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on Civil and Human Rights

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The Leadership Conference

June 18, 2012

Office of Management and Budget
Office of Information and Regulatory Affairs

Attention: CMS Desk Officer
Email: OIRA_submission@omb.eop.gov

RE: Draft Blueprint for Approval of Affordable State-based and State Partnership Insurance Exchanges

To whom it may concern:

On behalf of The Leadership Conference on Civil and Human Rights, we offer these comments in response to the Draft Blueprint for Approval of Affordable State-based and State Partnership Insurance Exchanges. The Leadership Conference is a coalition charged by its diverse membership of more than 200 national organizations to promote and protect the civil and human rights of all persons in the United States. The Leadership Conference's Health Care Task Force is committed to eliminating health disparities and ensuring that all people in the United States can access quality, affordable health care, without discrimination.

Health insurance Exchanges present one of the biggest opportunities and one of the biggest challenges, in reforming our health care system. Exchanges will bring new competition and consumer protections to the insurance market, and, if implemented effectively, can drive delivery and payment system reform and quality improvement. **Additionally, Exchanges have the potential to increase the equity of America's health care system.**

We encourage you to keep the latter outcome in mind going forward. We expect that a significant portion of Exchange enrollees will be of moderate means who may not have much prior experience with the private health insurance market or who are using the Exchanges to enroll in Medicaid/CHIP. These populations disproportionately include communities of color, women, individuals with disabilities, individuals with limited English proficiency (LEP), and low-income workers in rural or urban areas for whom transportation, internet/computer access, and access to health care providers is limited. **The Exchanges need to be built to meet the needs of these people.**

We are thus concerned that the blueprint does not inquire about Exchanges' compliance with § 1557 of the Affordable Care Act (ACA) and does not require the Department of Health and Human Services (HHS) to review Exchanges' specific plans with regard to providing assistance to individuals with disabilities and LEP.

We also note that non-discrimination responsibilities extend beyond these two groups and that Exchanges and HHS will need to take additional or different steps to ensure that other individuals, such as women, older Americans and transgendered individuals, receive appropriate assistance accessing Exchange coverage.

Nondiscrimination

As entities established under Title I of the ACA, the Exchanges must comply with the nondiscrimination provisions of § 1557 of the ACA. Section 1557 of the ACA forbids discrimination on the grounds of race, color, national origin, sex, age or disability in health programs or activities that are receiving federal financial assistance or by programs administered by an Executive Agency or any entity established under Title I of the ACA. Because Title I of the ACA requires the establishment of the Exchanges, all Exchanges, whether administered by the federal government or by the states, must comply with § 1557. In addition most, if not all, plans offered through the Exchanges, will be subject to § 1557, by virtue of receiving federal financial assistance, including credits, subsidies, or contracts of insurance.

Since 49 states and the District of Columbia received federal funds to plan and implement their Exchanges, Title VI of the Civil Rights Act of 1964 and § 504 of the Rehabilitation Act should apply (and § 508 of the Rehabilitation Act with regard to accessible websites). These should apply regardless of the type of Exchange. States that operate state-based Exchanges have directly received federal funds while a state that establishes a not-for-profit Exchange will be passing the federal funds to the non-profit so it would be subject to Title VI and § 504.

Under Title VI of the Civil Rights Act of 1964,[1] no federal funds can be used in a discriminatory manner, whether intentionally, or, pursuant to federal regulations, through disparate impact. Title VI applies to all programs receiving federal financial assistance, including private entities. Congress has defined covered programs to include "an entire corporation . . . if assistance is extended to such corporation . . . or which is principally engaged in the business of providing education, health care . . . ."[2] Discrimination under Title VI has been determined to include preventing meaningful access to federally funded services for "national origin minorities" with LEP (Title VI prohibits discrimination on the basis of national origin). In 1974, the Supreme Court concluded that programs with a discriminatory impact against individuals based on their language are akin to those which discriminate based on national origin.[3] Since states received federal Exchange planning grants to establish their Exchanges, they are subject to Title VI. Further, under Executive Order 13166, HHS should require that Exchanges comply with HHS' "LEP Guidance" issued by OCR and work with OCR to determine the most effective ways to assist Exchanges in complying with these laws. [4]

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[1] *See* 42 U.S.C. § 2000d (2006).
[2] *See* 42 U.S.C. § 2000d-4a (2006).
[3] *See Lau v. Nichols*, 414 U.S. 563 (1974).
[4] *See* Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition against National Origin Discrimination Affecting Limited English Proficient Persons (HHS LEP Guidance), a*vailable at* http://www.gpo.gov/fdsys/pkg/FR-2003-08-08/pdf/03-20179.pdf.

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Similarly, § 504 of the Rehabilitation Act prevents discrimination against otherwise qualified people with disabilities under any program or activity that receives federal funds. Similar to Title VI, federal fund recipients may not discriminate against people with disabilities, including those who have mental health, cognitive, or developmental impairments. As one example, Exchanges should provide sign language interpreters or other augmentative or auxiliary assistance to applicants or enrollees who are Deaf or hard of hearing or have other hearing impairments to comply with § 504.

Further, HHS's final Exchange eligibility and enrollment regulations, at § 155.120, specifically require states and Exchanges to comply with applicable nondiscrimination statutes; and not discriminate based on race, color, national origin, disability, age, sex, gender identity or sexual orientation.[5]

Therefore, HHS should consider the nondiscrimination requirements of § 1557, Title VI and § 504 as it reviews applications to establish State-based Exchanges and State Partnership Insurance Exchanges. Specifically, HHS should work to ensure that the Exchanges have specific plans and policies in place to reduce health disparities and provide equitable services, and are accessible to all groups, including individuals with limited English proficiency and disabilities. In addition, HHS should require that Exchanges seek out diverse representation from a variety of groups, including women, ethnic and cultural minorities, seniors and people with disabilities, at all stages of the planning and implementation process.

We thus recommend an addition to the Blueprint to the "Consumer and Stakeholder Engagement and Support" section that would require Exchanges to provide an attestation and supporting documentation outlining the policies and procedures the Exchange will use to implement and enforce § 1557, Title VI and § 504. Specifically, Exchanges should attest and provide supporting documents demonstrating that they have:

- Designated a person who will oversee compliance with § 1557, Title VI and § 504, including investigating complaints and ensuring health plan compliance; and
- Established a system for reviewing health plan compliance with § 1557, Title VI and § 504; and
- Established an outreach plan to inform consumers of their rights under § 1557, Title VI and § 504 and how to report suspected violations.

Culturally and Linguistically Appropriate Information and Information for Individuals with Disabilities

We greatly appreciate that HHS recognizes the importance of providing information in a culturally and linguistically appropriate manner and in alternate formats for individuals with

[5] 77 Fed. Reg. 18310, 18447 (March 27, 2012) (see 42 C.F.R. § 155.120).

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disabilities. We suggest that HHS expand on the required attestations to require Exchanges to provide documentation as to how it will provide meaningful access to this information.

2.0 – Consumer and Stakeholder Engagement and Support

In 2.3, CCIO requires that the Exchange provide culturally and linguistically appropriate outreach and educational materials including auxiliary aids and services for people with disabilities. For individuals with disabilities, this may involve providing materials in alternative formats that include, but are not limited to Braille, large font, and electronic formats such as Digital Accessible Information System (DAISY), e-text (rich text format, American Standard Code for Information Interchange (ASCII)), audio files (MPEG Audio Layer III (MP3), Waveform Audio File Format (WAVE or WAV), Media Player), and giving primary consideration to the preferred format of the individual with a disability. For individuals with LEP, the Exchanges will have to provide both oral and written information in non-English languages. Yet the description of supporting documentation does not require an Exchange to actually detail or provide any information specific to how it will notify applicants and enrollees that culturally and linguistically appropriate information or assist individuals with disabilities is available. We suggest HHS amend this section to require Exchanges to provide specific information that HHS can assess to determine compliance with both § 1557 as well as 2.3.

In 2.4, HHS requires states to provide a brief description of the call center's strategy plan for providing ***translation*** services (emphasis added). We believe this is an inadvertent error by HHS. Translation is the conversion of a written text into a corresponding written text in a different language.[6] We believe HHS meant to ask for a call center's plan for "interpreting services." Interpreting is the process of understanding and analyzing a spoken or signed message, and re-expressing that message faithfully, accurately and objectively in another language, taking the cultural and social context into account.[7] The purpose of interpreting is to enable oral communication between two or more individuals who do not speak each other's languages.[8] We urge HHS to make this change so that it receives the relevant information from Exchanges about their call centers, which will be primarily interacting with applicants and enrollees via oral communication. If a call center may subsequently send written materials to callers, then HHS should require Exchanges detail their plans for providing "interpreting and translation services" (or the broader term "language services" which encompasses both interpreting and translation).

In 2.4b, we appreciate HHS's requirement that Exchanges provide translation and oral interpretation services and auxiliary aids. We suggest that HHS require supporting documentation to document the Exchanges' relevant policies, procedures, and contracts to effectively comply with 2.4b. Another concern is that this requirement is a sub-requirement to 2.4, which focuses on call centers. Because both § 1557 and Title VI of the Civil Rights Act of

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[6] NCIHC *The Terminology of Healthcare Interpreting – A Glossary of Terms* (October 2001, revised August 2008)
[7] ASTM *Standard Guide for Language Interpretation Services* (F 2089-01 (reapproved 2007).
[8] NCIHC *The Terminology of Healthcare Interpreting – A Glossary of Terms* (October 2001, revised August 2008). For more information on interpreting and translation, see *What's in a Word: A Guide to Understanding Interpreting and Translation in Health Care*, available at http://www.healthlaw.org.

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1964 apply to Exchanges, we believe the responsibility to provide translation and oral interpreting services transcends the call center and applies to *all* Exchange functions in which the Exchange interacts with consumers. Thus we suggest separating 2.4b into its own section or elevating 2.4b to 2.4 and changing the existing 2.4 to 2.4b.

We also suggest that HHS add a new requirement that a state attest and provide supporting documentation of how its' Exchange will assist individuals with disabilities who interact with the Exchange, including through the call center That is, an Exchange should have policies and procedures in place to respond to callers using TTD/TTY or video relay services as well as other services for individuals with hearing or speech impairments. Exchanges must also provide supporting documentation for how they will initially train and support representatives to provide such reasonable policy modifications to individuals with disabilities as additional time to gather supporting documentation or granting specific appointment times or windows when specific appointments might not be typically available.

In 2.5c, we strongly support HHS's requirement that Exchanges' websites provide information in a manner that is accessible to individuals with disabilities and individuals with LEP. Again, we suggest that HHS require supporting documentation to ensure that Exchanges have needed policies, procedures, and contracts in place to effectively comply with 2.5c. A state should have to document the languages the Exchange will translate all or part of its website, how it will provide information to LEP individuals if a website is not available in their language, and how the Exchange will provide accessible information to individuals with disabilities and fillable online forms, including how it will comply with § 508 requirements. The final Exchange regulations also specifically require Exchanges to provide accessible websites to individuals with disabilities and those who are LEP.[9] We strongly believe that Exchanges should utilize the thresholds for translation outlined in The Leadership Conference's prior comments – 5 percent or 500 LEP individuals in the Exchange's service area. For oral language services, we strongly believe that HHS should not implement a threshold but require oral language services for all LEP individuals, consistent with HHS' longstanding LEP Guidance.[10] Exchanges should also provide sign language interpreters or other appropriate communication assistance for individuals with hearing impairments (since not all individuals with hearing impairments use sign language, other assistance may be needed including augmentative or auxiliary aids). We believe HHS should require states to identify their threshold languages for translation and detail their plans for providing translated materials and language services.

In 2.6, we appreciate HHS's attention to the development of the Navigator program. The ACA includes a specific requirement that Navigator programs provide information in a manner that is culturally and linguistically appropriate.[11] And the final Exchange regulations specify, in the preamble, that because Navigators are third parties under agreement (that is, the grant agreement) with the Exchange, the non-discrimination standards that apply to

[9] 77 Fed. Reg. 18310, 18448 (March 27, 2012) (see 42 C.F.R. § 155.205(c)).
[10] See footnote 4.
[11] ACA § 1311(i)(3)(E).

Exchanges in § 155.120(c) will also apply to entities seeking to become Navigators. We thus recommend that HHS add a new section 2.6d to require Exchanges to provide supporting documentation on the Navigator program will comply with these requirements, including the issues addressed above regarding translated materials and language services.

3.0 – Eligibility and Enrollment

In 3.3 and 3.3e, we support HHS's requirement that Exchanges have the capacity to receive information from applicants and enrollees who have disabilities or LEP. We suggest that HHS require supporting documentation so HHS can ensure that Exchanges have the needed policies, procedures, and contracts in place to effectively comply with 3.3.

In 3.4 and 3.4a, we appreciate HHS's requirement that Exchanges have the capacity to send notices in alternate formats and multiple languages. We suggest that HHS require supporting documentation, including actual notices in alternate formats and languages so HHS can evaluate them to ensure that Exchanges have complied with 3.4 and 3.4a.

In 3.9, we commend HHS's requirement that Exchanges provide notices in plain language. Section 1311 of the ACA defines the term to mean language that individuals with LEP, among other intended audiences, can understand. We thus suggest that HHS require supporting documentation that either outlines the Exchanges' plans for ensuring information is provided in plain language or actual documents that HHS can evaluate to ensure compliance with this requirement. We also suggest HHS require that Exchanges comply with any future guidance issued by HHS on these topics (as referred to in the response to comments in the Exchange regulation regarding assistance to LEP individuals, access standards and compliance with nondiscrimination standards).[12]

In 3.11, we encourage HHS to add requirements that the eligibility appeals process includes a capacity to receive information from and assist individuals with LEP and individuals with disabilities. As documented in 3.4 and 3.4a, providing notices in alternate formats and languages is a critical component but Exchanges must also develop the entire appeals process to be responsive to the needs of individuals with disabilities and LEP. This may require an Exchange to provide an interpreter during an appeals hearing, translate notices, or ensure that appeals hearings occur in an accessible space or that it provides augmentative or auxiliary aids for individuals with disabilities or enable individuals with disabilities to appear telephonically or via videoconferencing.

4.0 – Plan Management

Since the requirements regarding § 1557, Title VI and § 504 apply to Qualified Health Plans (QHPs) as well as Exchanges themselves, we suggest HHS add specific language in 4.0 so that QHP certification standards ensure QHPs' compliance with these laws. QHPs will receive

[12] 77 Fed. Reg. 18310, 18314 col. 3; 18320 (col. 1); 18327 (col. 2) (March 27, 2012).

federal funding for enrollees receiving advance premium tax credits (APTCs) or cost-sharing reductions and thus are subject to Title VI and § 504. Further, Exchanges must require QHPs to comply with § 1557 since Exchanges themselves must comply. The responsibility runs not only to the Exchanges themselves (as an entity created under Title I of the ACA and as federal fund recipients) but longstanding precedent exists that an entity directly subject to compliance with federal laws cannot then waive compliance with these requirements by its contractors. As HHS noted in the final Exchange regulations with regard to Navigators, because Navigators are third parties under agreement (that is, the grant agreement) with the Exchange, the non-discrimination standards that apply to Exchanges in § 155.120(c) will also apply to entities seeking to become Navigators. We believe the same rationale applies to QHPs.

7.0 – Organization and Human Resources

In 7.1b, the Blueprint addresses hiring strategies. We suggest HHS add language regarding hiring of competent bi-/multi-lingual and bi-/multi-cultural individuals in public-contact positions who can provide services in a culturally and linguistically appropriate manner. Further, an Exchange must ensure that any bilingual individual hired who, as part of job responsibilities, will provide services directly in a non-English language or serve as an interpreter is competent to do so. Self-identification as bilingual is not enough and Exchanges should have policies in place to identify and document the competencies required for bilingual individuals. Finally, the CCIIO should include language in the blueprint that expressly requires Exchanges to be equal employment opportunity employers that do not discriminate on the bases of of race, color, sex, religion, national origin, disability (mental and/or physical), age, genetic information, and prior EEO activity.

8.0 – Finance and Accounting

We suggest that HHS add a requirement, 8.1b, for Exchanges to document their budgets for providing culturally and linguistically appropriate services and assistance to people with disabilities. We believe Exchanges must specifically budget for these services to ensure funds are available. Otherwise, many Exchanges may not have funds when needed to purchase language services (including interpreting or translated materials) or provide augmentative or auxiliary aids. Without specific budget line items or authority, we have witnessed that many health care providers or state agencies fail to provide these needed services, even when required to do so by federal laws.

11.0 – Oversight and Monitoring

We appreciate the inclusion of 11.1 regarding oversight and monitoring. Since HHS recognizes that the provision of culturally and linguistically appropriate services and assistance to individuals with disabilities is critical for Exchanges, we suggest adding 11.1c to specifically require oversight and monitoring of the provision of these services. Without active oversight and monitoring, it is likely that disparities in access to care by underserved populations will continue despite eligibility for health insurance.

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12.0 – Contracting, Outsourcing, and Agreements

As stated above, it is critical that all contractors of an Exchange comply with the same federal laws that Exchanges must follow. We suggest HHS specifically require that Exchanges include language in all contracts requiring contractors to comply with § 1557, Title VI, and § 504 among other relevant civil rights laws. We suggest HHS require Exchanges provide the relevant language included in their contracts as supporting documentation.

Conclusion

We greatly appreciate the opportunity to comment on the Blueprint. Exchanges have significant potential to increase equity in our health care system by improving access and insurance coverage. However, unless conscious efforts are made to take advantage of these opportunities, populations facing discrimination and health disparities may not see the full benefits of Exchanges. We hope the HHS will consider our suggestions regarding the Exchange Blueprint to ensure the Exchanges deliver on their promise to all populations. If you have any questions about these comments, please contact Leadership Conference Health Care Task Force Co-chairs Christine Monahan at the National Partnership for Women & Families (cmonahan@nationalpartnership.org) and Mara Youdelman at the National Health Law Program (youdelman@healthlaw.org), or Leadership Conference Managing Policy Director Corrine Yu (yu@civilrights.org).

Sincerely,

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