doctors and hospitals, limiting benefits for Medicaid recipients, reducing the scope of covered services, requiring beneficiaries to pay larger co-payments and expanding the use of managed care.<sup>5</sup> The state budget challenges that states faced before June 30 made it clear states were facing the need to cut spending. The nation's high unemployment figures trickled down to the states in terms of growing numbers of Medicaid beneficiaries. That increase, coupled with declining federal support renders the Medicaid program particularly vulnerable to funding cuts.

It is clearly not only state fiscal realities that jeopardize the Medicaid program. While Medicaid affects many Americans, its beneficiaries are primarily children. Although children comprise the largest component of Medicaid beneficiaries, their care is not commensurate in expenditures. The disabled comprise only 18% of the Medicaid population, yet account for 44% of Medicaid expenditures. (See MACPAC chart below.)

**FIGURE 2-2. Distribution of Medicaid Enrollment and Benefit Spending by Basis of Eligibility, Estimated FY 2009**



Note: Adults and children are non-disabled enrollees under age 65 and 19, respectively. Reflects people ever enrolled during the year and includes federal and state dollars. Excludes the territories, disproportionate share hospital (DSH) payments, and adjustments.

Source: OACT 2010

<sup>2</sup> Altman, page 1.

<sup>3</sup> Medicaid and CHIP Payment and Access Commission (MACPAC). 2011. *Report to the Congress on Medicaid and CHIP*. Washington, DC MACPAC. <http://www.macpac.gov/reports>

<sup>4</sup> Pear, Robert (2011, June 15), As Number of Medicaid Patients Goes Up, Their Benefits Are About to Drop, *The New York Times*. Retrieved from <http://www.nytimes.com/2011/06/16/health/policy/16medicaid.html>

<sup>5</sup> Pear, page 1.

Another factor that jeopardizes the Medicaid program is that its beneficiaries are primarily children and the disabled- populations that do not have strong political clout. The Medicare and Social Security programs have not weathered the challenges facing Medicaid, likely because their beneficiaries have considerable political clout. Health policymakers must factor in this reality when reviewing the proposed rule comments and provide special consideration to comments from those who advocate on behalf of Medicaid beneficiaries.

#### **Proposed State Level Review Strategy**

NPAF applauds the Centers for Medicare and Medicaid Services' approach in establishing federal guidelines for states to demonstrate consistency with the access requirement using a standardized, transparent process, rather than setting nationwide standards. PAF's PDAR data on access issues confronting Medicaid beneficiaries reveals these challenges may often be state-specific. The proposed approach also allows CMS to truly partner with states, so that together CMS and states can identify solutions. NPAF also applauds the flexibility afforded states in identifying a number of appropriately addressed access challenges, and not limiting their response to the singular remedy of increasing provider payment rates. This approach may encourage states to increase provider payment rates as well as consider additional remedies.

While CMS has stated the rule is limited to access to care issues for all Medicaid services paid through a State plan under fee-for-service arrangements and does not expand to services provided through managed care arrangements, NPAF encourages CMS to consider the transferability of outcome data to access to care issues for Medicaid managed care arrangements. According to CMS' own Medicaid Managed Care Trends data, Medicaid managed care enrollment was 72% as of June 30, 2009. Therefore, the proposed rules will not apply to a majority of Medicaid programs, and its benefits will not be realized by that majority. As an increasing number of states are considering managed care plans to remedy escalating Medicaid costs, the growth of beneficiaries enrolled in these programs will likely continue. These patients may face some of the same access challenges and would likely benefit from the remedies CMS invokes for fee-for-service Medicaid patients to address them.

NPAF applauds CMS' adoption of the MACPAC-recommended three-part framework for access to care data elements. This framework includes information on enrollee needs, availability of care and providers, and utilization of services. NPAF welcomes the requirement that States must conduct access reviews for a subset of services each calendar year and release the results through public records or a website developed and maintained by the State by January 1 of each year. States are likely to have important data that will inform its policies regarding access to care. However, states may be also unwilling to identify access challenges which it does not have the resources to address. Therefore, the data elements may not be sensitive enough to track emerging access issues. NPAF suggests that CMS charge states with reviewing data compiled by patient advocacy groups that assist patients with access to care issues when identifying the subset of services upon which it is to report. These organizations have earned the respect of the patient community and will certainly have data that can guide state access improvement efforts. For example, Patient Advocate Foundation's PDAR, noted above reflects the extensive documentation recorded by PAF case managers as they resolve cases and input data on 260 unique data fields. PDAR data can be stratified by payor so as to compare access issues experienced by Medicaid patients as compared to those experienced by commercial payors. These data fields identify access challenges and have the specificity to address emerging Medicaid fee-for-service health access trends.

NPAF likewise applauds CMS' requirement that prior to submission of a State Plan Amendment (SPA), to reduce rates or alter the structure of provider payment rates in circumstances that could result in access issues for a covered service, the State would first need to submit information from an access review. That access review would be strengthened if its components included queries designed to

elicit information regarding the particular access issues that patient advocate groups routinely address on behalf of the patients they serve.

NPAF is in strong support of the proposal that States implement an ongoing mechanism that allows beneficiary feedback as well as the flexibility in which that feedback is allowed. States are likely to appreciate the ability to consider feedback mechanisms based on beneficiary hotlines or surveys, an ombudsman program, or other equivalent mechanisms. NPAF suggests CMS make explicit that which appears to be implicit- States may partner with patient advocacy and other nonprofit groups in securing comprehensive and credible beneficiary feedback. If a State relies on only its own data to understand beneficiary concerns, it will miss important feedback from patients who are less trusting of government. Patient advocacy groups have the trust of the patient as well as the sophistication to understand the scope of the access issue. States would be remiss and their data would be incomplete if they did not include patient advocacy group input when considering beneficiary feedback.

### **Data Measures to Demonstrate Sufficiency of Access**

While the entire proposed rule offers States and CMS the ability to partner in a way that assures meaningful access for Medicaid fee-for-service beneficiaries, the section regarding sufficiency of access to be supported by data merits the greatest consideration. The identification of trends and factors States could use to measure enrollee needs, the availability of care and providers, and utilization warrant careful consideration as this complex area must include a totality of relevant variables to competently guide State policy efforts and assure CMS of demonstrable consistency with the access requirement of section 1902(a)(30)(A). The statutory requirement that access by Medicaid fee for service patients be compared between the general population in the geographic area assures that these Medicaid patients have comparable access.

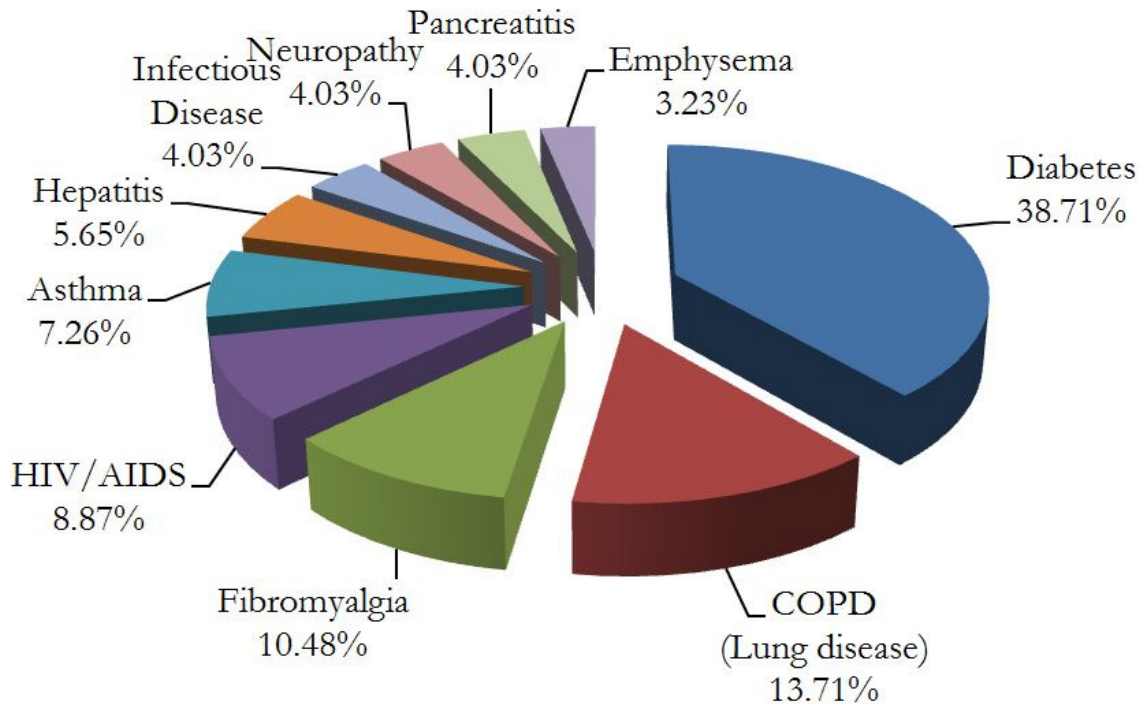
Patient Advocate Foundation's PDAR offers CMS and states the ability to identify the most prevalent access issues facing patients by a myriad of variables such as by both public and private insurers and by state. The PDAR data offer endless patient access comparisons. For example, as noted above, the MACPAC Medicaid data illustrate that although the disabled comprise only 18% of the Medicaid population, they account for 44% of Medicaid expenditures. The top 3 chronic or debilitating diagnoses for the 82,963 patients confronted with access to care issues served by PAF were diabetes (53%), osteoporosis (12%), and chronic obstructive pulmonary disease (8%). However, the top 3 chronic or debilitating diagnoses for patients confronted with access to care issues served by PAF were diabetes (38%), chronic obstructive pulmonary disease (14%) and fibromyalgia (10%). Because chronic obstructive pulmonary disease creates unique access issues for those who suffer from it, and because Medicaid recipients suffer from it disproportionately, Medicaid policies should carefully consider this and other prevalent diagnoses and what access challenges they represent for Medicaid patients.

Another interesting fact about PAF's Medicaid patient chronic or debilitating diagnoses relative to its general patient population is its ranking for HIV/AIDS. A ranking of Medicaid patients experiencing access to care issues by diagnosis reveals the fourth most prevalent disease diagnosis for this population is HIV/AIDS. However, a top-ten ranking of all PAF patients by top ten chronic or debilitating diagnoses does not include HIV/AIDS at all. Clearly, when considering access challenges experienced by Medicaid patients, special consideration needs to be given to those suffering from HIV/AIDS. Similarly, State Medicaid access rate reviews must carefully consider access rate reviews for providers who treat Medicaid patients with HIV/AIDS.

A breakdown of the top 10 diagnoses for Medicaid patients with chronic or debilitating diagnoses contacting PAF in 2010 is found on the next page.

# Top 10 Chronic or Debilitating Diagnoses of PAF Medicaid Patients

January 1, 2010 - December 31, 2010



Clearly, one existing data source that addresses general access to medical services that might be relevant to CMS' efforts to assure meaningful access for Medicaid fee-for-service beneficiaries is the PAF Patient Data Analysis Report. The 260 variables the PAF case managers collect data on include patient demographic information, disease-specific issues, employment and insurance-specific personal finance issues. Dobson DaVanzo & Associates assist PAF leadership in compiling the PDAR data. Dr. Allen Dobson was the former Director in the Office of Research at CMS. He assures, among other things, data relevancy to federal policymakers. A copy of the 2010 Patient Data Analysis Report accompanies this letter.

The data elements that are proposed to help a State determine whether Medicaid fee-for-service beneficiary needs were met represent a good start in this assessment. They include:

- Extent of knowledge that a service is covered by the Medicaid program;
- Success in scheduling a service appointment with a provider, including after hours as necessary;
- Satisfaction with the availability of service providers within a reasonable distance from home;
- Ability to obtain transportation to and from a scheduled appointment;
- Number and reasons for emergency room services received in the year;
- Number and reasons for missed appointments and means;
- Ability to either schedule an appointment or receive services in light of limited English language proficiency;
- Turnover in providers such as with homecare workers or personal care attendants; and
- Means and ability to seek help in scheduling service appointments

PAF suggests that the above data elements be qualified to accurately address the access issues Medicaid patients are likely to experience. The listing is also missing opportunities to gain information on other important patient access issues.

To begin, efforts to determine Medicaid beneficiary access challenges should first address beneficiary understanding of his or her ability to remain enrolled in the program. Some states require beneficiaries to constantly verify that they continue to be eligible for Medicaid services by reapplying for them within certain time intervals. Rather than first addressing access issues by querying whether a patient understands whether a service is covered by the Medicaid program, States and CMS must first consider the administrative burden that constant Medicaid eligibility reapplications represent for beneficiaries. Knowledge of Medicaid coverage issues may be inconsequential for patients who understand them, yet are not aware they or their children are no longer covered because eligibility fluctuates. States that have such a requirement should be responsible for the patient travel and other costs inherent to continuous beneficiary eligibility determinations.

Patient success in scheduling a service appointment with a provider may not elicit relevant information regarding the hardship of the distance that must be traversed to keep the appointment. In rural areas, although a provider might be located only 20 miles away, a patient may have to cross mountains to reach the provider. While an appointment may be secured, the provider may be so remotely located that the beneficiary may have to forego an entire work day to be seen by the provider.

Querying the ability to obtain transportation to and from a scheduled appointment may not reveal the financial hardship to the patient in securing the transportation. Once again, it also does not take into account the limited flexibility that low-income wage earners have in being able to miss work for long periods of time that may be necessary to reach a provider.

CMS aptly notes that the connection between the number of enrolled providers and the availability of services. States do license providers and should be require providers to include access-related questions when granting and renewing licenses. Providers should have to provide information on whether they are not only accepting Medicaid patients, but whether they are accepting **new** Medicaid patients. Virginia has used this approach successfully and therefore has data regarding provider access in rural areas that is superior to that of other states. Providers should also be required to notify the State within 90 days if they are no longer accepting Medicaid patients so that the State data on Medicaid provider availability are accurate.

#### Implementation of Access to Health Care Rules

CMS must assure that the resultant regulations are enforced so that they shape State efforts to provide meaningful access for Medicaid beneficiaries going forward. For example, if States know that CMS is unlikely to undertake enforcement actions if it has set Medicaid provider rates too low, it will simply proceed with the State Plan Amendment. Provider payment rate reductions should not be implemented prior to State Plan Amendment approvals by CMS. State payment rate reduction requests should be accompanied by data on cost to providers to deliver services. An approval process specified by time intervals should be clearly identified in the regulations.

NPAF comments on the specific proposed regulations are as follows:

#### Section 447.203(b)(2) and (3) Documentation of access to care and service payment rates

NPAF concurs that rate reviews should be conducted on an ongoing basis. This allows for CMS to collect data from states that may reveal serendipitous outcomes. While NPAF agrees they should be ongoing, it believes the review period proposed is too long. Providers may well opt to no longer participate in the Medicaid program if service rates are not reviewed for 5 years. Providers need not bear the burden of insufficient service payments for such a long time.

Section 447.203(b)(4)Mechanisms for ongoing input

NPAF once again reiterates the need for patient advocate input into the adequate access determination process. Those beneficiaries most in need of access to care, namely those suffering from a chronic, life-threatening or debilitating disease, rely on the patient advocate community to serve as their spokesperson while they channel their efforts into disease recovery or maintenance. The time periods for advocate group input should be continuous and should be differentiated from the mechanism provided for public input. The NPAF would welcome an opportunity to discuss this issue in greater detail with CMS leadership.

As noted above, this rule is an important one as it assures states are accountable for assuring that there is sufficient access to quality services for their Medicaid populations. NPAF would be pleased to respond to any questions about our recommendations that may arise in the future. We are also available to discuss, in greater detail, our suggestions regarding a role for the nonprofit community in the implementation of the rule.

Respectfully submitted,

A handwritten signature in black ink, appearing to read "Nancy Davenport-Ennis". The signature is written in a cursive style and is positioned above a thin yellow horizontal line.

Nancy Davenport-Ennis  
Chief Executive Officer and President