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Centers for Medicare & Medicaid Services
Department of Health and Human Services
Humphrey Building
200 Independence Ave., S.W. Room 445-G
Washington, DC 20201

Re: File Code CMS-2325-P
75 Fed. Reg. 56946 (Sept. 17, 2010)
NPRM re Section 1115 Demonstration Project Review Process

Submitted via email to <http://regulations.gov>

Dear CMS:

The National Center for Law and Economic Justice (NCLEJ) is a national organization that uses policy advocacy, litigation, and training to promote economic justice for low income individuals. In our work, we focus on ensuring access to Medicaid for low-income people and promoting access for people with disabilities. Over the decades we have had extensive experience with the 1115 demonstration project application and review process. From our perspective, the lack of adequate opportunity for public participation in this process has been a serious problem. Given the huge role that demonstration projects have had in shaping Medicaid at the state level and, in some cases, the troubling use of the 1115 process to limit benefits, greater transparency and opportunity for meaningful public input is long overdue.

We generally support the NPRM's proposals for public input in the 1115 process, as overall the NPRM would give the public opportunities to comment to the state and federal government on proposed demonstration projects; would make much more information about the proposals, progress, and evaluations of the projects publicly available; and would provide an opportunity for public input on the post-award progress of a demonstration project. We have the following specific comments to strengthen the proposed regulations:

1. Accessibility of posted materials to people with disabilities.

The proposed regulations provide that state applications for new demonstration projects and for extensions of existing projects must be submitted to CMS as both printed and electronic

documents, and provides that “[e]lectronic documents should comply with all applicable civil rights requirements related to accessibility, including the requirements under Section 508 of the Americans with Disabilities Act.” Proposed 42 C.F.R. § 431.412(b). We are pleased that the proposed regulation addresses accessibility of demonstration project documents, but have a number of comments about how this requirement could be strengthened and clarified.

- **The reference to Section 508 is not correct.** “Section 508 ” is shorthand for Section 508 of the Rehabilitation Act. Section 508 is not a section of the Americans with Disabilities Act. References in the final regulation and preamble to Section 508 should therefore refer to Section 508 of the Rehabilitation Act *and* the Americans with Disabilities Act.
- **The regulations should require all documents related to demonstration projects that are posted on the CMS and/or state websites to be accessible to people with disabilities and meet applicable accessibility standards.** The accessibility requirements in the proposed regulations do not go far enough. They apply only to the applications for demonstration projects and project extensions. (Section 431.412.) The proposed regulations require CMS and states to post many other documents related to demonstration projects on their websites.¹ By law, all of the documents and information posted on CMS’s website and State Medicaid agency websites must be accessible to people with disabilities. Documents posted on the CMS website must meet Section 508 accessibility standards;² documents posted on State Medicaid agency websites must comply with the ADA³ and Section 504,⁴ as well as state

¹ Specifically, the proposed regulations require states to post (i) comments on applications (proposed § 431.408(a)(1)(iii)); (ii) information on the public notice process, public input, public hearings (proposed § 431.408(a)(2)(i)); and (iii) annual reports on demonstration projects (proposed § 431.424(a)(2)). The proposed regulations also require CMS to post on its website: (i) the status of all state demo project submissions (proposed § 431.412(b)(3)); (ii) notice of receipt of a state's application (proposed § 431.416(b)(1)(i)); (iii) applications for demonstration projects and supporting information (proposed § 431.416(b)(1)(ii)); (iv) the proposed effective date of the demonstration project (proposed § 431.416(b)(1)(iii)); (v) information on where comments can be submitted to HHS (proposed § 431.416(b)(1)(iv)); (vi) as appropriate, status updates (proposed § 431.416(c)(1)); (vii) a list of issues raised through the comments process (proposed § 431.416(c)); and (viii) comments received by CMS (proposed § 431.416(d)).

² 29 U.S.C. § 794 d(a)(1); 36 C.F.R. pt. 1194.

³ 42 U.S.C. § 12132; 28 C.F.R. §§ 35.130(b)(1)(ii); (3)(i)-(ii); 35.160(a); U.S. Department of Justice, *Accessibility of State and Local Government Websites to People with Disabilities*, available at www.ada.gov/websites2.htm; U.S. Department of Justice, *ADA Best Practices Tool Kit for State and Local Governments*, Chapter 5: Website Accessibility Under Title II of the ADA, available at

website accessibility laws and policies.⁵ Thus, the regulations should make clear that all of the documents that must be submitted to CMS in electronic formats and/or posted on the CMS and/or state websites must be accessible to and usable by people with disabilities and meet applicable accessibility standards.

- **The regulations should make clear that websites and web pages that must be navigated to access documents regarding demonstration projects must be accessible to people with disabilities.** For a document posted on the web to be accessible to people with disabilities, both the document and the agency website and other web pages necessary to reach the document must be accessible. Therefore, the regulations should require webpages and links required to get to the demonstration project information on CMS's website and state agency websites be accessible to and usable by people with disabilities.

2. Project proposals to reduce eligibility or benefits.

The regulations should specifically require that applications for projects that would reduce or further limit eligibility or benefits contain a detailed explanation of the precise limits being proposed, the number of people affected, the consequences of the loss of services to individuals (e.g. in terms of overall health, ability to avoid institutionalization, etc), the effects and ultimate costs of loss of services or eligibility to health care delivery, how the state plans to deal with the implications of these consequences to individuals and the health care system, an analysis of the less harmful alternatives to the proposals and explanation of why the state rejected them. Proposed § 431.412 (a)(1) generally requires a comprehensive program description, description of how the proposal would vary from the current program and Act requirements, and enrollment and cost projections. However, given the serious consequences of reducing access to health care for individuals and the community, states should have an additional duty to justify any such proposals. We urge that HHS adopt a clear policy disfavoring such proposals, but if HHS is not prepared to do so, it should set a very high bar for states seeking to reduce or further limit benefits.

3. Publication of material on the web.

We support the proposal to require the posting, either by the state or by the federal agency, of specific documents on the web, but strongly recommend that the regulations provide

www.ada.gov/pcatoolkit/chap5toolkit.htm.

⁴ 29 U.S.C. § 794(a); 45 C.F.R. §§ 84.4(b)(1)(ii); (b)(4); 84.52(b)(2).

⁵ A list of state website accessibility laws and policies can be found at http://accessibility.gtri.gatech.edu/sitid/stateDocs_printable.php.

that specific additional material be published as well:

- **CMS should post the full administrative record:** CMS should post on the web the full administrative record regarding a demonstration application. Proposed § 431.416 (f) says that CMS will “maintain” an administrative record. The full administrative record contains material beyond what proposed § 431.416 (1) requires CMS to publish on the CMS website. Since the administrative record is available via a Freedom of Information Act request, CMS should routinely post the record on the web, so that the public can more fully understand the considerations underlying the decisions regarding the application.
- **If CMS declines to post the full administrative record for a demonstration project, it should at least publish additional specified material.** The final regulations should at least provide that CMS will post: 1) for approved applications, the approval documents, including final terms and conditions, waivers, expenditure authorities, and the award letter to the state; 2) the results of state implementation reviews, required under proposed § 431.420 (b)(1); 3) documents related to the suspension or termination of a demonstration project, pursuant to proposed § 431.420 (d); and 4) complaints and any CMS response thereto. As to the last, proposed § 431.420 requires CMS to review any documented complaints regarding state compliance with the project terms and conditions. Both the complaints and CMS’ response should be posted to the CMS website and to the state website, as the public has a strong interest in learning about such complaints and their resolution. The requirement for a post-award state public forum and the report thereon (which must be included in any demonstration extension application and the state annual report (see proposed § 431.412 (b)(2)(vii) and § 431.428 (a)(11)) does not appear to be intended to provide this information about complaints and CMS review of them.
- **State website postings regarding demonstration projects.** The final rules should require that a state’s website posting of demonstration project materials also contain a prominent link to the CMS website where additional demonstration project materials are posted and an explanation that the link is to further information regarding the state’s demonstration project that is available from CMS.

4. Period for public comment to CMS regarding demonstration applications.

Proposed § 431.416 (b) provides that CMS will provide a 30 day public comment period for demonstration applications. We recommend that the regulations provide that the 30 day period is a minimum comment period, and that CMS will provide a longer comment period as appropriate in individual cases. For example, demonstration applications often propose massive changes to the state’s health care system and raise complex issues. The public requires greater time to analyze and respond to such proposals. Just as HHS has public comment periods of varying lengths for proposed regulations (for example, there is a 60 day comment period for this

NPRM), it should likewise allow for varying periods in the 1115 comment process. The state public notice comment period is not a reason to adhere to a strict 30 day federal comment period. For one thing, the state’s demonstration application may change in response to public comments submitted during the state comment period and the public needs adequate time to respond to the submission to CMS. Second, the federal publication of state applications is likely to reach a broader audience of interested parties, including those outside of the state seeking a waiver who can address the experience within their own state or the implications of a particular application for their own state. They will need adequate time to review and comment.

5. Timetable for publication of material on the web.

The proposed regulations require that CMS and the state publish specific material on the web. See e.g. §§ 431.424 (c)(1)(state must post project evaluation design); (d)(state must post state evaluation reports); (g)(CMS must post evaluation materials); § 431.428(b)(2)(state must publish draft and final evaluation reports). There is no deadline for publishing these items. CMS should set a reasonable deadline by which these documents must be published. The absence of a deadline may be misinterpreted by states as signaling that publication is not critical. Without such a deadline, states may simply defer publication or put the posting task at the end of a long “to-do” list.

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