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September 28, 2011

Center for Medicare and Medicaid Services
Department of Health and Human Services
P.O. Box 8010
Baltimore, MD 21244-8010
Attention: CMS-9989-P

Submitted electronically to: <http://www.regulations.gov>

**Re: Comments on 45 C.F.R. Part 155 and 156: State-level health information
Exchanges; 76 Federal Register 41866 (July 15, 2011)
CMS-9989-P**

Dear Sir/Madam:

The National Center for Law and Economic Justice (NCLEJ) is a national organization that uses policy advocacy, litigation, training, and support for grassroots organizations to advance the cause of justice for low-income individuals. One focus of our work is ensuring that government programs and services for low-income individuals are accessible to and usable by people with disabilities. Over the years, we have also engaged in legal and other advocacy efforts to ensure that public benefits programs are accessible to people with limited English proficiency and to ensure that agency notices are readable to individuals served by public benefits programs. Our legal advocacy across the country has also focused on assuring that low-income people have prompt access to Medicaid and other benefits, and in the course of our advocacy we have become very familiar with and had to address the failures of large-scale public benefits modernization efforts. This experience informs our recommendations for implementation of Exchanges.

The following are our comments on the July 15, 2011 Notice of Proposed Rulemaking on the Exchanges and Qualified Health Plans required by the Affordable Care Act (ACA).

A. Comments on sections of the proposed regulations on disability rights laws and obligations

1. The final regulations should be revised to make clear that ADA and 504 obligations apply to all Exchange operations.

The proposed regulations refer to the Americans with Disabilities Act and Section 504 of the Rehabilitation Act and incorporate specific ADA/504 requirements in several places, specifically, in proposed §§ 155.120(c)(1)-(2) (Non-interference with Federal law and non-discrimination standards); 155.205(b)(2) (Required consumer assistance tools and programs of an Exchange); 155.210(d)(5) (Navigator program standards); 155.230(b)(2) (General standards for Exchange notices); and § 155.430 (Termination of coverage). We applaud HHS for recognizing the importance of requiring Exchanges to comply with disability rights laws, and for recognizing that compliance with these laws is essential to achievement of the goals of health care reform for individuals with disabilities.¹ Nevertheless, the proposed regulations do not clearly state that the ADA and Section 504 apply to *all* Exchange operations. And because the references to the ADA and Section 504 in the proposed regulations are haphazard, this may not be clear.

For example, in proposed § 155.205 (“Required consumer assistance tools and programs of an Exchange”) the reference to ADA and Section 504 is located in the section of the regulations on Exchange websites. Yet the ADA and Section 504 apply to all functions and services provided by Exchanges, including call centers, which are also addressed in this subsection of the regulations. The regulations do not mention the ADA and Section 504 in connection with call centers.

Similarly, the proposed regulation on Exchange notices (proposed § 155.205) states that Exchange notices must “ensure effective communication with individuals with disabilities.” (proposed § 155.205(b)(2)). The obligation to provide effective communication with individuals with disabilities, and the closely related obligation to provide auxiliary aids and services when necessary to provide effective communication, apply to all communication between Exchange and the public, not just Exchange notices. The obligation applies to telephone communication, in person communication, information provided on Exchange websites, communications and information provided by Navigators and other providers of consumer assistance, written materials provided by Exchanges, video materials used in education and outreach are all communications, and other types of communications.

¹ These regulatory provisions also implement ACA § 1557, which provides that Section 504 of the Rehabilitation Act applies to “any health program or activity, any part of which is receiving Federal financial assistance, including credits, subsidies, or contracts of insurance, or any program or activity that is administered by an Executive agency or any entity established under this Title.”

The final regulations should clearly state that the ADA and 504 apply to all Exchange operations, including but not limited to the application and application process, notices and informational materials provided by Exchanges, Navigators, and Qualified Health Plans; telephone communications with Exchange call centers; in person communications; Exchange websites; Navigator and other consumer assistance and outreach activities, appeals and complaint processes, and all other services and activities of the Exchange. The regulations should state that ADA and Section 504 requirements apply not just to programs, services and activities provided directly by Exchanges, but to all programs, services and activities provided by contractors, subcontractors, licensees, and others providing Exchange services.² HHS can accomplish this by revising the general section on non-discrimination (proposed § 155.120), creating a new section of the regulations, adding additional language into sections of the regulations on consumer assistance and navigators, call centers, etc.; or a combination of these approaches. The regulations should also state that the obligation to provide effective communication with individuals with disabilities applies to all communications, including face-to-face, telephone, internet, and text communications, to written material, to Exchange websites, and to materials provided in other formats or means (e.g., video).

2. The final regulations should contain more detail on what ADA/504 compliance requires in the operation of Exchanges.

The proposed regulations provide insufficient information on what compliance with the ADA and Section 504 requires Exchanges to do. Even when specific ADA/504 requirements are mentioned, such as the obligation to provide effective communication to individuals with disabilities when providing Exchange notices (proposed § 155.230(b)(2)), the proposed regulations do not explain that this requires Exchanges to provide written materials in alternative formats for individuals who are blind or vision impaired or to read notices to individuals who are unable to read them for disability-related reasons.

General statements in the regulations regarding the obligation to comply with the ADA and Section 504 are not sufficient. Most entities seeking to operate Exchanges are likely already aware that the ADA and Section 504 apply to Exchanges, as these laws have long applied to state and local Medicaid programs. Reminding them of this fact in the Exchange regulations is an important step, but without more, is unlikely to lead to ADA/504 compliance.

Although the ADA and Section 504 have applied to Medicaid and other public benefits programs for decades, many public benefits agencies do not comply with these laws in the operation of their public benefits programs. For several years, NCLEJ has worked in states and counties across the country to improve ADA and Section 504 compliance by public benefits agencies. Our experience is that officials at most of these agencies do not understand what these laws require, how they apply to public benefits programs, or what information to include in ADA/504 policies. Many have taken few or no steps to comply with the ADA and Section 504.

² 28 C.F.R. §§ 35.130(b)(1); (b)(3); 45 C.F.R. § 84.3(f).

Many do not have written ADA policies instructing staff to accommodate applicants and recipients with disabilities or identifying the types of accommodations that must be provided. If agencies have written policies, they are often extremely general and lack meaningful detail on what staff must do to meet ADA/504 obligations, or they address a limited number of topics. Some public benefits agency ADA/504 policies directly conflict with ADA/504 requirements or are extremely likely to result in ADA/504 violations.³ Many agencies do not comply with the ADA/504 policies they have. Given these deficiencies in agency policies, it is of little surprise that these programs often fail to comply with the ADA and 504.

Although the ADA and Section 504 protect individuals with any type of physical or mental impairment that substantially limits a major life activity,⁴ many public benefits agency staff equate “disability” with receipt of disability benefits, and do not understand that many individuals who do not receive disability benefits are entitled to accommodations under the ADA and Section 504. Public benefits agencies do a particularly poor job of accommodating individuals with mental health problems, cognitive disabilities, and any condition that is not visible, both because the disability may not be obvious and because there may be no uniform or obvious accommodation or accessibility feature (e.g., ramps, modification of a “no animal policy”) that individuals need. When accommodations require advance planning and/or cost money (e.g., providing sign language interpreters, converting materials into Braille, or providing individualized client notices in alternative formats), agencies usually do a poor job of providing them or erect unlawful barriers to obtaining them.

Many public benefits programs do not understand ADA and Section 504 requirements as they apply to effective communication. Staff in many public benefits agencies do not know what relay services are and how to use them, routinely disconnect relay calls, and in some instances, refuse to speak to individuals using relay services. Although some benefits agencies have policies requiring materials to be converted into alternative formats for visually impaired individuals, agencies often fail to implement them and routinely deny requests for alternative format materials. Many agency officials believe that providing materials in a single alternative

³ Examples include ADA/504 policies that: require individuals to request accommodations using a particular form; refer individuals needing help applying for benefits to outside agencies instead of providing the assistance; have multi-stage onerous procedures for obtaining accommodations; require individuals to be completely unable to do something to obtain an accommodation; encourage staff to use clients’ friends and relatives to interpret for individuals who are deaf; give agencies unlimited time to decide accommodation requests and ADA/504 grievances; require individuals with an ongoing need for accommodations to request the same accommodations over and over again; fail to specify whether the agency has a TTY or uses relay; do not address the obligation to accommodate people with mental health problems; and involve protective services whenever an individual with a mental health problem needs an accommodation.

⁴ 29 U.S.C. § 705(20)(B); 42 U.S.C. § 12102(1).

format (e.g., Braille) or communicating through a single alternative format (e.g., TTY) is sufficient, although the needs of individuals with disabilities differ, and no single alternative is effective for everyone with a disability.⁵

Many public benefits agencies provide inadequate notice of ADA/504 rights to applicants, recipients, and members of the public. Many agencies' ADA/504 notice of rights materials are for job applicants and employees, not individuals seeking or receiving benefits and services from the agency. If an agency has ADA/504 notice of rights materials regarding its services, these materials often contain a general statement that the agency does not discriminate on the basis of disability but not a statement of the right to accommodations. Often these materials lack information on who is protected by the ADA/504, have no examples of accommodations, and no information on how to request accommodations or, if accommodations are not provided, where to file a grievance. Benefits agency ADA/504 notice of rights materials are often written at a level that requires a college education or even a graduate degree to read and understand.

Although every state has an accessible technology law or policy requiring state agency websites to be accessible to people with disabilities, and adopting specific technical accessibility standards,⁶ NCLEJ has found that state public agency websites and portals have accessibility problems.⁷ Thus, adoption of a policy and particular accessibility standards, without more, does not result in accessibility. In addition, some state public benefits agencies have no written procedures implementing the state's accessible website policy or procedures for monitoring compliance with the policy.

When agencies contract out programs and services (such as call center operations, welfare-to-work programs, employability assessments), contracts typically contain boilerplate

⁵ To take TTYs (teletext typewriters) as an example, even if a call center has a TTY, it may need to take other steps to ensure effective telephone communication with individuals with disabilities because: 1) TTYs are a dying technology, and fewer people with speech and hearing impairments use them; 2) some individuals with disabilities don't have or are unable to use TTYs (e.g., individuals with both hearing and vision impairments who cannot read the TTY text); 3) TTYs are not an effective means of communication for individuals with a limited ability to read and write English. Increasingly, people with speech and hearing impairments are using other means to communicate remotely (e.g., captioned telephones, video relay, text-messaging, etc.).

⁶ See Hewlett Packard, *State Web Accessibility*, available at http://www.hp.com/hpinfo/abouthp/accessibility/State_Web_Accessibility.pdf for links to state accessible technology laws and policies.

⁷ National Center for Law and Economic Justice, *The Closed Digital Door: State Public Benefits Agencies' Failure to make Websites Accessible to People with Disabilities and Usable for Everyone*, (June 2010), available at www.nclej.org.

contract language on the ADA and Section 504, and agencies rarely provide additional information to contractors on what they must do to comply with the ADA/504 and rarely monitor contractor ADA/504 compliance. The predictable result is that at best, contractors take few or no steps to comply with the ADA and 504.

Given the serious deficiencies of many public benefits agency ADA/504 policies, procedures, and notice of rights materials, for the most part Exchanges will not be able to rely on and adapt states' existing ADA/504 policies, procedures, and notices for the Exchanges. Therefore, if HHS wants Exchanges to comply with the ADA and Section 504, it will have to do far more than incorporate references to the ADA and Section 504 into the Exchange regulations.

HHS must provide more direction to Exchanges on what ADA/504 compliance means for Exchanges by including more information in the Exchange regulations. For example, the regulations should state that the obligation to provide effective communication to individuals with disabilities⁸ applies to written materials provided by Exchanges, Navigators, and others engaging in outreach and consumer assistance; to websites; to call centers; and to face-to-face interactions between Exchanges, Navigators, and others engaging in outreach and consumer assistance. It should state that the obligation to provide effective communication includes the requirement to provide auxiliary aids and services when necessary for effective communication.⁹ It should state that written materials must be provided in alternative formats for individuals who are blind and those with vision impairments,¹⁰ and provide examples of alternative formats such as qualified readers, taped texts, Braille materials and displays, screen reader software, magnification software, optical readers, secondary auditory programs (SAP), large print materials, accessible electronic and information technology.¹¹ It should state that it also includes the obligation to make aurally delivered information available to individuals with hearing impairments,¹² and provide examples of auxiliary aids and services for individuals who are deaf or hearing impaired, including providing qualified interpreters on site or through remote video interpreting (VRI) services; notetakers; real-time computer-aided transcription services; open and closed captioning; voice, text, and video-based telecommunications products, including text

⁸ 42 U.S.C. §§ 12131(2); 12132; 28 C.F.R. § 35.160(a)(1).

⁹ 42 U.S.C. §§ 12103(1); 12131(2); 12132; 28 C.F.R. § 35.161(b)(1); 28 C.F.R. § 41.51(e); 45 C.F.R. §§ 84.52(b); 84.52(d).

¹⁰ 42 U.S.C. §§ 12103(1)(A); 28 C.F.R. § 35.104; 28 C.F.R. § 35.160(b)(1); 45 C.F.R. §§ 84.52(b); 84.52(d); *American Council of the Blind v. Astrue*, 2009 U.S. Dist. LEXIS 97599 (N.D. Calif. Oct. 22, 2010).

¹¹ 42 U.S.C. § 12103(1)(B); 28 C.F.R. § 35.104.

¹² 42 U.S.C. § 12103(1)(B); 28 C.F.R. §§ 35.104; 35.160(c)-(d); 45 C.F.R. §§ 84.52(b); 84.52(d).

telephones (TTYs), videophones, and captioned telephones; videotext displays; and accessible electronic and information technology.¹³

On website accessibility, the regulations should explain that accessibility requirements apply to all of the pages on a website that individuals seeking to apply for health benefits, who have already applied for health benefits, or who have questions about existing coverage would be likely to use; applications and forms, pages with contact information for the Exchange and Navigators, Frequently Asked Questions pages, and all functions that can be used to submit questions.

On call centers, the regulations should require call centers to provide an equal opportunity to individuals with disabilities to obtain information and apply for benefits, regardless of the means by which the individual contacts a call center (i.e., by voice telephone, relay services, or through a third party calling on an individual's behalf).¹⁴ It should state that relay calls should be treated like other calls.¹⁵ It should require call centers to configure automated systems used to answer and route calls and take messages to provide for effective real-time communication with individuals calling the center with TTY or relay.¹⁶ It should prohibit call centers from preventing staff from handling calls and providing information to third parties calling on behalf of an individual with a disability who cannot call on his or her own behalf, and require agencies to have reasonable policies on verifying that the individual with a disability authorized someone to call on his or her behalf that do not operate as a barrier to people with disabilities.¹⁷

The regulations should state that Exchanges, Navigators, and others providing consumer education and outreach, must provide reasonable accommodations to individuals with disabilities,¹⁸ and should provide examples of the types of accommodations that must be provided. Examples should include assisting individuals in completing forms and gathering any additional documentation required, additional explanations of rules and procedures, communicating with an individual through a different method than the Exchange or Navigator typically uses, relocating services to an accessible location or to a location an individual can travel to; traveling to an individual's home to assist a person in applying for benefits if the

¹³ 42 U.S.C. § 12103(1)(A); 28 C.F.R. § 35.104; 28 C.F.R. § 41.51(e); 45 C.F.R. §§84.52(b); 84.52(d).

¹⁴ 42 U.S.C. §§ 12131(2); 12132; 28 C.F.R. §§ 35.130(b)(1)(ii); 35.161(c); 45 C.F.R. §§ 84.4(b)(1)(ii); 84.52(d).

¹⁵ 28 C.F.R. § 35.161(b).

¹⁶ 28 C.F.R. § 35.161(c).

¹⁷ 28 C.F.R. § 35.130(b)(1)(ii); 35.130(b)(3); 45 C.F.R. §§ 84.4(b)(1)(ii); 84.52(d).

¹⁸ 42 U.S.C. §§ 12131(2); 12132; 28 C.F.R. § 35.130(b)(7); 45 C.F.R. § 84.4(b)(1)(vii).

individual cannot apply through other means,¹⁹ and providing in person information and assistance if an individual needs it for a disability-related reason.

The regulations should require Exchanges and Navigators to provide applicants, recipients, and the public with notice of ADA/504 rights²⁰ as they apply to Exchange services and functions; post these notice-of-rights materials on Exchange websites; and include it in materials provided to individuals who contact the Exchange.

The regulations should require Exchanges to have an ADA/504 Coordinator to oversee ADA/504 compliance²¹ and an ADA/504 complaint procedure for prompt resolution of complaints.²²

3. The final regulations should cross-reference applicable ADA/504 statutes and regulations.

The proposed regulations contain no cites to the ADA and Section 504. The regulations should cross-reference applicable sections of these statutes and regulations, and the references should be as specific as possible. For example, references to the obligation to provide effective communication should reference the regulation requiring effective communication, not just the ADA and 504 statutes. References to the statutory and regulatory definitions of auxiliary aids and services should be provided.

4. HHS should develop and make available resource materials to assist entities seeking to operate Exchanges in understanding their ADA/504 obligations and in developing the policies, procedures, and other materials necessary to comply.

The HHS should develop and make available various resources, including checklists, Frequently Asked Questions materials, manuals, and other materials that entities seeking to operate Exchanges can use to better understand and meet their ADA/504 obligations. HHS should also make available examples of model contract and Request For Proposal (RFP) language, and model ADA policies and implementation procedures. The final Exchange regulations should refer and link to these resources, and should encourage states to consult them. Some of the resource materials that we believe HHS should develop or gather and make available are described below:

¹⁹ 28 C.F.R. § 35.150(b).

²⁰ 28 C.F.R. § 35.106; 45 C.F.R. § 84.8.

²¹ 28 C.F.R. § 35.107(a); 45 C.F.R. § 84.7(a).

²² 28 C.F.R. § 35.107(b); 45 C.F.R. § 84.7(b).

Fact sheets and other technical assistance materials on particular topics examples

These materials should address the following topics, and many others:

1. The types of accommodations individuals with mental health problems and cognitive and developmental disabilities may need from Exchanges, Navigators, and others providing consumer assistance and outreach.
 2. How to write ADA/504 notice of rights materials that contain essential information and are written for those with a low reading level.
- What call centers must do to in setting up automated call answering, routing, answering and messaging systems to ensure that TTY and relay callers can have effective real-time communication with these systems.
 - Information about different alternative formats for written materials (e.g., explaining what minimum font large print must be, the formats electronic documents must be in to be converted into Braille, or compatible with screen reader software).
 - Information on different types of relay services, how they work and what hardware/software they require.

Checklists

HHS should develop checklists identifying the major issues that need to be addressed by Exchanges in achieving compliance with the ADA and Section 504. Checklists should cite to ADA/504 regulations, and provide links to technical assistance materials and other resources that provide additional information on the topic. Checklists should address the following topics, and others:

Exchange websites

- Websites must meet Section 508 standards or Wc3 2.0 guidelines.
- All of the pages and contact on the site that must be accessible, including the home page, all pages describing health insurance options, all application forms, all mechanisms for asking questions on line, etc.
- The need for the Exchange to have implementation procedures identifying the accessibility standards the website will meet and steps that will be taken to ensure that the website is accessible when created, that new

material posted is accessible, and that accessibility is maintained over time. The procedures should specify whose responsibility it is to engage in tasks, when those tasks will be done, and how they will be done (e.g., whether testing to monitor web accessibility use computer programs, individuals with disabilities, or both).

Materials provided by Exchanges, Navigators, other consumer outreach entities:

- Written materials and information (including but not limited to applications for Medicaid, CHIP, and other health insurance; comparative information on health insurance options; materials describing these options; notices provided to individuals; and other materials) must be provided in paper formats to individuals who do not use or have access to the internet.
- Written materials provided by Exchanges, Navigators, and others providing consumer assistance and outreach must be available in alternative formats to individuals with disabilities, including individuals who are blind and those with low vision.
- Information provided through sound (on websites, information kiosks, consumer education videos) must be provided in alternative formats for individuals who are deaf and those with hearing impairments.
- Exchanges, Navigators, and others providing Exchange services must have written policies requiring materials and information to be accessible and implementing procedures for doing so.

In person assistance provided by Exchanges, Navigators, other entities providing consumer assistance and outreach:

- Exchanges must provide in person information and assistance to individuals who, for disability or other reasons, need or want to in person communication and assistance.
- Bricks and mortar sites of Exchange, Navigators, and others providing consumer assistance and outreach that are open to the public, and brick and mortar sites used by these entities to provide face-to-face interactions with clients, must be physically accessible to and usable by people with disabilities, or if they are not accessible, the Exchange must have procedures in place (e.g., relocating services, home visits), to ensure that individuals with disabilities are provided with face-to-face interaction at an accessible location.

- Qualified sign language interpreters, video remote interpreting, or other auxiliary aids and services must be provided for face-to-face communications between Exchanges, call centers, and others engaged in Exchange functions and individuals who are deaf and hearing impaired when needed for effective communication. Face-to-face communications includes one-on one communications and group communications (e.g., orientation sessions, meetings open to the public, etc.)

Exchange call centers:

- Call centers must use either TTY or relay to communicate with individuals with disabilities to make outgoing calls to individuals with disabilities who have TTYs.
- Call centers must accept all incoming calls from individuals using any type of relay and treat them like other incoming calls.
- Training for staff on TTY and relay, including all of the different types of relay services that individuals may use to contact a call center.
- Call centers must ensure that automated call answering, routing, and messaging systems (IVR) are set up in such a way that they are usable by individuals calling the agency by TTY or relay.
- Call centers must have procedures permitting individuals to obtain information from call centers through third parties acting on their behalf, if needed for disability-related reasons.
- Call centers must have written policies requiring the entity to provide reasonable accommodations to individuals with disabilities who need them. Examples of accommodations should be provided.
- Call centers must have written implementation procedures that specify whose responsibility it is to provide accommodations, obtain materials in alternative formats, and do other things required to comply with the ADA.

Physical accessibility of sites used by Exchanges, Navigators, or others providing consumer assistance and outreach:

- Bricks and mortar sites open to the public, including sites owned and operated by others but used by Navigators to provide face-to-face interactions with clients, must be physically accessible to and usable by people with disabilities, or if they are not accessible, the Exchange must have procedures in place (e.g., relocating services, home visits), to ensure

that individuals with disabilities are provided with face-to-face interaction at an accessible location.

Accommodation policies and implementation procedures:

- Exchanges, Navigators, and others providing consumer assistance and outreach must have written policies requiring the entity to provide reasonable accommodations to individuals with disabilities who need them and written implementation procedures that specify whose responsibility it is to provide accommodations and do other things required to comply with the ADA/504.

Information kiosks

- Kiosks used to provide information must be designed and programmed to be accessible to and usable by individuals with disabilities.

Model RFP language

- Examples of RFP language that requires bidders to explain their qualifications for and experience in providing services in a manner that complies with the ADA and Section 504 and that requires them to explain in detail in their proposals how they will meet ADA/504 requirements.

Model policies and implementation procedures:

- Examples of reasonable accommodation procedures that address the accommodation needs of individuals with a wide range of disabilities (including mental health problems and cognitive disabilities); that require a wide range of accommodations to be provided; and that contain sufficient detail regarding whose responsibility it is to undertake particular tasks, when tasks must be completed, and who will perform them;
- Examples of agency procedures regarding providing materials in alternative formats that address a range of formats and methods for determining how many copies of materials to maintain in various alternative formats, given the population to be served, specify timetables, responsibilities, and other implementation details;
- Examples of agency website accessibility implementation procedures that contain meaningful detail;
- Examples of call center procedures for handling calls from third parties on an individual's behalf that balance security and privacy concerns with the

obligation to provide an equal opportunity to participate to individuals with disabilities;

Model contract language:

- Examples of contract language for different types of services contracts (e.g., website design and operation, call center operation, consumer assistance, etc.) that is sufficiently detailed regarding contractors' ADA/504 obligations;

Model ADA/504 notice of rights materials and procedures:

- Examples of ADA/504 notice of rights materials that are readable and contain information on who is protected by the ADA/504, the right to reasonable accommodations, examples of accommodations relevant to the agency's programs, information on how to request accommodations, the right to file a grievance, and where to file a grievance.
- Examples of procedures specifying when notice will be provided to program applicants and recipients, how and by whom it will be provided, and requiring the materials to be read and explained to individuals who need and want this assistance.

Policy Guidance on Exchanges and the ADA and Section 504:

In the past, HHS has issued Policy Guidance on the application of federal civil rights laws to particular types of programs and services.²³ HHS should consider issuing policy documents on particular topics relevant to Exchange operations such as the applicability of the ADA and Section 504 to call centers, or the obligation of Exchanges to provide materials in alternative formats. The guidance could provide examples of state Exchanges with policies and procedures implementing specific ADA/504 requirements, and best practices.

5. The final regulations should require entities seeking to operate Exchanges to submit detailed plans to HHS describing how they will meet ADA/504 requirements in the operation of Exchanges.

The proposed regulations do not require entities seeking to operate Exchanges to do anything to demonstrate that they have taken or will take steps to ensure that they will meet federal

²³ See, e.g., U.S. Department of Health and Human Services, Office for Civil Rights, *Prohibition Against Discrimination on the Basis of Disability in the Administration of TANF (Temporary Assistance to Needy Families)* (2001), available at www.hhs.gov/ocr/prohibition.html.

disability rights laws. This is a major shortcoming. It is not enough to provide entities seeking to operate Exchanges with the resource materials they need to know how to implement ADA/504 requirements. The regulations should require entities seeking to operate Exchanges to *submit detailed plans* to HHS on the steps they have taken or intend to take to address each of the requirements identified in the checklists suggested above. The regulations should require these plans to be submitted as part of the Exchange approval process in proposed § 155.105 and make clear that the ADA/504 implementation plan will be considered by HHS in deciding whether to grant permission to operate an Exchange.

The regulations should require the ADA/504 plan to describe in detail:

- Which Exchange functions the entity plans to design and/or operate directly, and which it intends to provide through contracts, memoranda of understanding, or other arrangements;
- For any program or service the entity intends to contact out, how the entity will ensure that Requests for Proposal (RFP) process for bidders seeking to operate and/or maintain Exchange websites and call centers and for navigators have the knowledge, experience and capability for providing access to people with disabilities.
- How the entity will ensure that contracts to operate and/or maintain Exchange websites and call centers and for navigators will ensure that contractors understand their obligation to comply with disability rights laws and understand what steps they must take to comply with these obligations.
- How the entity will ensure that the entity's own staff understand their obligation to comply with disability rights laws and understand what steps they must take to comply with these obligations.
- How the entity will require monitor compliance with civil rights laws by its own staff and contractors.
- How the entity will ensure through written policies and implementation procedures for staff and contractors that ADA and Section 504 obligations are met, including procedures for monitoring website accessibility and ensuring that accessibility is maintained over time.
- How the entity will provide materials in alternative formats to individuals with disabilities, including whether they intend to contract out to obtain alternative format materials.
- How the entity will inform people about their ADA/504 rights and the

ADA/504 grievance procedure.

- How the entity will ensure oversight and coordination between the different entities operating Exchange functions so each entity does not assume that another entity will meet the disability-related needs of individuals with disabilities.
- How the Exchange will ensure that individuals can apply and obtain information in person (see points 6 and 7 below).
- How the Exchange will ensure that materials that it did not create, but seeks to post, distribute, or otherwise make available, are accessible to individuals with disabilities, and whether the Exchange will convert those materials into accessible formats or require the originator of the materials or content will do so (see point 9 below).

The regulations should require entities seeking to operate Exchanges to submit relevant RFP and contract language and implementation procedures with their plans if available, and if not available, to submit detailed descriptions of what these documents will say and require entities to submit final documents when they are available.

The regulations should expressly prohibit entities seeking to operate Exchanges from simply restating the requirements listed above as statements of what the entity will do in their plans, and require plans to contain *meaningful detail* on *how* they intend to go about meeting this requirement.

6. Proposed § 155.405 - The final regulations should require Exchanges to permit people with disabilities and others to submit applications in person; the ADA/504 requires Exchanges to permit in person filing for people with disabilities who need it.

The proposed regulations require Exchanges to provide tools to allow for an applicant to file an application via an internet portal, by telephone through a call center, by mail, and in person. (proposed § 155.405(c)). HHS specifically requested comments on whether the final regulations should require Exchanges to make it possible for individuals to submit applications in person. The final regulations should require Exchanges to provide a mechanism for individuals to apply in person. Doing so is consistent with ACA and is required by federal disability rights laws.

ACA requires, or at a minimum, assumes, that individuals will be able to submit applications in person. ACA § 1413 provides that the Secretary of HHS shall develop and provide to each state a “single streamlined form that (I) may be used to apply for all applicable State health subsidy programs within the state; (ii) may be filed online, *in person*, by mail, or by telephone.” (emphasis added).

Allowing individuals to submit applications in person is consistent with the purpose of Exchanges and the goals of health care reform. The purpose of the Exchanges is to create a simple means by which individuals can obtain information on health insurance options and apply for health insurance. The goal of “no wrong door” is to make it as simple as possible to obtain benefits, even for individuals who are not sure where to apply. Allowing individuals to submit applications in person is consistent with this approach. Some individuals, including the elderly and individuals with disabilities, need face-to-face contact, explanations, and assistance to be able to obtain health insurance through an Exchange. If these individuals cannot apply for benefits and receive other assistance and information in person, at least one door is not open to them.

Not everyone has been touched by the digital revolution. Research indicates that there is still a “digital divide” in the U.S., and that a significant percentage of adults do not use the internet.²⁴ The elderly, people with low-incomes, and people with disabilities, are less likely to own and use computers, than others.²⁵ And, despite the apparent ubiquity of cell phones, some people still lack telephones.²⁶ Low-income individuals are less likely to have cell phones,²⁷ and less likely to have the funds to purchase service plans or minutes. Failing to provide an in person application process will have a disparate impact on these individuals. Further, in many cases, individuals need to submit an application in person because they need assistance in completing the application. For a variety of reasons, individuals may need or want to receive this help in person or may find the assistance more effective when provided in person.

The ADA and Section 504 require Exchanges to provide an equal opportunity to participate and benefit from programs and services of Exchanges, meaningful access to Exchange services,

²⁴ Lee Rainie, *Internet, Broadband, and Cell Phone Statistics*, (January 2010), Pew Internet & American Life Project, available at www.pewinternet.org/~media/Files/Reports/2010/PIP_December09_update.pdf.

²⁵ Susannah Fox, *Americans Living with Disability and Their Technology Profile*, Pew Internet & American Life Project (January 21, 2011), available at <http://pewinternet.org/Reports/2011/Disability.aspx> .

²⁶ Stephen J. Blumberg and Julian V. Luke, *Wireless Substitution: Preliminary Data from the January-June 2006 National Health Interview Survey*, National Center for Health Statistics, available at www.cdc.gov/nchs/data/hestat/wireless2006/wireless2006.htm.

²⁷ Amanda Lehnart, *Cell Phones and American Adults*, Pew Internet & American Life Project, (September 2, 2010), available at http://www.pewinternet.org/~media/Files/Reports/2010/PIP_Adults_Cellphones_Report_2010.pdf .

reasonable accommodations to individuals with disabilities.²⁸ Even if an Exchange does not generally permit individuals to submit applications in person, the ADA and Section 504 require that an Exchange do so for individuals with a disability who, as a result of a disability, would have difficulty applying by other means. These include individuals with cognitive impairments who are unable to articulate their needs by phone or become overwhelmed on the phone or are unable to tolerate long waits on the phone, individuals with disabilities who do not know how to use the internet and have difficulty communicating by phone, and individuals with disabilities who need substantial individual assistance to complete an application. For these individuals face-to-face communication is required by the ADA and 504.

Many individuals will have difficulty applying online and by phone for reasons other than disabilities (e.g., age, LEP). The regulations should require Exchanges to permit *anyone* who wants to submit an application in person to do so. The fact that the ADA and Section 504 require Exchanges to do so for some individuals means that Exchanges will be required to have a mechanism in place for face-to-face applications. Thus, providing this option for others who need assistance to have an equal opportunity to obtain health coverage should be minimally burdensome.

The regulations should make clear that individuals have a right to submit an application in person in every part of the state. This is particularly important because entities operating Exchanges may assume that Navigators are the most appropriate entities to accept in person applications, but Navigator services may be provided by a patchwork of entities, some of which serve only particular populations or serve only some parts of a state. Thus, entities operating Exchanges should be required to ensure that, regardless of the number of Navigators, populations and geographic area served by Navigators, individuals must be able to submit applications in person.

7. Proposed § 155.205 - The final regulations should require Exchanges to provide information in person to those who need or want it; the ADA/504 requires Exchanges to provide this to people with disabilities who need it.

Although the proposed regulations require individuals to be able to submit an application in person, they do not specifically require Exchanges to provide information and answer questions in person. Some individuals will want or need, in person communication to obtain information on health insurance options, and to get questions answered before they submit an application. For the same reasons discussed in point 6 above, the regulations should require Exchanges to provide information and answer questions in person. The ADA and Section 504 require Exchanges to provide this assistance to individuals with disabilities who need it, but many other people who may need or prefer to obtain information and assistance in person. The regulations should require

²⁸ 42 U.S.C. § 12132; 12182 (b)(1)(A)(ii); 28 C.F.R. §§ 35.130(b)(1)(ii); (7); 28 C.F.R. §§ 36.36.202(b); 45 C.F.R. §§ 84.4(b)(1)(ii); 84.52(b)(2); 45 C.F.R. § 85. 21(b)(1)(ii); *Alexander v. Choate*, 469 U.S. 287 (1985).

Exchanges to provide in person information and assistance to anyone who wants or needs it. Providing any less would be inconsistent with No Wrong Door.

8. Proposed § 155.205 - The final regulations should require Exchanges to provide copies of material to individuals even if the materials are posted on an Exchange website.

The final regulations should require Exchanges to provide copies of materials by mail or in person to individuals, and to permit individuals to request these materials from a call center, even if these materials are posted on the Exchange website. Some individuals with disabilities will be unable to access materials easily on a website for reasons related to their disabilities. For these individuals, provision of materials by mail or in person is required by the ADA/504. However many others will need or want copies of materials to be provided in person or by mail. Exchanges should not be permitted to assume that everyone has, has access to, or knows how to use, a computer. Research confirms that even now, not everyone has been touched by the digital revolution. The elderly, people with low-incomes, and people with disabilities, are less likely to own and use computers, than others.²⁹ Regulations should therefore require Exchanges to make materials available to individuals in person or by mail on request.

9. Proposed § 155.205(b) - The final regulations should address the allocation of responsibility between Exchanges and others for making materials and content accessible to individuals with disabilities.

Exchanges are likely to post on their website and distribute materials created by the Exchange, as well as materials that were created by other entities, including state Medicaid agencies and private insurers. The regulations should make clear that when an Exchange creates or develops materials, it has responsibility for converting those materials into alternative formats when needed by individuals with disabilities.

When Exchanges distribute materials or post web content that was developed by others, the situation is more complex. Unfortunately, despite a longstanding legal obligation of both Medicaid agencies and private insurers to provide written materials in alternative formats to individuals with disabilities who need them, many entities have not complied with this obligation. Thus, it is likely that these entities will provide at least some material and web content to Exchanges for public distribution or posting that is not in accessible formats. Exchange regulations should address what the ADA and Section 504 require of Exchanges in this situation. Failure to address this issue in the regulations is likely to result in situations in which neither the Exchange nor the originator of

²⁹ Susannah Fox, “Americans living with disability and their technology profile, Pew Research Center, (January 21, 2011), available at <http://pewinternet.org/Reports/2011/Disability.aspx>; RTC Rural, *Ruralfacts: Disability and the Digital Divide: Comparing Surveys with Disability Data* (June, 2006), available at <http://rtc.ruralinstitute.umt.edu/TelCom/Divide.htm>.

material provides the material in accessible formats, and both take the position that it was the other entity's obligation to convert them into alternative formats. Addressing this issue in the regulations will reduce problems and increase the likelihood that individuals with disabilities can obtain materials and information in formats accessible for them.

Entities operating exchanges are likely to take the position that requiring them to convert all of the inaccessible materials they receive from Medicaid agencies and private insurers for public distribution is burdensome and unfair, particularly since the creators of the materials have an independent obligation to provide those materials in alternative formats. At the same time, if Exchanges are not required to provide materials that they did not create in alternative formats, individuals with disabilities will be unable to access these materials from either entity.

We recommend that the regulations address the issue by requiring Exchanges providing materials or posting content it did not create to provide the materials in alternative formats when needed by people with disabilities. The regulations should further provide that if feasible, the Exchange should *convert* inaccessible materials and content it receives from other sources into alternative formats. However, the regulations should make clear that Exchanges can either convert the materials and content into alternative formats or ensure that the originators of the materials or content converts them into accessible formats when it provides them to the Exchange. This will encourage Exchanges and entities that created the materials or content to communicate about accessibility and agree on who will make the materials or content accessible. The regulations should encourage Exchanges and content originators (Medicaid agencies, insurers, or others) to address responsibility for converting these materials and content in written contracts, memoranda of understanding, or other agreements. This approach will increase the likelihood that individuals with disabilities will be able to obtain written materials and content in accessible formats from either the Exchange, or the creator of the materials or content, or both. It is also consistent with the ADA's approach in other situations in which multiple entities have or may have overlapping ADA obligations.³⁰

10. Proposed § 155.205(b)(2) - The final regulations should be revised to provide more accurate and detailed information on website accessibility standards.

The proposed regulations require Exchange websites to be accessible to people with disabilities in accordance with the ADA and Section 504 (proposed § 155.205(b)(2)). We have a number of recommendations to clarify and improve this section of the regulations.

The preamble provides far more detail regarding web accessibility than the proposed regulations on web accessibility. The proposed regulations require Exchange websites to be accessible to people with disabilities "in accordance with the Americans with Disabilities Act and Section 504 of the Rehabilitation Act." In contrast, the preamble states:

³⁰ See, e.g., 28 C.F.R. § 36.201(b) (addressing allocation of responsibility between landlords and tenants under Title III).

At this time, the Department will consider a recipient's Web sites, interactive kiosks, and other information systems addressed by section 508 as being in compliance with section 504 if such technologies meet those standard We encourage States to follow either 508 guidelines or guidelines that provide greater accessibility to individuals with disabilities. States may wish to consult the latest section 508 guidelines issued by the U.S. Access Board or W3C's Web Content Accessibility Guidelines (WCAG) 2.0.

(Preamble to proposed § 155.205, 76 Federal Register 41876). We recognize that HHS may wish to say less in the regulations and provide more information in the preamble on this topic for several reasons, including the fact that the Department of Justice may issue ADA regulations on website accessibility.³¹ Nevertheless, we believe that the regulations should provide as much information as possible regarding HHS's position at this time. HHS can revise the regulations on this or any other issue in the future if necessary.

We recommend that:

- If HHS's position is that satisfying 508 standards meets the requirements of Section 504, this should be stated in the Exchange regulations, not just the preamble.
- If HHS's position is that Exchanges can comply either with 508 or Web Content Accessibility Guidelines (WCAG) 2.0 guidelines, the regulations, and not just the preamble, should say so.
- Section 508 standards should be referred to as "standards," not "guidelines." The technical requirements developed by the Access Board to implement Section 508 are standards, not guidelines.
- The preamble to the final regulations should reference HHS Health Information Technology Guidance,³² and provide a link to it, but should not characterize it as "guidance regarding the requirements of section 504 with respect to Web site

³¹ U.S. Department of Justice, *Non-Discrimination on the Basis of Disability; Accessibility of Web Information and Services of State and Local Government Entities and Public Accommodations*, Advanced Notice of Proposed Rulemaking, 75 Federal Register 13457 (July 26, 2010).

³² Department of Health and Human Services, Office of Consumer Information and Insurance Oversight, Centers for Medicare and Medicaid Services, *Guidance for Exchanges and Medicaid Information and Technology (IT) Systems*, available at http://cciio.cms.gov/resources/files/exchange_medicaid_it_guidance_05312011.pdf.

accessibility.” It contains no more information on web accessibility than the preamble to the Exchange regulations.

11. Proposed § 155.430 - The final regulations should require Qualified Health Plans to provide accommodations to individuals with a broad range of disabilities when terminating coverage.

The proposed regulations require Qualified Health Plans (QHPs) to establish standards for termination of coverage that require issuers of QHPs to provide reasonable accommodations to individual with mental or cognitive conditions, including mental and substance abuse disorders, Alzheimer’s disease, and developmental disabilities before terminating coverage for such individuals.” We are pleased that HHS recognizes that individuals with these disabilities may be particularly vulnerable and in need of accommodations when coverage is terminating, and agree that these disabilities should be mentioned in the regulation. However, as QHPs have an obligation to provide reasonable accommodations to anyone with a disability who needs them when coverage is being terminated, we recommend that HHS revise the language to require QHPs to establish standards for termination of coverage that require issuers of QHPs to provide reasonable accommodations to individual with disabilities, including but not limited to individuals with mental or cognitive conditions. The final regulations should state: “QHPs must establish standards for termination of coverage that require issuers of QHPs to provide reasonable accommodations to individual with disabilities before terminating coverage of such individuals. Those standards must specifically address individuals the needs of individuals with mental or cognitive conditions, including mental and substance abuse disorders, Alzheimer’s disease, and developmental disabilities.”

12. Proposed § 155.705 - The final regulations should require Small Business Health Options (SHOs) to comply with the ADA and Section 504 and other civil rights laws in their operations.

Proposed § 155.705 (Functions of a SHO) provides that “The SHO must carry out all of the functions of an Exchange described in this part and in parts C, E, H, and K.” We propose two changes to this language. First, the regulations should require SHOs to *comply with the requirements* of parts C, E, H, and K, not just carry out the functions. As some of the provisions in parts C, E, H, and K pertain to *how* an Exchange must perform particular functions (e.g., in a manner that meets ADA and 504 requirements), the regulations should made clear that the functions described in those parts, and the manner in which they must be performed, apply to SHOs.

Second, the regulation should require SHOs to comply with some sections of part B as well. Proposed section 155.120, “Non-interference with Federal law and non-discrimination requirements The general non-discrimination requirements,” is located in part B. The general language prohibiting discrimination on the basis of race, color, national origin, disability, age, sex, gender identify or sexual orientation should apply to SHOs.

13. Proposed § 156.230 and § 156.250 - The final regulations should require Qualified Health Plan materials and communications other than applications and notices to be accessible.

Proposed § 155.250 requires applications and notices issued by Qualified Health Plans (QHP) to enrollees to meet the requirements of § 155.230(b), which requires notices to provide meaningful access to individuals with disabilities. We support this requirement, but recommend that the regulations be broadened in three ways:

- The regulation should contain general language requiring QHPs to provide effective communication with individuals with disabilities. It should mention applications and notices, but make clear that the obligation extends to other communications as well.
- The regulations should require provider directories (referred to in proposed § 156.230) to be provided in accessible formats, including accessible formats that are not online.
- The regulations should require QHPs providing documents and content to Exchanges to be provided to the public (such as materials describing coverage) to provide these materials to Exchanges in accessible formats. Doing so will lessen the problem addressed in recommendation 9 above, and will alleviate the burden on Exchanges to either make those materials accessible to come to an agreement with the QHP about who will do so.

14. Proposed § 156.250 - The final regulations should require Qualified Health Plan directories to include information on provider accessibility and be provided in alternative formats.

Proposed § 156.250 requires Qualified Health Plans (QHPs) to make their provider directories available to Exchanges, but says very little about the information that must be included in these directories. The only information the proposed regulations require directories to include is information on which providers are not accepting new patients. The regulations should require directories to include information needed by people with disabilities to determine whether providers' services are accessible to them. It should specifically require QHPs to include the following information for each medical provider:

- Whether the provider's office (including parking lot, front entrance, waiting area, bathrooms, and examination areas) are accessible to individuals who use wheelchairs and have mobility impairments.
- Whether the provider's equipment (including examination table, xray machines and

other equipment) is accessible to individuals with disabilities.

- Whether the provider provides qualified sign language interpreters to individuals who need them.

The preamble to the final regulations should refer to the joint technical assistance materials issued by the Department of Health and Human Services and Department of Justice on accessible medical care for individuals with mobility disabilities.³³

B. Comments on the proposed regulations' treatment of compliance with Title VI and ACA requirements regarding language services for those with limited English proficiency

We acknowledge and support HHS's reference in various sections of the proposed regulations to the obligation to provide meaningful access for those with limited English proficiency (see, e.g. proposed § 155.205 (b)(2); 155.210 (d)(5), 155.230 (b)(1)). However, we recommend that the final regulations be strengthened to specify precise obligations and to include reference to language assistance obligations in other regulations, beyond those that currently refer to language assistance obligations. Our comments on these issues follow. In addition, we generally support the comments of the National Health Law Program on these issues.

Although states have been under the obligation to comply with Title VI for decades, in our experience compliance with language assistance requirements falls short in too many public benefits agencies. The development of Exchanges provides a critical opportunity to make sure that Title VI compliance is built in from the start. Incorporating more detailed provisions regarding language assistance obligations will help focus Exchanges' attention on meeting their legal obligations.

1. Specific reference to the language access requirements should be included in various sections of the final regulations.

We recommend that provisions regarding language assistance should be included in the following regulations:

- § 155.200 - Functions of an Exchange
- § 155.205 - Required Consumer Assistance Tools and Programs of an Exchange
- § 155.210 - Navigator Program Standards
- § 155.230 - General Standards for Exchange Notices
- § 155.400 - Enrollment of Qualified Individuals in QHPs

³³ U.S. Department of Justice, Department of Health and Human Services, *Access to Medical Care for Individuals with Mobility Disabilities* (July 2010), available at www.ada.gov/medcare_ta.htm.

- § 155.410 - Initial and Annual Open Enrollment Periods
- § 155.105 - Service Area of a QHP
- § 156.200 - QHP Issuer Participation Standards
- § 156.225 - Marketing of QHPs
- § 156.250 - Health Plan Application and Notices
- § 156.265 - Enrollment Process for Qualified Individuals
- § 156.270 - Termination of Coverage for Qualified Individuals
- § 156.290 - Non-Renewal and Decertification of QHPs

2. The final regulations should cite to Title VI of the Civil Rights Act, implementing regulations, and HHS Guidance on serving LEP individuals.

The proposed regulations do not refer to any underlying laws or policy regarding obligations to serve individuals with limited English proficiency (LEP). The regulations should refer to Title VI of the Civil Rights Act, HHS regulations implementing Title VI, and HHS Policy Guidance addressing the obligation of recipients of federal financial assistance to provide meaningful access to Limited English Proficient Persons³⁴ and provide a link to the Guidance.

3. Final regulations must include specific obligations regarding language assistance services.

We recommend that the final regulations include the following specific obligations regarding language assistance:

- Require translation of notices and vital documents when 5% or 500 LEP individuals are included in an Exchange or QHP's service area.
- Require inclusion of translated taglines in at least 15 languages on all Exchange and QHP notices and vital documents and websites with information on how to access translated documents and oral language assistance.
- Require provision of effective oral communication for all LEP individuals regardless of whether translation thresholds are met.
- Prohibit the use of machine or free commercial translation as these programs do not provide translations that are accurate enough to use in the health care context.

³⁴ U.S. Department of Health and Human Services, Office for Civil Rights, *Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons*, available at www.hhs.gov/ocr/civilrights/resources/laws/revisedlep.html

- Require that once an individual has requested notices in another language, the Exchange should provide subsequent notices in that person’s language.
- 4. The final regulations should require entities seeking to operate Exchanges to submit detailed plans to HHS describing how they will comply with Title VI and the ACA with respect to language services.**

The proposed regulations do not require entities seeking to operate Exchanges to demonstrate that they have taken or will take steps to ensure that they will meet Title VI and ACA obligations to provide language services. For the reasons discussed above in Part A. 5, the regulations should require entities seeking to operate Exchanges to submit detailed plans to HHS on the steps they have taken or will take to assure compliance with Title VI and ACA obligations. The regulations should require entities to submit these plans to HHS with their request for HHS approval to operate an Exchange, and should make clear that HHS will consider the LEP implementation plan in deciding whether to approve the Exchange. The regulations should make clear that the plan is not a boilerplate statement and should specify the elements of the detailed plan, which include requirements that the entity:

- Develop an estimate of the language needs of the population
- Describe how it will meet its language obligations via provision of translated documents and interpretation in dealing with individuals by phone, the web, or in person
- Describe how it will ensure that any entity to which it contracts out a function will comply with Title VI and ACA requirements
- Describe how it will ensure that its staff is trained on Title VI and ACA obligations and the specific steps they must take to provide language services
- Describe how the entity will monitor its own performance regarding language services and that of any contractors
- Describe how it will ensure through written policies and procedures for staff and contractors that Title VI and ACA obligations are met

The regulations should also require entities to submit relevant RFP and contract language and implementation policies with their plan or as soon thereafter as they become available.

- 5. HHS should provide resources to assist entities in complying with their language service obligations.**

HHS should make available models and best practices regarding language services so that

entities do not have to reinvent the wheel.

C. Comments on Proposed § 155.230 Regarding Exchange Notices

We appreciate HHS's acknowledgment that notices, applications, and forms must be in plain language and provide meaningful access to those with LEP and effective communication for people with disabilities. In Parts A and B above, we have commented on notice issues related to compliance with ADA/504 and Title VI. Part D. 14 below comments in general on the readability of information for consumers. These comments also apply to proposed § 155.230. In addition, we recommend that the final regulation be strengthened as follows:

- 1. Proposed § 155.230 (a) - The final regulation should require notices to include an explanation of the reason for the action being taken and information on the right to help in understanding the notice or submitting an appeal if needed.**

The final regulation should require a statement of the reason for the action being taken. This is important for any notice of action. In the case of adverse actions, notice to the individual must include an adequate explanation of the reason for the action, so that the individual understands the basis for the action and has a meaningful opportunity to decide whether to appeal and to prepare for an appeal. An adequate explanation of the reason for the adverse action is element of adequate notice, required by Medicaid regulations, 42 C.F.R. § 431.210, and due process.

The final regulation should also strengthen subsection (a)(1) to include the requirement that the notice give information about the right to assistance in understanding the notice or submitting an appeal, if applicable.

- 2. Proposed § 155.230 - The final regulations should require a second notice to be sent if the action will result in termination of coverage and the enrollee has not responded to the first notice.**

A notice relating to termination is so critical that a follow-up notices should be required if the enrollee does not respond to the first notice. We make this recommendation, although it is not possible to comment fully since HHS has not yet issued proposed regulations regarding appeals.

- 3. Proposed § 155.230 (c) - The final regulations should require Exchanges to consult with stakeholders regarding notices.**

The final regulation should require that the Exchanges' annual assessment of the appropriateness and usability of notices include consultation with relevant stakeholders regarding the readability and accessibility of notices. Relevant stakeholders include individuals with disabilities, those with LEP, those with limited education, and their advocates.

D. Other Comments on Specific Proposed Regulations

1. Proposed § 155.105 - The final regulation should require the Exchange governance regulations to apply to entities other than HHS operating parts of HHS-facilitated Exchanges.

The proposed regulations do not require HHS-facilitated Exchanges to comply with Subpart C of the regulations (General Standards Related to the Establishment of an Exchange by the State). We have some concerns about this, particularly since the regulations provide no information on how federally-facilitated Exchanges will operate, and it is possible that in some states, HHS will assume some but not all functions of a state's Exchange. The regulations should require Exchanges that are operated in part by entities other than HHS to comply with Subpart C of the regulations for the functions they operate. Requirements regarding governments board structure and governance (proposed § 155.110), non-discrimination requirements (proposed § 155.120), stakeholder consultation (proposed § 155.130) and other requirements in Subpart C should apply to entities other than HHS operating part of an Exchange.

2. Proposed § 155.105 - HHS guidance should specify areas for HHS's pre-approval review of State Exchanges.

In the preamble to the proposed regulations, HHS notes that it will issue additional guidance regarding the detailed information and documentation that a state must provide regarding how it meets the standards in proposed § 155.105 (b). We recommend that the HHS guidance specify that HHS's review will include, among other things, careful attention to the capacity of the Exchange and its technology (web site, call centers, telephone systems, etc.) to comply with the Americans with Disabilities Act/Section 504, Title VI and ACA requirements as indicated by the entity's detailed plans regarding both ADA/504 and Title VI compliance (see Sections A and B, above); the system's capacity to issue proper notices; and the overall adequacy of the systems (e.g. telephone, web, call centers) to handle the expected volume of consumers promptly and accurately. In our experience, these elements have not received careful attention in the planning, design, and implementation of recent state public benefits computer and/or modernization systems (e.g. Colorado, Texas, Indiana). As a result, implementation resulted in thousands of individuals experiencing lengthy delays and unlawful denials and terminations of assistance. We also recommend that HHS guidance indicate that HHS's review during the approval process will also consider whether key stakeholder input has been obtained and considered; plans for testing systems to work out glitches before full-scale launch; adequate training of staff; and plans for dealing with unanticipated problems during implementation. FNS's recent report regarding recent SNAP modernization initiatives (many of which also involve Medicaid)³⁵ makes similar recommendations for future efforts.

³⁵ U.S. Department of Agriculture, Food and Nutrition Service, *Enhancing Supplemental Nutrition Assistance Program (SNAP) Certification: SNAP Modernization Efforts - Final Report* (June 2010), available at www.fns.usda.gov/ora/MENU/Published/snap/snap.htm.

- 3. Proposed § 155.105 - The final regulations should require State Exchanges to demonstrate that they have adequate accountability procedures.**

HHS must require State Exchanges to demonstrate that they have adequate accountability processes for measuring and assessing their performance and for undertaking corrective action, where appropriate. This is especially important with respect to consumer assistance tools and programs.

- 4. Proposed § 155.105 - The final regulation should require that HHS post on the web documents related to HHS's approval of a state's Exchange Plan and operational readiness (including documents submitted by the state).**

Posting would be an efficient use of HHS resources as it would eliminate the need for HHS to respond to inevitable FOIA requests and would promote transparency in government operations.

- 5. Proposed § 155.105 - The final regulations should require a meaningful public comment process on a State's Exchange Plan.**

As part of the approval process, HHS should require a State to show that there was a meaningful public comment process on the Exchange Plan. A public comment process for such a significant undertaking is important for transparency and accountability.

- 6. Proposed § 155.105 - The final regulations should include requirements that States secure HHS approval for significant contracts for Exchange functions.**

In recent years, several states (e.g. Indiana, Colorado, Texas) have entered into costly contracts for public benefits modernization that have had disastrous results for program administration and for public benefits applicants and recipients. Greater oversight of the contracting process, a more public contracting process, and stronger contracting standards may help avoid future disastrous contracts. HHS should establish baseline standards for contracting related to Exchange functions and require States to secure HHS approval for significant contracts.

- 7. Proposed § 155.110 - The final regulations should require Exchanges to post their policies and procedures on the web.**

All Exchanges, whether state agencies or other entities, should be required to post their policies and procedures to the web, so that the public has ready access to these materials.

- 8. Proposed § 155.110(d) - The regulations should require Exchanges to post governance documents on their websites.**

The proposed regulations require Exchanges to make documents identified in proposed §155.110(d) "publicly available." The regulations should require exchanges to post governance

documents on their websites, as this is an efficient way to make these documents available to the public.

9. Proposed § 155.110(c)(3) - The final regulations should add representatives of health insurance trade organizations to the list of entities considered to have a conflict of interest.

We support HHS's efforts in the proposed regulations to limit participation in governing boards of Exchanges by those with a conflict of interest, but recommend that the proposed regulation be strengthened. Proposed § 155.110(c)(3) prohibits Exchange governing boards from having "a majority of voting representatives with a conflict of interest, including representatives of health insurance issuers or agents or brokers, or any other individual licensed to sell health insurance; . . ." Representatives of health insurance trade associations are not mentioned. Although these individuals are not licensed to sell insurance, they represent the interests of their members, who are so licensed. For the same reasons that health insurers should not have a voting majority on these boards, health insurers and representatives from trade organizations for insurers should not have a voting majority.

10. Proposed § 155.130(c) - The final regulations should broaden the definition of consumer advocates with whom Exchanges must consult and should specify minimal elements of the consultation process.

First, we support HHS's decision to require Exchanges to regularly consult with stakeholders, including consumers and advocates, but we recommend that the characterization of consumer advocate stakeholders be revised and broadened. Specifically, we recommend that Exchanges be required to consult with advocates for Medicaid and CHIP recipients. These advocates represent a broader group than those for the "hard-to-reach" populations described in the proposed regulation. Moreover, advocates for Medicaid and CHIP recipients have a detailed understanding of both individuals' experiences and systemic issues. They can make a valuable contribution to the Exchange.

As to the reference to advocates for enrolling hard-to-reach populations in subsection (c), we recommend that the final regulations use the term "underenrolled" rather than "hard-to-reach." The latter term implies that these individuals have difficulty obtaining or maintaining health coverage for reasons that relate to their personal characteristics or circumstances. Our experience has been that many individuals with disabilities as others have difficulty obtaining and maintaining benefits, such as Medicaid, as a result of problems in the design and administration of these programs. "Underenrolled" avoids characterizing the reason for non-enrollment.

Proposed § 155.130(c) requires that Exchanges consult with "advocates for enrolling hard-to-reach populations, which include individuals with mental health or substance abuse disorders." We suggest that the regulation also include advocates for those with other disabilities and those with limited English proficiency.

Second, we also recommend that the final regulation prescribe minimum required elements of the consultation process to ensure a meaningful process. The regulations should require Exchanges to provide an opportunity for both oral and written input into key policy decisions that affect the consumer experience, including call centers, web sites, outreach and education, navigators, notices, etc.

11. Proposed § 155.205 - The final regulations should specify the types of assistance that call centers are expected to provide and require that call centers operate outside of normal business hours.

We strongly recommend that HHS include in the final regulation the points made in the preamble at 76 Fed. Reg. 41875 regarding the scope of services that call centers must provide. We also strongly recommend that the final regulations require that the call center operate outside of normal business hours and adjust staffing levels in anticipation of periods of higher call volumes. This is essential if consumers are to have meaningful access to call centers.

12. Proposed § 155.205 - The final regulations should require Exchanges to meet benchmarks for performance of key functions, including call centers.

We also recommend that HHS establish benchmarks for key consumer assistance functions, including call centers and websites. For example, as to call centers, benchmark standards should address overall issues such as capacity and performance and include areas such as: telephone capacity to assure that calls will be answered without repeated busy signals and thus limit abandoned calls; wait times when the phone is answered; staff response times; quality of the staff response; and consumer satisfaction. These standards should reflect measures used in industries where consumer service is a priority. It is critical that HHS insure that Exchanges are developed with clear expectations as to the level of service to be provided. Our experience with the poor performance of public benefits modernized systems in recent years in Texas, Indiana, and Colorado has convinced us that state and other entities have overlooked key ingredients of ensuring consumer service. As a result, tens of thousands of eligible individuals unnecessarily suffered from delays, denials, and terminations. Rather than leaving each state Exchange to re-invent the wheel regarding performance - or overlook critical consumer assistance measures - HHS should establish benchmark standards. If these standards are not set out in the final regulations, the final regulations should at least refer to the requirement to meet the standards developed in HHS sub-regulatory policy.

13. Proposed § 155.205 - The final regulations should require that Exchanges provide in person assistance for those who need it.

For the reasons discussed in Part A. 6 and 7, the final regulation should require that Exchanges provide in person assistance to all who seek it.

14. Proposed § 155.205 - The final regulations should require Exchanges to establish a complaint process.

In a brief discussion of the consumer assistance function, the preamble recognizes that Exchanges will receive various requests for assistance from consumers, including complaints, and must be able to make appropriate referral. However, the proposed regulation does not require the Exchange to have a complaint procedure. The final regulations should so require. Although the proposed regulations require Exchanges to establish an appeals process for eligibility determinations (proposed Sec. 155.205(d)), individuals may seek to file complaints on matters other than eligibility determinations and actions for which an appeal is appropriate, and Exchanges should have a process so they can do so. The ADA and Section 504 regulations already require entities operating Exchanges to have a grievance process for the prompt resolution of complaints. 28 C.F.R. § 35.107(b); 45 C.F.R. § 84.47(b). We recommend that the final regulations require Exchanges to have a process similar to the ADA/504 grievance process for prompt resolution of other types of complaints, so that Exchanges will not have to create two distinct complaint processes.

15. Proposed § 155.205 - The final regulations should require Exchanges to maintain and report data to HHS on consumer complaints.

Exchanges must have a system for recording relevant information about complaints and their resolution and for taking systemic corrective action where warranted. Exchanges should be required to report this information to HHS.

16. Proposed § 155.210 - The final regulations should prohibit state and local public benefits agencies from serving as Navigators.

We have serious concerns about the proposal to allow any “eligible public or private entities” to serve as a Navigator. (Proposed § 155.210(a)). Under the proposed regulations, a state or local Medicaid or cash assistance agency could serve as a Navigator, provided that the agency could demonstrate that it meets other regulatory requirements.

Welfare and public benefits agencies should not be permitted to be Navigators, and the regulations should expressly exclude them from eligibility. First, there is a well-founded public perception that these agencies are not client-friendly. Further, in many states, these agencies have a long history of adopting programs and practices that create barriers to accessing benefits. While this generalization may not universally apply, in NCLEJ’s experience over decades of advocacy on public benefits issues, public assistance agencies do not have the trust of a large segment of the population they are supposed to serve. The message of health care reform - that coverage is (almost) universal, and the goal of the Exchanges – to create easy access to health benefits – is a radical departure from the traditional public assistance message which is to discourage participation or to put people through multiple hoops and hurdles to obtain benefits. Public benefits agencies will have to undergo a radical culture change with health reform. For now, they

are not in a position to be Navigators.

- 17. Proposed § 155.210(b)(2) - The final regulations should prohibit trade, industry, or professional associations from operating as the sole Navigator in a state or locality and should require at least one consumer or community group to serve as the Navigator in each locality.**

The proposed regulations would permit an Exchange to contract solely with a Chamber of Commerce and a trade, industry, or professional association to serve as a navigator and have no consumer or community groups serving in this capacity. (Proposed § 155.210(b)(2)). We do not think that is appropriate. The regulations should prohibit trade, industry and professional associations to serve as the only Navigator in an area and require at least one consumer or community group to serve as the Navigator in each area.

- 18. The regulations should require all Exchange-related written materials to be readable and usable and should contain specific readability standards.**

The ACA requires insurers seeking to certify their health plans to provide information to Exchanges in plain language “that the intended audience, including individuals with limited English proficiency, can readily understand and use because that language is concise, well-organized, and follows other best practices of plain language writing.”³⁶ The Advanced Notice of Proposed Rulemaking sought comments on the specific planning steps Exchanges should take to ensure that they are accessible to individuals with low literacy,³⁷ but the proposed regulations say very little about the issue. Proposed § 155.230(b) requires notices to be accessible and readable; and proposed § 155.210(d)(5) requires Navigators to “provide information in a manner that is culturally and linguistically appropriate to the needs of the population being served by the Exchange,” but neither refers specifically to individuals with low literacy or to readability. The proposed regulations do not expressly require any materials other than notices to be readable. The regulations should require all materials provided by Exchanges, Navigators, or others conducting education and outreach, including notices providing information on health insurance options, websites, applications, notices, notice of rights materials, and other written materials, to be readable and usable by those with low literacy, to the greatest extent possible.

In addition, the regulations should contain standards or goals regarding the grade reading level that materials should be written for. The required reading level should be low, given the data on literacy in the U.S. Specifically:

- 1) Many individuals do not complete high school: A high school diploma is the

³⁶ ACA § 1311(e)(3)(B).

³⁷ 75 Fed. Reg. 45584, 45587 (August 3, 2010).

highest level of achievement for only 31% of Americans age 25 or older.³⁸

2) Grade level does not always reflect reading ability: The U.S. Department of Education has found that less than three-quarters of 12th graders are proficient at reading.³⁹ Thus, a significant percentage of high school graduates cannot read and understand documents that require a 12th grade reading level.

3) People with disabilities are more likely than others to have reading difficulties: One study found that people with disabilities are over-represented among individuals who are “below basic literacy.” Almost half of the individuals with less than a basic level of literacy had at least one disability, compared with less than one-third of adults in the general population.⁴⁰

CMS has recently issued materials on how to write materials for Medicaid, Medicare, and CHIP audiences that are readable and effective.⁴¹ In these materials, CMS states that intended readers of Medicaid, CHIP, and Medicare materials are likely to have basic literacy skills (i.e., low literacy).⁴² We recommend that the regulations require that information provided by Exchanges, Navigators, and others in connection with Exchange activities, to the greatest extent possible, be written for those with basic literacy skills as defined in the National Assessment of Adult Literacy. In addition, the final regulations, preamble, or both, should contain a link to the toolkit or a website containing the toolkit and other resource materials that can assist Exchanges in developing materials that are effective for those with low literacy skills.

³⁸ U.S. Census Bureau, Statistical Abstract of the United States, 2010, at tbl. 226, available at www.census.gov/compendia/statb/cats/education/educational_attainment.html.

³⁹ U.S. Department of Education, National Center for Education Statistics, *The Nation's Report Card: 12th Grade Reading and Mathematics 2005*, (2007), p. 1-5, available at <http://nces.ed.gov/nationsreportcard/pubs/main2005/2007468.asp>.

⁴⁰ U.S. Department of Education, National Center for Education Statistics, *A First Look at Literacy of America's Adults in the 21st Century*, (2005), pp. 3-5, available at <http://nces.ed.gov/NAAL/PDF/2006470.pdf>.

⁴¹ U.S. Department of Health and Human Services, Center for Medicare and Medicaid Services, *TOOLKIT for Making Written Material Clear and Effective*, available at www.cms.gov/WrittenMaterialsToolkit.

⁴² *Id.*, at § 1 p. 5.

19. Proposed § 155.405 - The final regulations should require Exchanges to permit in person filling of an application and provide in person assistance as needed.

For the reasons discussed in Part A. 6 above, we strongly support the proposed regulation requiring Exchanges to permit in person filing of applications for all who so choose. As part of the requirement to accept in person applications, the final regulation should also require Exchanges to provide in person assistance in filing the application to those who need it.

20. Proposed § 155.405 - The final regulation should limit the information that can be required to that which is essential.

The preamble seeks comment on whether HHS should codify a requirement that applicants may not be required to answer questions that are not relevant to eligibility and enrollment. We strongly recommend that HHS include this requirement in the final regulations and that the regulations make clear that the Exchange can require only the minimum information necessary to determine eligibility and enroll those seeking coverage. From our experience with public benefits agencies, we are aware that state agencies too often seek unnecessary information or prohibited information about people in the household who are not applying for benefits. The final regulation should put Exchanges on notice about the limits of the information they can require and this restriction should apply to whatever application the Exchange uses - the model streamlined form or an alternative application.

21. Proposed § 155.405 - The final regulation should impose conditions for including requests for optional information.

To the extent that Exchanges are permitted to request optional information not necessary to determining eligibility and enrollment on application forms, the regulations should explicitly require that any optional information be prominently identified and that consumers be explicitly told that declining to answer will not affect their eligibility or enrollment. Online applications must be designed so that applicants can bypass any optional information easily. If applicants do not understand that certain information is optional, they may be deterred from applying.

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