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October 4, 2010

Center for Medicare and Medicaid Services
Department of Health and Human Services
P.O. Box 8010
Baltimore, MD 21244-8010
Attention: OCII0-9989-NC

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

Re: Comments on 45 CFR Part 170: State-level health information exchanges; 75 Federal Register 45584 (August 3, 2010)

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 state health information exchanges.

We are writing to provide comments in response to the August 3, 2010 HHS Advance Notice of Proposed Rulemaking on the American Health Benefits Exchanges that states will establish as a result of the Patient Protection and Affordable Care Act (PPACA). These comments respond to the following sections of the Advance Notice of Proposed Rulemaking:

- Section C, Question 8: Specific planning steps that HHS should require Exchanges to undertake to ensure that Exchanges and the information provided by Exchanges are accessible and available to individuals from diverse cultural

origins, those with low literacy, disabilities, and limited English proficiency.

- Section C, Question 5: Considerations for states as they develop web portals for the Exchanges.
- Section C, Question 1: General Requirements for Exchanges

1. Accessibility and availability of exchanges to individuals with low literacy

Recommendation: HHS regulations should require entities operating Exchanges to ensure that Exchange websites, and material provided by the Exchanges are written, to the greatest extent possible, so they can be read and understood by individuals with limited literacy.

PPACA 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.”¹ Therefore, it is necessary and appropriate for HHS to require entities operating Exchanges to take specific steps to comply with this requirement. Given the functions of the Exchanges, which include informing individuals of eligibility requirements for the Medicaid and CHIP programs or any applicable State or local public program, and enrolling individuals in those programs if the Exchange determines they are eligible;² and the requirement that health insurance options be provided in a standardized format,³ it is critical that Exchange websites, and information provided by Exchanges, to the greatest extent possible, provide information that is written as simply and clearly as possible, so it can be read and understood by as many people as possible.

There is substantial evidence indicating that a significant percentage of the U.S. population have low levels of literacy. Specifically:

1) Many individuals do not complete high school: A high school diploma is the highest level of achievement for only 31% of Americans age 25 or older.⁴

¹ PPACA § 1311(e)(3)(B).

² PPACA § 1311(d)(4)(F). 75 Federal Register 45585 (August 3, 2010).

³ PPACA § 1311(d)(4)(E).

⁴ 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.

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.⁵ 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.⁶

Recommendation: HHS regulations should require the information on Exchange websites and provided by Exchanges through other means, to the greatest extent possible, to be written at a 5th grade reading level.

In 1999, HHS issued materials for states on improving readability of Medicaid notices and program materials.⁷ In these materials, HHS recommended that states draft Medicaid notices so they could be read and understood by individuals with a 5th grade reading level.⁸

Recommendation: HHS should revise and reissue the 1999 materials on drafting readable documents and make them available to entities operating Exchanges, or provide or make available to comparable materials on readability.

Requiring Exchanges to provide written materials that, to the greatest extent possible, are readable for those with a 5th grade reading level is not sufficient. Exchanges need assistance in how to accomplish this task. HHS should provide resources to Exchanges on how to meet this requirement. We therefore recommend that HHS revise and reissue the 1999 HHS materials on readability or make comparable materials available to Exchanges. The HHS 1999 materials are an invaluable resource. They contain detailed information on how to draft documents that are

⁵ 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>.

⁶ 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>.

⁷ U.S. Department of Health and Human Services, Health Care Financing Administration, Center for Medicaid and State Operations, *Reading and Designing Print Materials for Beneficiaries: A Guide for State Medicaid Agencies*, (Oct. 1999).

⁸ *Id.*, p. 9.

likely to be read and understood by individuals with lower reading levels.⁹ These materials were developed over a decade ago, and, to our knowledge, are not available on the HHS website. Thus, entities developing the Exchanges are unlikely to be aware of them.

Recommendation: HHS regulations should require entities operating Exchanges to submit plans to HHS explaining the specific steps they will take to ensure that Exchange websites and material provided by Exchanges are written so they can be read and understood by individuals with limited literacy.

HHS should require states to develop and submit to HHS plans on how they intend to ensure that the Exchanges takes steps to ensure that materials that they provide are readable to as many people as possible. Planning increases the likelihood that Exchanges will comply with this requirement.

2. Accessibility of Exchange websites to individuals with disabilities

Recommendation: HHS regulations should make clear that Exchange websites and information and applications on Exchange websites must be accessible to and usable by people with disabilities.

Websites operated by Exchanges, and information and applications provided on those websites, must be accessible to and usable by people with disabilities. Web accessibility is fundamental to achieving the intended purpose of the Exchanges. It is also the law. Exchange websites must be accessible regardless of who operates them. Websites operated by states or entities under contractual, licensing, or other arrangements with states must comply with Title II of the Americans with Disabilities Act (ADA).¹⁰ Exchange websites operated by non-profit entities must comply with Title III of the ADA.¹¹ Websites operated by recipients of federal financial assistance, and the Exchange website operated by HHS, must comply with Section 504

⁹ Some factors affecting readability of a document are the number of syllables in the words used, the number of words in a sentence, and number of sentences in a paragraph (fewer are better); use of passive sentences (fewer are better); and the use of technical jargon (the less the better). Readability is improved when a document uses the second person and addresses the reader directly. Many aspects of document layout, including font style and size, justification, use of white space, and use of lists rather than blocks of text, also affect readability.

¹⁰ 42 U.S.C. § 12132.

¹¹ 42 U.S.C. § 12182; Department of Justice, *Nondiscrimination on the Basis of Disability; Accessibility of Information Services of State and Local Government Entities and Public Accommodations*, Advance Notice of Proposed Rulemaking, 75 Federal Register 43460, 43463 (July 26, 2010).

of the Rehabilitation Act (Section 504).¹²

The ADA and Section 504 prohibit entities operating the Exchanges from excluding individuals with disabilities from Exchange websites, denying individuals with disabilities the benefits of Exchange websites, or otherwise discriminating against individuals with disabilities.¹³ In addition, the ADA and Section 504 require Exchanges to provide meaningful access to individuals with disabilities.¹⁴ Specifically, Exchanges must provide an equal opportunity to individuals with disabilities to participate in and benefit from programs and services¹⁵ and cannot be administered in a manner that has a discriminatory effect.¹⁶ If Exchange websites and their content are not accessible to and usable by people with disabilities, these requirements are violated. There is no way that Exchanges can provide an equal opportunity to obtain information and insurance to people with disabilities unless Exchange websites are accessible to people with disabilities for the following reasons:

1) Operation of a website to provide information on health insurance, and providing a mechanism for individuals to be screened for Medicaid and CHIP, apply for these benefits, and enroll in Medicaid and CHIP programs if eligible, are among the chief functions of the Exchanges.¹⁷ Exchanges cannot provide an equal opportunity to participate in and benefit if key functions are not accessible.

2) Even if Exchanges provide information and the ability to apply for Medicaid and CHIP through means other than their websites and these other avenues are accessible to people with disabilities, Exchanges will still need to make their websites and web content accessible. As the Department of Justice has observed, it is difficult, if not impossible, to provide alternatives to the web that provide the same degree of access, given that the internet provides 24 hour a day, 7 day a week access to information and services.¹⁸ Thus

¹² 29 U.S.C. § 794(a).

¹³ 29 U.S.C. § 794(a); 42 U.S.C. § 12132; 42 U.S.C. §§ 12182(a).

¹⁴ *Alexander v. Choate*, 469 U.S. 287 (1985).

¹⁵ 42 U.S.C. § 12182((b)(1)(A)(ii); 28 C.F.R. § 35.130(b)(1)(ii); 28 C.F.R. § 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).

¹⁶ 28 C.F.R. § 35.130(b)(3)(i); 28 C.F.R. § 36.204; 45 C.F.R. § 84.4(b)(4); 45 C.F.R. § 85. 21(b)(3)(ii).

¹⁷ PPACA §§ 1311(d)(4)(C); (E); (F); 75 Federal Register 45585.

¹⁸ U.S. Department of Justice, *Nondiscrimination on the Basis of Disability of Web Information and Services of State and Local Government Entities and Public Accommodations*, Advance Notice of Proposed Rulemaking, 75 Federal Register 43460, 43466 (July 26, 2010);

providing other means of access does not provide the equal opportunity required by the ADA and Section 504.

Thus, Exchanges cannot sidestep their obligation to make websites accessible by making information and applications available through other means.

Recommendation: HHS regulations should require entities operating Exchanges to submit plans explaining the specific steps they will take to ensure that Exchange websites are accessible to and usable by people with disabilities and to ensure that accessibility is maintained over time.

In establishing rules for exchanges, HHS should be mindful that some state Medicaid agency websites are not fully accessible to individuals with disabilities. In June 2010, the National Center for Law And Economic justice issued a report on web accessibility and usability of state Medicaid, cash assistance, and Food Stamp agency websites in California, Florida, Michigan, New York, and Texas.¹⁹ The report found that state agency websites in all five states had accessibility problems that make it difficult or impossible for some people with disabilities to do one or more of the following:

- Obtain information on public benefits programs
- Obtain information on program eligibility requirements
- Obtain information on how to apply for benefits
- Apply for benefits online
- Contact the agency for assistance or to request an application

In addition, some of the websites had problems in design, layout, and number of steps required to obtain information that made the websites difficult for anyone to use. We have no doubt that other state Medicaid agency websites have similar problems.

Given the existing accessibility problems with state Medicaid websites, HHS must ensure that Exchange websites do not have similar problems. One way to increase the likelihood that

U.S. Department of Justice, *Accessibility of State and Local Government Websites to People with Disabilities*, available at www.ada.gov/websites2.htm.

¹⁹ 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.

Exchanges consider and takes steps to ensure that materials that they provide are readable to as many people as possible is to require them to develop and submit to HHS detailed plans on how they intend to achieve and maintain website accessibility.

Recommendation: HHS regulations should require entities operating Exchanges to identify in their plans which accessibility standards, guidelines, or checklists they will use to achieve and maintain website accessibility.

There are several resources available to Exchanges seeking to develop and maintain accessible websites and web content:

- 1) The U.S. Access Board has issued detailed standards for web accessibility that implement Section 508 of the Rehabilitation Act, which applies to the federal government and requires electronic and information technology to be accessible to and usable by people with disabilities unless it would be an undue burden.²⁰
- 2) The Web Accessibility Initiative of the World wide Web Consortium (WC3) has issued voluntary international guidelines for web accessibility.²¹
- 3) The U.S. Access Board is in the process of reviewing proposed revisions to Section 508 standards. One purpose of the revisions is to harmonize Section 508 standards with WCAG guidelines.²²
- 4) The Department of Justice (DOJ) has issued an *ADA Best Practices Toolkit for State and Local Governments* that provide guidance to state and local governments on how to achieve compliance with Title II of the ADA.²³ Chapter 5 of the Toolkit addresses website accessibility; an addendum to that chapter contains a checklist for assessing the

²⁰ 29 U.S.C. § 794d (a)(1) (Section 508); 36 C.F.R. pt. 1194 (Access Board Section 508 standards).

²¹ www.w3c.org.

²² Architectural and Transportation Barriers Compliance Board, *Americans with Disabilities Act (ADA) Accessibility Guidelines for Buildings and Facilities; Telecommunications Act Accessibility Guidelines; Electronic and Information Technology Accessibility Standards*, Advanced Notice of Proposed Rulemaking, 75 Federal Register 13457 (March 22, 2010). The recommended changes to Section 508 standards are available at www.access-board.gov/508.htm.

²³ U.S. Department of Justice, *ADA Best Practices Toolkit for State and Local Governments*, available at www.ada.gov/pcatoolkit/toolkitmain.htm.

accessibility of state agency web pages and web content.²⁴

5) DOJ has also issued *Accessibility of State and Local Government Websites to People with Disabilities*,²⁵ which instructs public entities on crafting an action plan for developing and maintaining accessible websites, provides examples of accessible features for websites, and contains notes containing specific steps for improving website accessibility.

6) States have web accessibility statutes and policies that apply to state agency websites. These laws and policies typically require state agency websites to comply with Section 508 standards, WCAG standards, or a combination of the two.²⁶

In July, 2010, DOJ issued an Advance Notice of Proposed Rulemaking indicating that the agency is considering revising its Title II and Title III ADA regulations to establish requirements for web accessibility.²⁷ Nevertheless, HHS must address the issue of web accessibility in its Exchange regulations, even if DOJ has not issued final web accessibility regulations when HHS promulgates regulations on Exchanges, for several reasons:

1) DOJ's Advance Notice of Proposed Rulemaking states that DOJ "is considering" issuing regulations on web accessibility.²⁸ It does not say that a decision has been made. HHS could wait in vain for DOJ to issue web accessibility regulations or standards that never come.

2) Even if DOJ issues regulations or standards, its timetable for doing so is unclear. Under PPACA, Exchanges must be operational by January 1, 2014.²⁹ This will require extensive planning and preparation. Exchanges are likely to need standards and guidance

²⁴ *Id.*, Chapter 5 Addendum: Title II Checklist (web Accessibility), available at www.ada.gov/pcatoolkit/chap5chklist.htm.

²⁵ U.S. Department of Justice, *Accessibility of State and Local Government Websites to People with Disabilities*, available at www.ada.gov/websites2.htm.

²⁶ http://accessibility.gtri.gatech.edu/sitid/stateDocs_printable.php.

²⁷ Department of Justice, *Nondiscrimination on the Basis of Disability; Accessibility of Information Services of State and Local Government Entities and Public Accommodations*, Advance Notice of Proposed Rulemaking, 75 Federal Register 43460, 43463 (July 26, 2010).

²⁸ 75 Federal Register 43460.

²⁹ PPACA § 1311(b)(1).

before DOJ regulations are final.

3) Even if DOJ promulgates web accessibility regulations, DOJ has indicated that it may not adopt a single set of technical web accessibility standards or guidelines for Title II and Title III entities to follow.³⁰ DOJ may give entities an option of choosing which standards to follow or could require entities to meet outcome measures. Thus, DOJ rulemaking may not result in a mandate that Exchanges comply with a particular set of web accessibility standards.

Given the current lack of a uniform set of technical accessibility standards applicable to Title II and Title III websites, and the need for HHS to provide rules and guidance to Exchanges sooner rather than later, we recommend that HHS give Exchanges flexibility in the means by which they achieve web accessibility. If DOJ subsequently promulgates regulations adopting a particular set of web accessibility standards, HHS can modify the Exchange regulations at that time.

Recommendation: HHS regulations should require entities operating Exchanges to describe in their plans how they intend to ensure that potential contractors are knowledgeable about the steps they need to take to achieve and maintain web accessibility and are required to achieve and maintain accessibility of the website.

It is possible that entities operating Exchanges will contract out at least some of the responsibility for designing and managing Exchange websites to other entities. To ensure that websites are accessible, Exchanges will also need to have:

- 1) Language in Requests for Proposal (RFPs) requiring contract bidders seeking contracts to develop or maintain Exchange websites to explain in detail the procedures they will use to obtain and maintain web accessibility.
- 2) Contract language requiring contractors that develop or maintain Exchange websites to ensure the accessibility of the website and requiring contractors to comply with the Exchange's web accessibility policies and procedures.

Given the importance of RFP and contract language, entities operating Exchanges should be required to describe in detail how they intend to ensure that RFPs seek relevant information from bidders on their awareness and knowledgeable of accessibility issues and how they intend to ensure that contracts impose clear-cut and specific accessibility obligations on contractors involved in Exchange website development and maintenance. The regulations should make clear that boilerplate anti-discrimination language in RFPs and contracts is not sufficient.

Recommendation: HHS regulations should require entities operating Exchanges to

³⁰ 75 Federal Register 43465.

describe in their plans what policies and procedures they have or intend to develop for achieving and maintaining accessibility of Exchange websites.

It is critical that entities operating Exchanges have detailed policies and procedures describing how the Exchange will achieve and maintain web accessibility. The regulations should require entities to specify in their procedures who will be responsible for changing or posting new content, how this will be achieved in a way that maintains accessibility, what type of steps the Exchange will take to test and monitor web accessibility, whose responsibility it is to test and monitor, how often this testing will occur, and other similar information.

3. Availability of materials and information in alternative formats

Recommendation: HHS regulations should require entities operating Exchanges to provide materials to individuals with disabilities in alternative formats when necessary to provide meaningful access to the information and effective communication.

The ADA and Section 504 require entities subject to these laws to provide effective communication with individuals with disabilities.³¹ One facet of effective communication is providing information and materials in formats that are accessible. Written materials must be provided to individuals with vision and other impairments in alternative formats when necessary to provide effective communication, unless it would be a fundamental alternation or undue burden to do so.³² Examples of alternative formats include qualified readers, taped texts, audio recordings, Brailled materials and displays, screen reader software, optical readers, secondary audio programs, large print materials, accessible electronic information and technology, or other effective methods of making visually delivered materials available to individuals who are blind or have low vision.³³

Making Exchange websites accessible to and usable by individuals with disabilities does not eliminate or change the independent obligation of Exchanges to provide copies of written materials to individuals in alternative formats because:

- Research indicates that there is still a “digital divide” in the U.S., and that a

³¹ 42 U.S.C. § 12132; 42 U.S.C. §§ 12182(a); (b)(2)(iv); 28 C.F.R. § 35.160(a); 28 C.F.R. § 36.303(c); 45 C.F.R. § 85.51(a).

³² 29 U.S.C. § 794(a); 42 U.S.C. §§ 12132; 12182(b)(2)(iii)-(iv); 28 C.F.R. § 35.160(b)(1); 28 C.F.R. 36.303(a); 45 C.F.R. § 84.52(d)(1); 45 C.F.R. § 85.51(a)(1); *Astrue v. American Council for the Blind*, 2009 U.S. Dist. LEXIS 97599, at *55 (N.D. Calif. Oct.. 22, 2010).

³³ 42 U.S.C. § 12103(1); 28 C.F.R. § 35.104; 28 C.F.R. § 36.303(b)(2).

significant percentage of adults do not use the internet.³⁴ Low income individuals and those with less education are less likely to use the internet than higher income individuals and those with more education.³⁵

- Many individuals with disabilities do not use the internet. Individuals with disabilities are less likely to use and have access to the internet than others.³⁶

Thus, Exchanges will have to make paper copies of materials available to at least some individuals. If it does so, it must provide these same materials in alternative formats to individuals with disabilities.

HHS regulations should require entities operating Exchanges to specify in their plans the specific steps they intend to take to ensure that materials are provided to individuals with disabilities in alternative formats.

Exchanges are more likely to provide materials in alternative formats if they have a plan for doing so. Entities operating Exchanges will need to determine how they will get materials produced in alternative formats, how they intend to notify consumers of the right to request materials in alternative formats, and other operational details. Regulations should require entities to include this information in their plans.

HHS regulations should require entities operating Exchanges to convert materials that they develop or originate into alternative formats.

Exchanges are likely to provide both materials they have developed as well as materials that were prepared 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 a responsibility for converting those materials into alternative formats when needed by individuals with disabilities.

HHS regulations should permit Exchanges to allocate responsibility for converting materials they did not develop into alternative formats to the entities that developed them and should require entities to specify in their plans whose responsibility it will be to convert specified materials into alternative formats.

³⁴ Lee Rainie, *Internet, Broadband, and Cell Phone Statistics*, (January 2010), Pew Research Institute, Pew Internet & American Life Project, available at www.pewinternet.org/~media/Files/Reports/2010/PIP_December09_update.pdf.

³⁵ *Id.*

³⁶ 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>

When Exchanges distribute materials that were developed by others, the situation is more complex. It has been our experience that despite a longstanding legal obligation of both Title II and Title III entities to provide written materials in alternative formats to individuals with disabilities who need such materials, many entities have not complied with this obligation. We recognize that it could be perceived as unfair to impose on Exchanges a responsibility for converting the materials from Medicaid agencies and insurers into alternative formats when these insurers and agencies have had a longstanding independent obligation to do this that they have not complied with. Yet, individuals with disabilities who need these materials in alternative formats should not be unable to get them in an accessible format from the Exchange, simply because the Medicaid agency or insurer has fallen down on its legal obligation.

We recommend that the HHS regulations require entities operating Exchanges to make clear that when Exchanges provide materials that they did not develop, they must provide them in alternative formats when needed by people with disabilities. Further, the regulations should make clear that Exchanges need not actually be responsible for converting materials they did not originate or develop into alternative formats; they do, however, have to work together with Medicaid agencies and insurers to reach an understanding about whose responsibility it is to convert those materials into alternative formats. Further, this allocation of responsibility for specified materials must be included in the Exchange's plan.

4. Accessibility of Exchange telephone hotlines to individuals with disabilities

Recommendation: HHS regulations should require entities operating Exchanges to submit plans specifying how they will ensure that telephone hotlines are accessible to people with disabilities.

PPACA requires exchanges to operate toll-free telephone hotlines to respond to requests for assistance.³⁷ These hotlines must be accessible to and usable by individuals with disabilities, including individuals with speech and hearing impairments, those with manual or motor impairments, and individuals with disabilities who need the assistance of another person to make phone calls and interact with the hotline. Both the ADA and Section 504 and regulations implementing these laws require entities subject to these laws to provide effective communication with individuals with disabilities.³⁸

Section 508 of the Rehabilitation Act, which applies to HHS, requires electronic and information technology, including voicemail, interactive voice response (IVR) systems, and messaging systems, to be accessible to and usable by people with disabilities, unless it would be

³⁷ PPACA § 1311(d)(4)(B).

³⁸ 42 U.S.C. § 12132; 42 U.S.C. §§ 12182(a); (b)(2)(iv); 28 C.F.R. § 35.160(a); 28 C.F.R. § 36.303(c); 45 C.F.R. § 85.51(a).

an undue burden.³⁹ The Access Board has issued Section 508 accessibility standards for telecommunications products⁴⁰ that the federal government must comply with. Some states have adopted these standards.⁴¹ However, even if states have not, the more general requirements of the ADA and Section 504 apply and require state Exchanges to provide effective remote communication with individuals with disabilities.

Recommendation: HHS regulations should require entities operating Exchanges to specify in their accessibility plans how, if they intend to use automated systems for answering and routing calls or taking messages, they will ensure that people with disabilities, including TTY and relay users, can access the Exchange hotline by phone.

Automated telephone systems that answer calls, route callers to appropriate extensions, and take messages present a number of accessibility problems for individuals with disabilities:

- Individuals who are hard of hearing may have difficulty hearing menu options and voicemail messages, particularly if they are in the high frequency range, the message is spoken too rapidly, or poor-quality technology impairs sound clarity.⁴²
- Some automated systems do not connect directly to teletext telephones (TTYs), so TTY callers must use relay services to place a call. Yet these automated phone systems may not be programmed to provide insufficient time for relay callers to hear and select options, because of the additional time it takes for relay operators to convey prompts, menus, and messages to the relay user, and for the relay user to respond⁴³
- Some automated telephone systems disconnect callers who do not respond within the allotted time period.⁴⁴

³⁹ 29 U.S.C. § 794d(a)(1)(A)(i).

⁴⁰ 36 C.F.R. § 1194.23.

⁴¹ See http://accessibility.gtri.gatech.edu/sitid/stateDocs_printable.php.

⁴² Northern Virginia Resource Center for Deaf and Hard of Hearing Persons, *Guidelines for Voice Menu Systems to Serve Deaf and Hearing Impaired Individuals*, (“Guidelines for Voice Menu Systems”) at 1, available at <http://www.nvrc.org/MediaLibrary/Voice%20Menu%20Sys%205-08.pdf>

⁴³ *Id.*

⁴⁴ *Id.*

U.S. Access Board Advisory Guidance to regulations under Section 255 of the Communications Act⁴⁵ notes that automatic systems for answering phones and routing calls are not usable by deaf and hard of hearing individuals. The Access Board recommends augmenting automated systems with an automated TTY system, or creating an option for deaf callers to opt out of the automated system.⁴⁶

Recommendation: HHS regulations should require entities operating Exchanges specify in their accessibility plans steps they intend to take to train staff on making and receiving relay calls, to ensure that individuals using a relay to place calls have an equal and meaningful opportunity to communicate with the Exchange by phone.

Many individuals with disabilities use relay services, including voice relay and video relay, to communicate by phone. In some instances, individuals answering telephones are not adequately trained on what relay services are and how to accept relay calls, and as a result, hang up on relay callers. In other instances, entities have refused to accept relay calls, insisting that the individual seeking information call “directly.”

Recommendation: HHS regulations should state that individuals with disabilities may use a variety of means to contact entities remotely and make clear that Exchanges cannot choose a single means of remote communication with individuals with disabilities (e.g., TTY) and require all people with disabilities to use it. Exchanges should be required to have policies and procedures in place to communicate with individuals using a wide range of information and communication technology, and to specify in their accessibility plans how they will ensure that the exchange provides effective communication with individuals a range of disabilities and communication abilities and needs.

Some entities assume that as long as they provide one alternative means of communication that they have met their legal obligation to people with disabilities. But one size does not fit all. To take TTYs as an example, even if a hotline has a TTY, it may need to take other steps to ensure effective telephone communication with individuals with disabilities because:

- TTYs are a dying technology, and fewer people with speech and hearing impairments use them now than in the past. Increasingly, people with speech and hearing impairments are using other means to communicate remotely (e.g., captioned telephones, video relay, text-messaging, etc.).

⁴⁵ 47 U.S.C. § 255.

⁴⁶ 36 C.F.R. Part 1193 app. A, § 1193.33(b), 63 Fed. Reg. 5608, 5637.

- TTY is not an effective for some individuals with hearing and impairments. For example, some individuals with hearing and vision impairments cannot use a TTY because they cannot read the print on the TTY machine.
- TTY is not an effective means of communication for individuals with a limited ability to read and write English.

Exchanges must assume that there will always be some individuals with disabilities who cannot use or do not have access to a particular means of communication or particular type of information and communication technology.

Recommendation: HHS regulations should require entities operating Exchanges to describe in their plans how they intend to ensure that Exchange and any contractors operating hotlines purchase and install telecommunications equipment and services that are accessible to people with disabilities, and should describe policies and procedures Exchanges will develop to ensure that web accessibility is achieved, maintained, and monitored. HHS regulations should also require Exchanges to submit these policies and procedures to HHS.

Section 255 of the Communications Act requires telecommunications products and services designed, developed, and fabricated after February 8, 1996 to be accessible to and usable by people with disabilities if readily achievable.⁴⁷ If accessibility is not readily achievable, telecommunications products and services must be compatible with devices and equipment used by people with disabilities to achieve access, such as TTYs and assistive listening devices, if doing so is readily achievable.⁴⁸ The law applies to telecommunications equipment; telecommunications services (including regular telephone calls and computer-provided directory assistance), call waiting, speed dialing, caller ID, call tracing, and repeat dialing; and information services (including voicemail systems and interactive voice response systems).⁴⁹ Yet, because the law does not apply directly to purchasers and users of telecommunications equipment and services, entities purchasing, using, and installing equipment and services may be unaware of the range of accessible options available.

Recommendation: HHS regulations should require entities operating Exchanges to develop policies for handling calls from third parties who are calling on an individual's behalf that ensure that individuals with disabilities who ask another person to call on his or her behalf have an equal and meaningful opportunity to obtain information by phone from the exchange.

⁴⁷ 47 U.S.C. §§153; 255(b); (c); 47 C.F.R. §§ 6.5(a)(1); (b)(1); 36 C.F.R. § 1193.21.

⁴⁸ 47 U.S.C. § 255(d); 47 C.F.R. §§ 6.5(a)(2); (b)(2); 36 C.F.R. § 1193.21.

⁴⁹ 47 U.S.C. §§ 255(b), (c); www.access-board.gov/about/laws/telecomm.htm.

Some individuals with disabilities need a third party to make phone calls on their behalf. NCLEJ is aware of situations in which government agencies and contractors operating government call centers refuse to speak to anyone but the individual on whose behalf information is sought.

Recommendation: HHS regulations should require entities operating Exchanges to communicate with individuals with disabilities through text-based communication if feasible to do so. It should also require Exchanges that choose to make this method of communication available to develop policies to ensure that messages are checked, read, and responded to within reasonable time periods.

Some individuals with disabilities use text-based communication (including email, text messaging, and instant messaging) as a primary means of remote communication.

Recommendation: HHS regulations should Exchanges to specify in their plans the nature and frequency of their training on disability related issues; and should require Exchanges to specify how they intend to ensure that contractors providing Exchange-related services train staff on these issues.

Exchange hotline staff must be trained on how to make TTY and relay calls and answer incoming calls, if the Exchange uses a TTY; Exchange policies and procedures for answering TTYs, checking for messages, etc.; how to make and take incoming relay calls; strategies for communicating effectively with hard of hearing individuals; policies and procedures regarding third party communications and individuals with disabilities; on the obligation to modify policies and practices when necessary for people with disabilities; Exchange policies and procedures for providing written materials in alternative formats to individuals with disabilities and how and where to obtain these materials; and other issues related to serving individuals with disabilities.

5. Exchanges must provide face-to-face interaction when necessary for individuals to have an equal and meaningful opportunity to obtain information and benefit from programs and services of the Exchange

Recommendation: HHS regulations should require entities operating Exchanges to provide in-person information and assistance to individuals who need it and should require plans to specify how they will meet this obligation.

There are some individuals who, for a variety of reasons, are unable to obtain the information they need from websites and telephone hotlines, and some who are unable to apply for benefits online. For example, some individuals with cognitive impairments may be unable to articulate their needs by phone and may not know how to use a computer or the internet; some individuals with mental health problems may become overwhelmed easily and may therefore be unable to complete an application online. In addition, limited-English speaking individuals, individuals with limited literacy or education, and individuals who are not computer literate or do

not have access to computers may not be able to access exchange services that are available solely on-line. For these individuals, face-to-face communication with someone who can assist them in completing a Medicaid application or answer questions about insurance options may be critical. As for those with disabilities, it is required by the ADA, and Section 504, which require entities to provide an equal opportunity to participate and benefit from programs, reasonable accommodations, and meaningful access to programs.⁵⁰

Indiana's recent unsuccessful public benefits modernization initiative, which initially relied on the internet and call centers as replacement for staffed agency offices that provided in-person assistance has demonstrated that vulnerable populations need in-person assistance to help them navigate the complex benefits system. Indiana is still in the process of working out the right balance.

HHS should require that the Exchanges publicize and provide alternatives to online information and services and specify how they will make sure that there are public access computers and assistance (e.g. kiosks in exchange offices or other appropriate public offices) for those who do not have access to a computer.

Relying on limited public sources, such as public libraries, is not adequate, given their limited availability, lack of privacy, etc.

Recommendation: HHS regulations should require entities operating Exchanges that intend to use other organizations to provide face-to-face communication and assistance to individuals who need it to ensure that community partners have the resources and training they need to provide this assistance and explain how they will do so in their plans.

In recent years, some state public benefits agencies have undertaken “modernization” efforts that have typically involved closing some “brick and mortar” public benefits offices, laying off large numbers of agency staff, and establishing telephone hotlines to provide information and accept applications. Some of these modernization efforts have included reliance on “community partners,” such as social service organizations, libraries, and other not-for-profit entities, to serve as entry points into the program, by having computer terminals for the public to use to apply for benefits online. States have asserted that “community partners” would create additional avenues for accessing benefits, and more than make up for office closures.⁵¹ Too often, however, states

⁵⁰ 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).

⁵¹Mary R.Mannix, Cary LaCheen, Henry A. Freedman, and Marc Cohan. “Public Benefits Privatization and Modernization: Recent Developments and Advocacy,” *Clearinghouse Review* (May-June 2008), available at www.nclaj.org/key-issues-privatization.php.

have failed to provide these community organizations with the training and resources needed to provide meaningful assistance to individuals who need help applying for benefits online. Indeed, states have consistently failed to make clear their expectation that these organizations to assist applicants who needed help. State benefits agencies have a legal responsibility to assist individuals in applying for benefits; if they are not going to do it themselves, they must ensure that others do. But this step was largely absent from state efforts. Giving a senior center a computer does not ensure that individuals get the help they need to apply for benefits.

It is critical that HHS require Exchanges that intend to meet their obligation to provide face-to-face contact by using community-based organizations to describe in their plans how they intend to ensure that these organizations have the training and resources they need to assist individuals who need help.

6. HHS Must Set Standards for Careful Development and Deployment of Technology Systems Used by Exchanges to Avoid Unnecessary Implementation Disasters

States, including Indiana, Colorado, and Texas, have made disastrous attempts in recent years to launch ambitious public benefit eligibility modernization projects, through adoption of comprehensive new computer systems, greater reliance on call centers and the internet to accept applications and manage cases, and document imaging to deal with paperwork. While the underlying goals of promoting access were laudable, the execution was seriously flawed, leading to massive denials, delays, and termination of benefits for eligible individuals and litigation. These disasters forced the states to halt further roll-out, or abandon or significantly modify the initiatives. These states continue to struggle today with the aftermath of these botched efforts, including class action litigation.⁵² Some of the litigation has been brought by program beneficiaries (including litigation brought by NCLEJ) and some by states against private vendors (e.g. Indiana is suing IBM over its performance regarding the modernization contract).

⁵² For a summary of pre-deployment and ongoing complaints regarding the Colorado Benefits Management System (CBMS), the integrated computer eligibility system, see, Letter from Denver, Broomfield, Arapahoe and Fremont Counties to Hammons (Co. Dept. of Human Services) and Reinertson (Co. Dept. Of Health Care Policy and Financing) (August 13, 2004) (Att. A) and Letter from Colorado County Social Services Directors Administration to Gov. Bill Ritter et al. (July 12, 2010) (Att. B). For information on the Texas Integrated Eligibility and Enrollment Services Project (TIEES), see “Updating and Outsourcing Enrollment in Public Benefits: The Texas Experience”, Center for Public Policy Priorities (Nov. 2006), available at www.cppp.org; An Audit Report on The Supplemental Nutrition Assistance Program at the Health and Human Services Commission, Texas State Auditor’s Office, Report No 10-026 (March 2010). For information on state modernization efforts in general, see Mannix, LaCheen et al, “Public Benefits Privatization and Modernization: Recent Developments and Advocacy”, *supra* n. 51.

The lessons learned from these failures – some of which are very basic, making the failed state efforts even more troublesome – should be incorporated in HHS requirements for state exchanges. These include the need for:

- careful planning and design with input from key stakeholders;
- piloting and incremental roll-out to work out glitches before full-scale launch;
- adequate funding and staffing;
- thorough training of staff;
- transparency and involvement of the public in implementation;
- adequate systems to deal with low-income people’s needs in the event of problems; and
- active federal oversight to ensure compliance with federal law.

A recent report from the USDA Food and Nutrition Services (FNS)⁵³ examines recent state SNAP modernization initiatives (many of which also involve Medicaid) and makes similar recommendations for future efforts.

HHS should take the lead in identifying best practices and setting standards, based on industry best practices, for performance of basic systems. States should not have to re-invent the wheel, and should have ready access to best practices and the lessons from related efforts. As to the technology standards for exchanges, the Sept. 3, 2010 recommendations of the HIT Policy & Standards Committee Enrollment Group⁵⁴ are a good start. As to specific features, such as telephone call centers, there should be uniform benchmark standards for critical performance measures for specific features, such as telephone call centers (e.g. capacity of the system to handle

⁵³ 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.

⁵⁴ U.S. Department of Health and Human Services, Office of the National Coordinator for Health Information Technology, *HIT Policy & Standards Committee Enrollment Workgroup – Recommendations* (September 3, 2010) available at http://healthit.hhs.gov/portal/server.pt?open=512&objID=1815&parentname=CommunityPage&parentid=7&mode=2&in_hi_userid=11113&cached=true. On September 17, HHS Secretary Kathleen Sebelius adopted these recommendations with minor modifications. See <http://www.ihealthbeat.org/features/2010/federal-policies-help-drive-more-growth-in-eprescribing.aspx>

calls, response times, etc.).

Computer systems, with their embedding of program rules in code, present challenges in assuring that program rules are correctly reflected in code and that the rules underlying automated decisions are decipherable and correct. These challenges raise due process issues for consumers – do they allow for adequate notice to consumers about decisions in their case and an opportunity to be heard? To address these issues, experts suggest requiring 1) that source codes should be public; 2) independent full testing of software using expected and unexpected fact patterns; and 3) that for individual cases the systems should be able to generate audit trails of the facts and rules used in a particular decision in order to provide individuals adequate notice of the basis for decisions.⁵⁵

7. HHS Should Provide Clear Guidance as to How to Determine Eligibility for Lawfully Present Immigrants and Those in Mixed Status Families

To avoid unnecessary confusion on the part of exchanges and individuals and assure that those eligible can access coverage, HHS should provide clear guidance on how to determine eligibility for lawfully present immigrants and those in mixed status families. At least, HHS should bar exchanges from asking inappropriate questions about immigration status and SSNs and require that information collected be used only for program administration and eligibility determination. It is essential to provide clear and accurate information to immigrants so as not to deter eligible individuals from enrolling. HHS instructions should bar exchanges from asking inappropriate questions regarding ineligible family members that may deter participation in child-only coverage. In some cases, states and localities currently fail to administer their programs appropriately with respect to immigrant eligibility and, as a result, deter participation by eligible individuals. HHS should require that exchanges act correctly from the start.

8. HHS Should Require That Entities Operating Exchanges Demonstrate Their Compliance With Title VI Language Access Requirements

HHS guidance outlines the steps that covered entities need to take to provide meaningful access to Limited English Proficient (LEP) individuals. 68 Fed. Reg. 47311 (Aug. 8, 2003). In our experience, states and other covered entities do not fully meet their current obligations. Accordingly, it is critical that as exchanges are established, HHS clearly communicate that entities operating exchanges must get it right with respect to language access, and must demonstrate with specific plans, posted on the web, how they will do so. To begin with, entities operating exchanges must identify the language needs of the population. HHS should provide resources and

⁵⁵ Danielle Keats Citron, “Technological Due Process”, 85 Washington University Law Review 1249 (2008).

instructions as to how to do an effective assessment and identify models so that exchanges do not have to start from scratch. One such model is California’s methodology for identifying language access needs for the Food Stamp population, developed in 2007 in response to our lawsuit, *Vu v. Mitchell*. The methodology, for which the state agency received an FNS Regional Office commendation, uses Census and other data. See Att. C.

9. Additional recommendations

Recommendation: HHS should require entities operating Exchanges to provide an opportunity for public participation in the development of plans for serving individuals with limited literacy, disabilities, limited English proficiency.

Recommendation: HHS regulations should require entities operating Exchanges to post their plans online on Exchange websites.

Recommendation: HHS should provide resources to entities to develop plans for serving individuals with disabilities, those with limited literacy, and those with limited English proficiency, including model policies and procedures, best practices, checklists, and training.

Conclusion

Thank you for giving us an opportunity to provide these comments.

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