

September 4, 2012

Centers for Medicare & Medicaid Services
Office of Strategic Operations and Regulatory Affairs
Division of Regulations Development
Room C4-26-05
7500 Security Boulevard
Baltimore, Maryland 21244-1850

RE: CMS-10440 – Data Collection to Support Eligibility Determinations for Insurance Affordability Programs and Enrollment through Affordable Insurance Exchanges, Medicaid and Children’s Health Insurance Program Agencies

CMS-10438 – Data Collection to Support Eligibility Determinations and Enrollment for Employees in the Small Business Health Options Program

CMS-10439 – Data Collection to Support Eligibility Determinations and Enrollment for Small Businesses in the Small Business Health Options Program

Dear Sir/Madam,

The National Health Law Program (NHeLP) is a public interest law firm working to advance access to quality health care and protect the legal rights of low-income and underserved people. NHeLP provides technical support to direct legal services programs, community-based organizations, the private bar, providers and individuals who work to preserve a health care safety net for the millions of uninsured or underinsured low-income people. With the implementation of the new health reform law, it is critical to ensure that low-income and underserved individuals who are eligible for Medicaid, CHIP, Advanced Premium Tax Credits and cost-sharing assistance are found eligible for relevant subsidies and programs so they can fully benefit from the promises of health reform. The single streamlined application is a critical step to identify which individuals are eligible for which programs and ensure a seamless eligibility process. We appreciate the ability to provide comments on the Data Elements and commend HHS for its significant work on the streamlined application to date.

I. General Principles Relevant for All Data Elements

To meet the goal of a single, streamlined application, HHS should incorporate a number of general principles as it develops the applications for the Exchange and SHOP.

a. Consumer Centric and Simple

The application, whether online, paper, or by telephone, should be as simple as possible, asking questions that are only relevant to determine eligibility for those applying for coverage or to prevent discrimination (such as demographic data), to minimize the burden on applicants. Any program information, regardless of modality should:

- Be written in plain language at an appropriate reading level to accommodate people with low literacy,
- Be offered in multiple languages, meeting the meaningful access standards for persons with limited English proficiency,
- Conform to rules ensuring equal access to persons with disabilities, and
- Be focus group tested for readability and comprehension.

b. Connect Applicants with Available Assistance

The new coverage world of the Affordable Care Act (ACA) is complicated and will likely draw many to apply who are unfamiliar with health insurance, both public and private. Assistance for applicants will be available through a number of resources, such as navigators and toll-free hotlines. Information accompanying the application should let families know how they can get personalized assistance, including the availability of language services. Additionally, HHS should require states to comply with requirements to provide application assistance in a culturally competent manner that effectively communicates to immigrant families.

HHS should require health insurance affordability programs to collect information from assisters as a condition of their access to the online application when helping individuals through the process. The Exchange website should include a portal for navigators and authorized assisters to use that would require them to be authorized to login and to provide specific information to the Exchange and/or state for tracking oversight purposes. Ideally, this portal will provide assisters with additional functionality and tools to ensure that individuals are successfully enrolled, while safeguarding individual data.

c. Consider the Modality in Which People Apply

While the data elements, and likely many of the questions, will be the same regardless of how a family applies, HHS should keep in mind the various modalities when developing the application to maximize the functionality and ease of use, while simultaneously addressing the inherent challenges in each.

i. Online Applications

Of all the modalities, online applications have the greatest potential to simplify and speed the eligibility and enrollment process through the use of dynamic questioning and “real-time” verification. The online application should be “smart,” tailoring the questions based on the responses provided. For example, if an individual looks to be eligible for Medicaid and not for APTCs, he should not be asked any questions about access to

affordable employer-based coverage, as it is not a condition of eligibility for Medicaid. Customizing the application process to fit the circumstances of individual applicants will ease the burden of completing it by skipping questions that are not required instead of expecting individuals to self-identify such questions. However, a pre-screening of eligibility that skips questions should not invalidate the application if it turns out that the applicant is eligible for a different coverage option (i.e., the dynamic process pre-screens the applicant as Medicaid eligible and does not ask about access to affordable employer-based coverage). If additional information is needed, HHS should require the agency to contact the applicant.

Additionally, in an online environment, technology allows the health insurance affordability programs to “ping” various data sources throughout the process and provide applicants with helpful hints along the way. Alternatively, the system could inform applicants of the information on file by automatically pre-populating the application and then asking for verification. Such approaches will likely speed the application process and minimize the amount of follow-up required to resolve any inconsistencies, especially if such verifications are done in real-time. The federal data hub and states sources of data will allow states to provide income information, as well as accelerate the pace of other verification requirements, such as citizenship, through the data match with the Social Security Administration. As much as is feasible, verification of available data should occur as the application proceeds, providing the applicant with feedback and pre-populated data when available.

In the online version, alerts could advise applicants how information will be used before the system takes a next step. For example, when entering the Social Security Number (SSN), immigration status, income, and other personal information, the system could prompt the applicant with a message that tells how the information will be used before the applicant proceeds.

It is also likely that families may need to stop and return to the application at various points in time. As such, HHS should build that functionality into any application system, particularly in an online self-service environment, such as through the establishment of an online account. Additionally, applicants need to have the ability to skip ahead and submit an application once a core set of questions are answered.

ii. Paper Applications

While a paper application will take longer to process than the online application and denies individuals the benefits of real-time eligibility, offering paper applications is an ACA requirement. In fact, individuals will likely continue to widely use paper applications in Medicaid and CHIP and they will continue to be an important avenue to coverage for many. For example, people have different levels of trust with the security of the Web and may be more willing to apply using a paper application.

While tailoring the application to a particular individual is not possible on a paper application, it is still very important that applicants be aware of what questions are

optional and which are required. As such, the paper application in particular will need to have clear instructions and guidance regarding what items are necessary for submission. In developing the application, HHS should consider what data pieces are essential for eligibility determinations, which can be collected after a determination has been made, and which can be skipped entirely. They may also want to consider a shorter application, in addition to the model application, that simply has these core elements.

HHS must ensure the paper application is appropriate for individuals with low literacy levels and those who have difficulty completing forms. Use of plain language, white space, and clear instructions are critical to the success of the paper application. The application should highlight minimal data requirements in a way that individuals are directed to provide the essential data elements needed to constitute a valid application.

iii. Telephone Applications

HHS should not assume that those taking applications over the phone will be able to communicate the online application in a way that easily gathers the relevant information. Instead, HHS and/or the states should develop a script of questions and prompts that is more conversational in nature and should design a worker view that will facilitate their data entry. Alternatively (and ideally), a worker portal should be developed to provide an interactive tool for conducting telephone applications while completing an online application. For limited-English proficient (LEP) individuals, it will be critical to provide quick and easy access to language services through all call centers. In addition, as applicants may also start the process through a hotline or other consumer assistance tool, having the ability to save and transfer application information in a secure fashion will simplify the process for families and prevent them from having to start an application over should they return to complete the application over the phone or choose a different modality such as completing the application online.

d. *Consumer Testing*

We appreciate that HHS has sought stakeholder input in the development of the application, including through ongoing consumer testing. Such efforts should continue and be structured to include families at all income levels, those living in more complex coverage situations, and limited English proficient individuals. For example, it will be very important to test the application on families in situations where the parents are covered in the Exchange and the children are covered under Medicaid or CHIP, to ensure that families can provide the information necessary to be enrolled in the appropriate source of coverage. Additionally, HHS should field test any language that is developed for the instructions, welcome messages, etc., to ensure that applicants understand what HHS is attempting to convey. Also, HHS should test how individuals react to the use of pre-populated applications or “helpful hints” to determine the best way to present readily available data to applicants.

II. Introductory Information, CMS–10440

For many individuals this will be the first time they qualify for any type of financial assistance to secure health coverage, so language that lets individuals know that they may qualify for coverage now even if they were not able to get assistance in the past is very important to include on any application welcome page and accompanying outreach materials. In addition, it may be helpful to provide a dollar figure for the upper eligibility levels to educate individuals about their potential eligibility for financial assistance, as individuals may think they earn too much to be eligible. However these limits should be communicated carefully to avoid discouraging individuals with gross income slightly above the limits because they could still be eligible given the complexity in how income is counted. Additionally, for the paper application, care should be taken not to convey too much narrative text that could discourage individuals with low literacy skills.

The introductory information on the application – both in paper and electronic forms – is critical to ensuring that applicants feel secure in submitting personal and often confidential information to determine their eligibility for a range of programs. This is particularly true for families who may have mixed immigration statuses where some individuals may be eligible for assistance and others may provide application information. We thus recommend that HHS address certain issues right on the front page of the application or the opening webpage of the electronic application.

In particular, to connect immigrants and their family members to coverage and care, Exchanges must overcome immigrants' concerns about the privacy of personal information and about the heightened complexity of eligibility rules pertaining to mixed-status families. Online and paper forms should encourage the applications of eligible family members, even if doing so requires a somewhat longer and more complicated application. Applications should also help ensure that each low-income family can connect to affordable coverage, even if only through the health care safety net. Effective applications will address and overcome barriers such as limited-English proficiency and distrust of government.

This should include statements about the confidentiality of the information provided, legal protections including nondiscrimination, availability of free language services, information about the application process, and how to file complaints both generally and regarding discrimination.

It is critical that HHS determine the appropriate methods to communicate this information, likely through an attached set of instructions. Some introductory information should be on the front page or homepage of the application while other information can be in attachments as long as the attachments or instruction booklet is prominent and provided to all applicants.

RECOMMENDATION: We recommend HHS use the following statements which should be focus tested for literacy and cultural and linguistic appropriateness:

If you do not speak English, we will get an interpreter to help you for no cost to you. Please call (XXX) XXX-XXXX .

Families that include immigrants are welcome to apply for help with health insurance costs.

You may file applications for families that include some members applying for health coverage and others who are not. You do not have to provide a Social Security number (SSN) or citizenship or immigration status for those in your family who are not seeking coverage. We will not delay or deny health coverage because there are family members who are not seeking coverage. For those who do not apply, we can give you information about other ways to get health care.

We will keep all the information you provide private and secure as required by law. We will use it only to check if you are eligible for health insurance.

Under federal law, discrimination is not permitted on the basis of race, color, national origin (language or limited English proficiency), sex, or disability. To file a complaint of discrimination, go to www.hhs.gov/ocr/office/file.

Further, Medicaid and CHIP rules require states to provide assistance with an application. 42 CFR §§435.908 and 457.340(a). These regulations also allow individuals chosen as assisters by individuals to help them navigate application. HHS should require states to provide application assistance in a culturally competent manner that effectively communicates to immigrant families the information they need. Since the application includes applying for Medicaid and CHIP, this regulation applies to the Exchanges as well.

RECOMMENDATION: Inform the household contact at the beginning of the application that assistance is available, in a preferred language, or that the state will accept information from an assister chosen by the application filer.

Finally, we are concerned that some individuals may not understand that applying for insurance will not affect one's immigration status. This is also an area where providing up-front information to applicants and their household members can assist in allaying fears and ensuring all eligible individuals do apply.

RECOMMENDATION: We recommend HHS use the following statements which could be included in instructions that accompany an application:

Applying for health insurance or getting help with health insurance costs will not make you a "public charge" and will not affect your immigration status or chances of becoming a lawful permanent resident (getting a "green card") on that basis. Applying for health benefits won't prevent you from becoming a citizen, as long as you tell the truth on the application.*

** People receiving long-term care in an institution may face barriers getting a green card. If you have concerns or questions about this, you should talk to an agency that helps immigrants with legal questions.*

We also recommend that HHS translate the paper application into multiple languages. This will assist applicants, applicant assisters, navigators, and others who will provide application assistance to limited English proficient (LEP) individuals. We also recommend that HHS create an on-line application in at least the most prevalent languages of those who will be eligible to apply and enroll. And as noted below, under “Taglines”, the on-line application homepage or landing page must have taglines in at least 15 languages that inform LEP individuals how to obtain assistance via phone, email, in-person and via web.

a. Privacy Statement

The application will gather a great deal of personal information from applicants about themselves and their household members. It will be important that individuals are confident that their personal data is secure and will be kept confidential. It is also important to reassure individuals that all information provided will be used solely for the purpose of determining eligibility for affordable health insurance programs. Such language will be especially critical for those residing in mixed-immigration status families.

We support the inclusion of a privacy statement and recommend that it come at the very beginning of the application before the individual begins entering any personal information. Privacy is a distinct issue and applies regardless of whether the applicant is seeking financial assistance and thus it should be kept separate from this and other questions. The privacy statement should make it clear what information the application will collect, how it will be used, who it will be shared with, how it will be stored and for how long. This information should be written in plain English.

Applicants should be provided with information on civil rights protections as state agencies and their contractors, including navigators and brokers, must comply with non-discrimination laws in all areas including marketing, outreach, and enrollment. 45 CFR §§ 155.120(c), 155.205, 155.210, 155.220, 155.1055(b), 156.200(e), 156.220. Informing individuals at the outset of their civil rights protections may encourage some to apply who would otherwise be reluctant.

While privacy, civil rights, and third party authorization is important information, HHS should ensure it is organized in a fashion that does not discourage an individual from starting and finishing the application process. Having this information in a separate set of instructions, along with rights and responsibilities, may be most effective in achieving this goal, particularly in a written application. A box that is clicked for more information is also another way to provide information but may be easily skipped over by applicants. Focus group testing will be important to determine the best content and format for explanatory text.

For immigrant families, privacy and security of personally-identifiable information (PII), including its collection, use, and disclosure by state agencies and their contractors, is of paramount concern. Exchange rules restrict any use and disclosure of information the state collects to only those purposes necessary to carry out specified Exchange and SHOP functions. 45 CFR §§155.260, 155.705(a), 155.210(c)(1)(v), 155.220(d), 155.730(g). Final Medicaid rules extend confidentiality protections to non-applicant information and to the use of an SSN, applying privacy restrictions broadly to renewal and verification processes. 42 CFR §§431.10, 431.300, 431.305, 435.916, 435.945, 435.907, 435.908. A statement providing an assurance of privacy should inform immigrant families that information will not be used for enforcement purposes.

RECOMMENDATION: Provide reassuring messages about protection of privacy with a privacy statement such as:

We will keep all the information you provide private and secure as required by law. We will use it only to check if you are eligible for health insurance.

Further, we support requiring the Exchange to provide notice to applicants of any eligibility determinations made by the Exchange. 45 C.F.R. § 155.310(g). The preamble to the NPRM addressing this section stated several additional intentions for this notice that should be reflected in the application system. Specifically, the preamble specifies that notice will be provided in writing, and that the Exchange will only provide a single notice at the end of the eligibility determination process. The preamble also states that this notice will provide applicants with a record of the steps taken, details of any additional action needed to complete the application process, and information about the appeals process. Finally, the preamble suggests that the notices provided pursuant to this part must comply with § 155.230. HHS should ensure all of these requirements are reflected in the notices provided to eligible and ineligible applicants.

In addition, for individuals who chose not to go through a full Medicaid determination upon initial application and are found eligible for the new Medicaid expansion category, this notice should inform them of their option to request a full Medicaid eligibility determination, as described in § 155.345(c). It should also provide those applicants with information that will help them to understand under what circumstances seeking such a determination might be advantageous to them.

As we mentioned below under “Income and Additional Information,” for many individuals, a full screen and eligibility for “traditional” Medicaid may offer a wider scope of services or services of particular need for the individual. For example, depending on the state and its selected benchmark plan for the new Medicaid expansion population, certain services – for example, home and community based services – may only be available through “traditional” Medicaid. Yet having a full screen for Medicaid may require additional time and documentation which some individuals may choose to forego. Thus, the application must clearly explain the differences between “traditional” and “new expansion” Medicaid so that applicants can make a truly informed decision.

b. Nondiscrimination

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

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

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

¹ See 42 U.S.C. § 2000d (2006).

² See 42 U.S.C. § 2000d-4a (2006).

³ See *Lau v. Nichols*, 414 U.S. 563 (1974).

⁴ See Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition against National Origin Discrimination Affecting Limited English Proficient Persons (HHS LEP Guidance), available at <http://www.gpo.gov/fdsys/pkg/FR-2003-08-08/pdf/03-20179.pdf>.

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

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

Therefore, HHS should consider the nondiscrimination requirements of § 1557, Title VI and § 504 as it develops the application (and approves any state-developed alternatives). Specifically, HHS should work to ensure that the application and application process do not discriminate and provide equitable access to all groups, including individuals with limited English proficiency and disabilities.

c. State Alternate Applications

Given the significant resources and focus testing that HHS has used to develop the application, we are concerned about the process by which HHS will consider and approve state alternate applications. If a state seeks to use an alternative application, we believe the following principles must apply:

- **Transparency** – HHS must ensure that the state consults with consumers and representatives from low-income and underserved communities in the development and testing of an alternate application. In addition, we believe the transparency regulations adopted for § 1115 waivers should apply to any state that seeks approval for an alternative application.
- **Standardization of demographic data collection** – HHS should require states to collect at least the same demographic data, using the same fields and standards, on a state application as on the model application to ensure consistency and comparability in future analysis. States should be allowed to collect more – but not less – data.

d. Notices

We urge CMS to finalize the notices that Exchanges will use to notify individuals of eligibility and submit these to formal notice and comment rulemaking. If a state seeks to use alternates, we recommend that the Secretary also approve the notices using the same transparency requirements as for § 1115 waivers.

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

III. Baseline Applicant Information, CMS–10440

a. Household Contact Information

We fully support the collection of preferred language data as part of the household contact information. The household contact collects is the individual who the Exchange will contact for any questions about the application unless an authorized representative is identified. Language data can help ensure that the Exchange has accurate information for the best way to communicate with the contact. If an Exchange needs to follow-up with a contact who is limited English proficient (LEP) or may need assistive or augmentative communication assistance, the Exchange must do so in a linguistically appropriate manner to comply with § 1557 of the Affordable Care Act as well as Title VI of the Civil Rights Act of 1964 and § 504 of the Rehabilitation Act. For example, if a household contact's preferred language is Spanish, all communications between the Exchange and the contact should occur in Spanish including oral communication and written notices and information. The Exchange must have the necessary resources to provide these services by utilizing translated vital documents and competent interpreters and/or bilingual staff to communicate with the household contact.

We also maintain that the data element for household contact information should include specific information about the scope of a household contact's role (if that person is not an applicant or member of the household). First, the contact person should have a limited scope and duration of representation, solely focused on eligibility matters. The contact should not have authorization to speak to QHPs or healthcare providers on behalf of applicants or access applicants' health records. Second, adult applicants must knowingly consent to have a non-household member contact. The application should document this consent and ensure that consent is informed. We strongly urge HHS to issue specific guidelines governing privacy and the role of a household contact.

Similarly, we urge HHS to clarify the role of an authorized representative. It is vitally important that applicants and assistors understand the differences between being an applicant, an application filer, household contact, "person acting responsibly," and authorized representative. One individual may serve in one, two or three of those roles. Since an individual's rights are at stake, as well as the possibility of having to pay penalties or forego enrollment in insurance affordability programs depending on the eligibility determination, individuals must understand all potential consequences of designating who will fill these roles. The scope and duration of representation should be made clear to the applicant and household contact, as well as the ability to change or revoke authorization at any time. Willful, informed consent should be documented at the signature page of the application. Exchanges must also ensure this information is accurately and effectively communicated to low-literacy individuals who may not understand the terminology and in a culturally and linguistically appropriate manner for individuals who are limited English proficient or the designation may not be informed and legal.

For the same reasons explained below regarding the importance of collecting race and ethnicity data from applicants, we strongly urge HHS to require collection of race and ethnicity data from the household contact, using the IOM Standards. Exchanges must ensure their compliance with ACA Section 1557 as well as existing civil rights laws such as Title VI of the Civil Rights Act of 1964. Without collecting this data, Exchanges will be unable to identify whether discrimination occurs on the basis of a household contact's race or ethnicity.

Pursuant to 42 C.F.R. § 435.908, a Medicaid agency must allow an applicant to choose an individual to accompany, assist, and represent the applicant in the application and redetermination processes. We believe the same should apply for applying through an Exchange since individuals can apply for Medicaid and CHIP through the Exchange. We do wish to clarify, however, that designating an authorized representative for assistance with the application should ***not*** automatically authorize that same individual to serve as the authorized representative for redetermination. Rather, the Exchange should inform enrollees, at the time notices regarding redetermination are sent, whether the individual wishes to designate an authorized representative for the redetermination process.

In addition, we support asking the household contact whether they are applying for coverage for self. If a household contact is not an applicant, then the application must not ask for their citizenship or immigration status, or other information not necessary to determining the eligibility of an applicant, and may ask the contact's SSN only as a request/option, not a requirement.

As noted above in the section "Introductory Information", Medicaid and CHIP rules require states to provide assistance with an application. 42 CFR §§ 435.908, 457.340(a). This allows individuals chosen as assisters by individuals to help navigate applications. HHS should require states to provide application assistance in a culturally competent manner that effectively communicates to immigrant families the information they need.

***Recommendation:* Inform the household contact at the beginning of the application that assistance is available, in a preferred language, or that the State will accept information from an assister chosen by the application filer. We recommend this information appear on the front page of the application. If HHS does not adopt this recommendation, we suggest ensuring that the information is extremely prominent on the front page of any instructions or accompanying materials.**

RECOMMENDATIONS:

- Maintain collection of preferred language of household contact.
- Collect race and ethnicity information from household contact.

- Provide detailed information, in low-literacy and culturally and linguistically appropriate manner, about the role of the household contact, scope of representation, privacy protections, and consent.
- Provide detailed information, in low-literacy and culturally and linguistically appropriate manner, about the role of the authorized representative, scope of representation, privacy protections, and consent.
- Prohibit agents, brokers and assisters from serving as a contact for an applicant.

b. Applicant/Non-Applicant Information

This section is likely to be one of most difficult for applicants, as it will require that they provide information on their tax-filing unit as anticipated for the following year. Who files taxes together is pursuant to IRS rules and can include unrelated people or relatives (such as an aunt who lives with family). These households differ from current Medicaid households and will likely cause confusion for those who are familiar with the Medicaid rules but are less knowledgeable about tax-filing units. In addition, other features of the new MAGI approach, such as children being considered in the household of whoever claims them, regardless of where they reside, as well as differences between Medicaid and the APTC determinations, increase the difficulty and the importance of accurately eliciting information from applicants.

Because of these complexities, HHS must provide clear instructions, definitions, and an easy-to-understand explanation of who should be included and why. For example, definitions of “primary tax payer,” “dependent,” and “household” are a must. HHS should also emphasize that people can still apply and may be eligible for coverage even if they did not file taxes last year. For those who did file, it will also be helpful to encourage them to gather last year’s tax return ahead of time to help guide them through the process. While their family structure may be different in the year to come, this will, at a minimum, provide a starting point. Questions should also be included to determine whether they anticipate any changes (e.g., Do you plan on getting married in the upcoming year?).

As noted in the online application section above, HHS should group together questions or check boxes asking if each individual listed is applying for coverage, as well as seeking financial assistance in paying for coverage. It will be important to define “assistance” so applicants do not overlook this question when, in fact, they may be eligible for help affording health insurance.

For young adults between 20 and 26, the application should ask if they were in foster care. Regulations have not been issued on Medicaid for young adults so it is not clear if eligibility for extended Medicaid is available only to those who were in foster care through the age of 18 or some other criteria. Thus HHS will need to tailor the wording of the question based on the regulation.

i. SSN

We recognize that HHS requests the Social Security Number (SSN) to help quickly verify income information. We are concerned, however, that a request for an SSN may deter some eligible individuals from applying. Thus, the language explaining the request for the SSN is critical. We recommend HHS include specific language, as follows, to explain the request for an SSN:

To complete this application you only need to give SSNs of family members who are applying for health insurance and have SSNs. We use SSNs to check the amount of money you make (your income), to see if you and/or your family can get help with health insurance costs. Providing SSNs may speed up your application process. If you don't have an SSN, we can help you apply for one [call (XXX) XXX-XXXX].

You do not have to give an SSN or immigration status for anyone who is applying for Emergency Medicaid or [state funded program].

The Appendix A table on data elements says that SSNs are optional for non-applicants, implying that they are never optional for applicants. That implication is incorrect, because the SSN may be required of applicants only if they are eligible for an SSN. See 42 CFR §435.910(h), §457.340(b); 45 CFR §155.310(a)(3)(i). This exception is important to mixed-status immigrant families, who may have family members who are eligible for benefits but not eligible for SSNs or eligible only for non-work SSNs. Some applicants who are eligible for emergency Medicaid or for prenatal care under CHIP may not be eligible for an SSN. The regulations specify that they may enroll using a unique identifier.

RECOMMENDATION: Require SSNs only of applicants who are eligible for SSNs, and explain that other applicants may be assigned a unique identifier for purposes of enrollment in coverage.

We support requesting, but not requiring, SSNs of non-applicants. Under § 1902(a)(7) of the Social Security Act, information concerning applicants, beneficiaries, and non-applicants may be used and disclosed only for purposes directly connected with administering the state plan. The state may require an applicant to provide only that information which is necessary to make an eligibility determination, whether for the Exchange, Medicaid, or CHIP, or for a purpose directly connected to administration of the program. 42 CFR §§ 431.300(b), 435.907(e), 435.948(c), 457.340(b); 45 CFR §§155.305(f)(6), 155.310(a), 155.315(i).

RECOMMENDATION: In asking for SSNs, clarify that failure to provide an SSN for a non-applicant does not affect the eligibility of applicant family members. We recommend the following language:

You do not have to provide a Social Security number (SSN) for those in your family who are not seeking coverage. We will not delay or deny health coverage because there are family members who are not seeking coverage.

RECOMMENDATION: Accompany all optional SSN requests with the notifications required by the Privacy Act: at the time the SSN is requested, the agency must provide clear notice to the non-applicant: (1) that furnishing an SSN is voluntary, (2) the authority for the request, and (3) the purpose for the request/ how the SSN will be used.

ii. **Eligible Immigration Status**

We support requiring information on immigration status **only** of applicants. We support asking if the applicant has an “eligible immigration status” and providing a definition of that term, to help applicants and their assisters answer accurately.

RECOMMENDATIONS:

- Provide the definition of “lawfully present” that lists the categories of eligible immigration status in an accompanying instruction booklet or materials or, for the online application, in a linked document that applicants can open in a new tab or webpage while still accessing the application.
- When issuing the model application, expand the list of immigration categories included in the definition of lawful presence to include, at a minimum, children and adults eligible for employment authorizations, and state flexibility to include new categories as they become available. For the full recommendation, see comments from the Center on Children and Families on the proposed definition of “lawfully present.”
- In asking for immigration status, clarify that failure to provide immigration status for a non-applicant does not affect the eligibility of applicant family members. Recommended language is as follows:

You do not have to provide citizenship or immigration status for those in your family who are not seeking coverage. We will not delay or deny health coverage because there are family members who are not seeking coverage.

iii. **Data on Race and Ethnicity**

We strongly support the collection of race and ethnicity information from all applicants and the household contact. Having this data is critical so the Exchange can ensure its compliance with ACA § 1557 and Title VI of the Civil Rights Act of 1964 but also so that it can transmit this information to Qualified Health Plans (QHPs) and navigators for their compliance. We recommend that Exchanges collect race and ethnicity data using the standards put forth by the Institute of Medicine in its 2009 report, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. Exchanges should also provide this data to QHPs which should stratify all of their analyses by race, ethnicity and language data (among other demographic data) to identify any disparities and develop plans to ameliorate them. Further, if any Exchange seeks Secretarial

approval of an alternate application, HHS should require the Exchange to use the same data fields/standards to collect race and ethnicity to allow comparison among and between Exchanges. Without having the same data fields, comparison is near impossible, as we have seen with HHS' allowance of state Medicaid programs to determine their own fields for collecting race and ethnicity.

Collecting race and ethnicity data is critical for a number of reasons:

- **Complying with ACA § 1557 and Title VI of the Civil Rights Act of 1964** – for the Exchange to ensure it does not discriminate against individuals – applicants as well as household contacts – based on their race or ethnicity, the Exchange needs to have data on all applicants so that it can accurately analyze and stratify its data and, if needed, implement corrective action plans.
- **Assisting insurers** – transferring race and ethnicity data of applicants from Exchanges to insurers can assist insurers to comply with § 1557 and Title VI.
- **Assisting navigators** – transferring race and ethnicity data of applicants and household contacts from Exchanges to navigators can assist them to comply with § 1557 and Title VI.
- **Assisting healthcare providers** – if the Exchange collects this data and transfers it to QHPs who transfer it to healthcare providers, it can assist them to comply with § 1557 and Title VI.

Significant research documents disparities in both access to and receipt of healthcare. As the Institute of Medicine has noted:

A fundamental step in identifying which populations are most at risk is to collect data on race, ethnicity, and English-language proficiency. A large body of research has documented disparities in access to, and quality of, health care that are revealed when quality of care measures are examined by these variables.⁶

While the household contact may assist with an initial application, applicants and non-applicant household members likely will interact with the Exchange on an ongoing basis to get information, submit renewal applications, and file complaints. Thus, the Exchange will benefit from having race and ethnicity data on all applicants and non-applicants to prevent discrimination. For example, once an Exchange determines eligibility, applicants and other non-applicant members of the household – rather than (or in addition to) the household contact – may contact the Exchange with questions about selecting a QHP, accessing services, finding support, or to report changes in status/income. Further, the Exchange is the most centralized source for many newly eligible individuals to obtain insurance and thus its goal of one-stop shopping is equally

⁶ Institute of Medicine, [Report Brief: Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement](#) (2009) at 1.

effective for data collection – if the Exchange collects this data and ensures its availability to others who need it, it can preclude multiple requests for the same information.

According to the Institute of Medicine,

While a range of health and health care entities collect data, the data do not flow among these entities in a cohesive or standardized way. Entities within the health care system face challenges when collecting race [and] ethnicity. . . data from patients, enrollees, members, and respondents.⁷

Many insurers historically have expressed the inability to collect race and ethnicity data from enrollees since most enrollees interact with their employers (during enrollment) and health care providers (when seeking services). The Institute of Medicine notes that health plans may have limited opportunities for direct contact with enrollees during which the data can be collected and the need for the data explained.⁸ Aetna, which was the first national commercial plan to start collecting race and ethnicity data for all of its members, has only been able to collect race and ethnicity data from 30-35% of its population.⁹ As the IOM recognized, the:

limited success of Aetna with data collection. . .after several years of concerted effort suggests that the upper limit of data collection by health plans with presently known direct methods may be far below the level necessary for identifying disparities in quality of care through stratified analysis. . .¹⁰

We have the ability to fix this problem and ensure that going forward we have comprehensive collection of race and ethnicity data that is critical to access and prohibiting discrimination across all sectors of the healthcare arena. To ensure that QHPs have comprehensive race and ethnicity data on those it serves, it is essential that the initial streamlined application collect and share it. Given our experience in expanding demographic data collection generally, seeking the addition of new fields to existing data collection instruments and changing systems would likely involve significant costs that can be avoided when we have the historic opportunity to include collection of race and ethnicity at the initial concept and application build. As one example, the Social Security Administration collects data from Medicare applicants but does not collect language data. We learned from HHS and SSA staff that for SSA to begin collecting this data and upgrade its data systems would require hundreds of millions of dollars. If we do not require the collection of race and ethnicity now, later decisions to do so will likely be stymied by high costs.

⁷ Institute of Medicine, [Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement](#) (2009), at 127.

⁸ Institute of Medicine, [Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement](#) (2009), at 133.

⁹ *Id.* at 134.

¹⁰ *Id.* at 134-135.

The other benefit of the Exchange collecting race and ethnicity data is the ability to set national standards which can ensure the ability to analyze and compare across Exchanges and QHPs. For example, current CMS policy for Medicaid allows states to collect race and ethnicity data of enrollees using state-determined categories. This has created widespread variations and an inability to effectively use this data for cross-state comparison. If HHS sets one standard for collecting race and ethnicity data on the single, streamlined application, we believe this will increase consistency and comparability of this data, a critical element to analyzing and comparing data. We recommend that Exchanges collect race and ethnicity data using the standards put forth by the Institute of Medicine in its 2009 report, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. Exchanges should use this data to analyze their processes to ensure they do not discriminate against racial and ethnic groups. And Exchanges should share this data with QHPs and navigators and encourage them to stratify their data by race and ethnicity to identify any disparities in access, services or care. Further, if any Exchange seeks Secretary approval of an alternate application, HHS should require the Exchange to use the same data fields/standards to allow comparison among and between Exchanges. Without having the same data fields, comparison is near impossible, as we have seen with HHS' allowance of state Medicaid programs to determine their own fields for collecting race and ethnicity.

The benefit of an Exchange collecting and providing race and ethnicity data to QHPs is in ensuring compliance with ACA § 1557 and Title VI. QHPs should use this data to stratify their own quality and claims data to identify and correct healthcare disparities. QHPs can also use stratified data to indicate on which areas market-based strategies to reduce health and health care disparities should focus.

Healthcare providers and navigators also need this data to ensure compliance with ACA § 1557 and Title VI, and identify any potential discrimination or healthcare disparities. If an Exchange collects this data and makes it readily available to its network providers, a healthcare provider can ensure that it is equitably treating all individuals regardless of race or ethnicity.

Further, collecting this data on all applicants and non-applicants will ensure Exchanges (and QHPs and navigators) will have the information necessary to ensure compliance with Title VI of the Civil Rights Act of 1964 as well as § 1557 of the ACA.

Under Title VI of the Civil Rights Act of 1964,¹¹ no federal funds can be used in a discriminatory manner, whether intentionally, or, pursuant to federal regulations, through disparate impact. Title VI applies to all programs receiving Federal financial assistance, including private entities. Congress has defined covered programs to include “an entire corporation . . . if assistance is extended to such corporation . . . or which is principally engaged in the business of providing education, health care”¹² A program also includes “[t]he entire plant or other comparable, geographically separate facility to which

¹¹ See 42 U.S.C. § 2000d (2006).

¹² 42 U.S.C. § 2000d-4a (2006).

Federal financial assistance is extended, in the case of any other corporation, partnership, private organization, or sole proprietorship.”¹³ Since Exchanges are receiving federal funds to initiate their programs, they are subject to Title VI. Further, HHS’ regulations governing Exchanges prohibit discrimination. QHPs are also subject to Title VI because they will receive federal financial assistance through the payment of premiums for individuals receiving advanced payment tax credits on behalf of eligible individuals and to offset cost-sharing for low-income individuals. HHS’ Office for Civil Rights has outlined expectations for compliance with Title VI in its *Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons* (LEP Guidance) available at <http://www.justice.gov/crt/about/cor/lep/hhsrevisedlepguidance.php>. Exchanges and QHPs must ensure that they do not discriminate against anyone served, which likely will include many non-applicants who contact the Exchange or QHPs on behalf of applicants/enrollees.

In addition to Title VI, Exchanges and QHPs must comply with the nondiscrimination provisions of § 1557 of the ACA. Section 1557 expressly extended the protections of Title VI to “any health program or activity, any part of which is receiving **Federal financial assistance, including credits, subsidies, or contracts of insurance**, or under any program or activity that is administered by an Executive Agency or any entity established under this title.”¹⁴ The nondiscrimination protections apply to any financial assistance provided through the ACA, including the tax credits and cost-sharing subsidies in the Exchanges.¹⁵ This provision also applies to all entities created by Title I of the ACA which includes Exchanges and those entities participating in the Exchanges, including QHPs. QHPs have a responsibility to prohibit discrimination and healthcare disparities, in addition to Title VI of the Civil Rights Act of 1964, because of these nondiscrimination requirements.

The data elements specify collecting race and ethnicity data only from applicants. We urge CMS to include collection of race and ethnicity data from **all** applicants and non-applicants. This is particularly important for applicants who are minors or have legal guardians to have the data of their parent/guardians as well. We believe Exchanges should collect this from all non-applicants because the Exchange will not be able to predict who in the household it will interact with and cannot discriminate against anyone in the household who may seek information or assistance for applicants. For example, a non-applicant may need to assist household members with applications and obtaining information from an Exchange. This could include a non-applicant child seeking coverage for an older parent; an adult child with developmental or other mental disabilities; or other family members who may need assistance. Since we cannot accurately to initially predict how individuals and households will interact with the Exchange, we believe HHS should expand race and ethnicity data collection as widely as possible to ensure effective methods are in place to ensure compliance with § 1557 and Title VI.

¹³ 45 C.F.R. § 80.13(g) (2010).

¹⁴ *Id.* § 1557(a) (2010) (emphasis added).

¹⁵ *Id.*

For more on the application of Title VI and § 1557 to Exchanges and QHPs, see NHeLP's Short Paper, *The Application of PPACA § 1557 and Title VI of the Civil Rights Act of 1964 to the Health Insurance Exchanges*, available at http://www.healthlaw.org/index.php?option=com_content&view=article&id=511:health-reform-short-papers&catid=51.

While some may posit that collecting race and ethnicity at the provider level would be useful due to the face-to-face interaction, we do not believe this is the optimal place for collection. First, some individuals may visit multiple providers in one year. If these providers do not all utilize the recommended best practice of having patients' self-report race and ethnicity data, it is possible that one patient may have different races attributed on different claims (e.g. Provider A asks patient to self-report and records Hispanic while Provider B assumes patient is non-Hispanic). No method would exist to reconcile or correct this information. Second, collecting at the provider necessarily duplicates efforts since patients may see multiple providers or have multiple visits and data would be reported each time. If collected on enrollment, the data is collected once and transmitted to all parties who can benefit from its use. Further, given that claims databases are likely not going to interoperate with Exchange enrollment databases, it is unlikely that Exchanges would be able to easily access this data if reported on claims or at the provider level. Since the Exchange needs this data itself and also has the capacity to transfer enrollment data to QHPs, the optimal time to collect this data is at enrollment. Indeed HHS recognized this in historical discussions when advocates suggested amending HIPAA and other claims forms to collect race and ethnicity data; HHS stated that it was more appropriate to collect this data at enrollment rather than on claims.

RECOMMENDATION: To encourage individuals to provide this data, we believe HHS should include a statement on the application explaining the need for this data. We suggest the following:

We ask for your race and ethnicity so that we can review application information to make sure that everyone gets the same access to health care. This information is confidential and it will not be used to decide what health program you are eligible for. You do not have to provide your race and ethnicity to complete the application.

iv. Data on Sex

We also fully support collecting data on the sex of applicant(s). Comprehensive and accurate data collection is necessary to identify, understand, and eventually eliminate sex disparities in health. Such data will help researchers, policy makers, and public health workers understand where sex disparities exist, target interventions to the populations that need them most and tailor those interventions to the specific needs of the community. Accurate data collection for sex also makes it possible to understand and address intersectional health disparities. For example, African-American women

have a higher prevalence of diabetes than either white women or African-American men.¹⁶ Without accurate data on race and sex, important health disparity information would be lost. The higher prevalence of diabetes in African-American women would be masked if data were collected and reported on sex or race alone. Data on sex must therefore be collected throughout the health care system in a way that allows for meaningful analysis of sex disparities in health and that aids in the analysis of intersectional health disparities.

As discussed above, the Data Elements on this application are important tools for ensuring that the Exchanges and QHPs fully comply with the nondiscrimination requirements of ACA §1557. Section 1557 includes protections on the basis of sex, which the Office for Civil Rights at the Department of Health and Human Services has indicated includes gender identity.¹⁷ Therefore, the data collected by the application should also reflect the health insurance needs and experiences of the transgender population. To do so, the question regarding sex should specify *sex assigned at birth*, which is the sex listed on the original birth certificate. For non-transgender people, this element is identical to traditional concepts of sex as male or female. This male/female Data Element can be combined with the Data Element on gender identity described below to provide accurate information on the transgender population.

v. Data on gender identity

Sources such as the Institute of Medicine¹⁸ and Healthy People 2020¹⁹ report that transgender people, particularly transgender people of color, are more likely than the general population to be uninsured and face significant health and health care access disparities. The disparities transgender individuals face include higher rates of conditions such as HIV/AIDS, substance use, and mental health concerns such as depression, anxiety, and suicide, as well as obstructed access to urgent and routine medical care. The 2011 *National Healthcare Disparities Report* from the Agency for Healthcare Research and Quality (AHRQ) identifies transgender individuals as the most vulnerable of the lesbian, gay, bisexual, and transgender (LGBT) populations.²⁰

¹⁶ Brancati, F.L. et al., (2000). Incident Type 2 Diabetes Mellitus in African American and White Adults
The Atherosclerosis Risk in Communities Study, *Journal of the American Medical Association*, 283, 2253-2259.

¹⁷ Letter from Leon Rodriguez to Maya Rupert. 2012. Available from <http://www.scribd.com/doc/102491874/HHS-Response-1557-7-12-12>.

¹⁸ Institute of Medicine. 2011. *The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding*, available at <http://www.iom.edu/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx>.

¹⁹ Department of Health and Human Services. 2010. *Lesbian, Gay, Bisexual, and Transgender Health*, available at <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=25>.

²⁰ Agency for Healthcare Research and Quality. 2012. *National Healthcare Disparities Report*, available at <http://www.ahrq.gov/qual/nhdr11/nhdr11.pdf>.

A lack of health insurance coverage is a major driver of health and health care access disparities among the transgender population. According to the AHRQ report, which cites data from a national study of more than 6,400 transgender individuals, more than 30 percent of transgender people of color lack health insurance coverage, and approximately half of transgender respondents had to postpone medically necessary care for financial reasons.²¹ Further, transgender people are more than twice as likely as the general population to make less than \$10,000 per year,²² meaning that a significant proportion of the transgender population will be newly eligible for Medicaid or eligible for Exchange subsidies. To identify and connect these individuals with appropriate coverage, Exchanges and Medicaid programs should collect data on gender identity in addition to data on sex.

In the “Applicant” and “Applicant/Non-Applicant” data elements we therefore recommend the addition of a Data Element on gender identity. Like race and ethnicity, this Element should be *optional*, since the Affordable Care Act prohibits rating on the basis of sex, including gender identity, and health status, including a transgender medical history. The Element described below is based on similar questions already in use on some state and local health surveys and federally supported health programs.²³ The use of this Element, like demographic Data Elements asking about race and ethnicity, should include training for individuals involved in collecting and processing these data. Information on staff training for using the gender identity Data Element can be found in the 2012 “Guidance for HIV Surveillance Programs: Working with Transgender-Specific Data” developed by the Centers for Disease Control and Prevention.²⁴

RECOMMENDATION: Include a question asking gender identity as follows:

What is your current gender identity? Gender identity is an individual’s internal understanding of one’s own gender.

- *Male*
- *Female*

²¹ *Id.* (citing Grant, JM, Mottet LA, Tanis J, et al. 2011. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*, available at http://www.thetaskforce.org/reports_and_research/ntds.

²² Grant, JM, Mottet LA, Tanis J, et al. 2011. *Injustice at Every Turn: A Report of the National Transgender Discrimination Survey*, available at http://www.thetaskforce.org/reports_and_research/ntds.

²³ See e.g. Health Resources and Services Administration. 2012. “Annual Ryan White HIV/AIDS Program Services Report (RSR) Instruction Manual.” Available from <http://hab.hrsa.gov/manageyourgrant/files/hab2011rsrinstrmanual.pdf>

U.S. Substance Abuse and Mental Health Services Administration. 2012. Government Performance and Results Act (GPRA) “Client Outcome Measures for Discretionary Programs Question-By-Question Instruction Guide.” Available from https://www.samhsa-gpra.samhsa.gov/CSAT/view/docs/SAIS_GPRA_Services_Tool_QxQ_final.pdf.

²⁴ Centers for Disease Control and Prevention. 2012. “Guidance for HIV Surveillance Programs: Working with Transgender-Specific Data.”

- *Transgender, female to male*
- *Transgender, male to female*

vi. **Data on Relationship Status and Sexual Orientation**

Research shows that family structures today are increasingly diverse.²⁵

- Only 25 percent of American households consist of a married man and woman and their children;
- Nearly 20 million children under the age of 18 (1 in 4) live with one parent; and
- Two million children are being raised by same-sex couples²⁶

To accurately reflect the current realities of families, state Exchanges and Medicaid programs must be able to capture information about same-sex couples and their children, among other diverse family structures. We therefore recommend that the application allow respondents to indicate that they are in a domestic partnership or civil union, in addition to the option indicating marriage, and that the application consistently uses “Parent 1” and “Parent 2” instead of “Mother” and “Father.”

A demographic characteristic closely related to relationship status is sexual orientation. To better understand the significant health disparities associated with minority sexual orientation, the application should also include an *optional* Element regarding sexual orientation. The following Data Element is based on research by the Williams Institute, a national sexual orientation and gender identity law and policy think tank at the UCLA School of Law.²⁷ It is currently being used successfully on numerous state and local surveys and in administrative data collection efforts by federally supported health programs.²⁸ It is also the basis for current efforts by the National Center for Health Statistics to develop a sexual orientation question for federally supported health surveys.²⁹ The use of this Element, like demographic Data Elements asking about race,

²⁵ Talaris Institute. 2010. “Parenting in a Changing World.” Available from <http://www.talaris.org/our-research/parenting-in-a-changing-world/>.

²⁶ Movement Advancement Project, Center for American Progress, and Family Equality Council. 2011. “All Children Matter: How Legal and Social Inequalities Hurt LGBT Families.” Available from <http://www.children-matter.org>.

²⁷ The Williams Institute. 2009. “Best Practices for Asking Questions about Sexual Orientation on Surveys.” Available from <http://williamsinstitute.law.ucla.edu/wp-content/uploads/SMART-FINAL-Nov-2009.pdf>

²⁸ See California Health Interview Survey. 2011. “CHIS 2009 Adult Questionnaire Version 3.4.” Available from <http://www.chis.ucla.edu/pdf/CHIS2009adultquestionnaire.pdf>; Massachusetts Department of Health and Human Services. 2012. “2012 Behavioral Risk Factor Surveillance System Questionnaire.” Available from <http://www.mass.gov/eohhs/docs/dph/behavioral-risk/survey-12.pdf>

²⁹ Department of Health and Human Services. 2011. “Plan for Health Data Collection on Lesbian, Gay, Bisexual, and Transgender (LGBT) Populations.” Available from <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlid=209>

ethnicity, and gender identity, should include training for individuals involved in collecting and processing these data.

RECOMMENDATION: Include a question asking sexual orientation as follows:

Do you consider yourself to be:

- *Straight or heterosexual*
- *Gay or lesbian*
- *Bisexual*

vii. Data on Preferred Language

Similar to collecting race and ethnicity, collecting language data is critical for compliance with civil rights laws as well as planning to ensure that Exchanges, QHPs, providers, and navigators have appropriate language services available. The application should collect data on whether an individual speaks a non-English language or ASL or reads Braille so that the Exchange – as well as QHPs, navigators and healthcare providers – can provide appropriate assistance.

According to the Institute of Medicine:

Compelling evidence exists that patients with limited English-language proficiency encounter significant disparities in access to health care, decreased likelihood of having a usual source of care, increased probability of receiving unnecessary diagnostic tests, more serious adverse outcomes from medical errors, and drug complications.³⁰

IOM also noted that local, state, and federal agencies all have roles to play in gathering and analyzing data for use in designing interventions and informing policy.³¹ Further, the IOM stated that:

By inclusion of this standardized information in electronic health record systems, it will be possible to stratify quality performance metrics, combine data from various sources, and make comparisons across settings and payment mechanisms.³²

The data elements specify collecting preferred language data only from the Household Contact. We urge CMS to include collection of language data from ***all*** applicants and non-applicants. This is particularly important for applicants who are minors or have legal guardians, of their parent/guardians as well. We believe Exchanges should collect this

³⁰ Institute of Medicine, [Report Brief: Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement](#) (2009) at 2.

³¹ *Id.*

³² *Id.* at 3.

from all non-applicants because the Exchange will not be able to predict who in the household it will interact with. For example, an LEP non-applicant may need to assist household members with applications and obtaining information from an Exchange. This could include a non-applicant assisting an older individual (e.g. the applicant is the parent of the non-applicant who may have employer-based insurance) in applying or selecting coverage; an adult child with developmental or other mental disabilities; or other family members who may need assistance. Since we are unable to accurately to initially predict how individuals and households will interact with the Exchange, we believe HHS should expand language data collection as widely as possible to ensure effective language services are in place.

While having the preferred language of the household contact is important, the Exchange needs to collect the preferred language for all applicants so it has a complete understanding of the populations it serves. And in situations where a parent or guardian may not be an applicant (for example in the situation of an LEP grandparent eligible for Medicare taking care of a grandchild or in mixed-status families where some individuals may not be eligible for coverage but will coordinate the health care for eligible applicants), the Exchange needs this information so that it can have the appropriate services in place to serve those who call or interact with the Exchange. Having this data is important for myriad reasons including:

- **Planning** – for the Exchange to identify and monitor what language services it needs to have in place as it likely will have interactions with applicants in addition to the designated household contact.
- **Complying with ACA § 1557, Title VI of the Civil Rights Act of 1964, and Section 504 of the Rehabilitation Act** – for the Exchange to ensure it does not discriminate against LEP individuals, individuals who are deaf or hard of hearing or blind or visually impaired, the Exchange needs to have data on all applicants so that it can accurately analyze and stratify its data and, if needed, implement corrective action plans.
- **Assisting insurers** – transferring preferred language data from Exchanges to insurers can assist insurers in having comprehensive data on all enrollees to ensure effective provision of language services and prevent discrimination.
- **Assisting navigators** – providing language data to navigators for their service planning to ensure effective provision of language services and prevent discrimination.
- **Assisting healthcare providers** – if the Exchange collects this data and transfers it to insurers, insurers can provide it to healthcare providers who can benefit from knowing in advance which patients need language services.

Almost 20% of the population speaks a language other than English at home. Over 24 million, or 8.7% of the population, speak English less than very well and should be

considered limited English proficient (LEP) for healthcare purposes.³³ This includes 47% of Spanish speakers, 33% of speakers of other Indo-European languages, 49% of speakers of Asian and Pacific Islander languages, and 30% of speakers of other languages.

Numerous studies have documented the problems associated with a lack of language services, including one by the Institute of Medicine, which stated that:

Language barriers may affect the delivery of adequate care through poor exchange of information, loss of important cultural information, misunderstanding of physician instruction, poor shared decision-making, or ethical compromises (e.g. difficulty obtaining informed consent). Linguistic difficulties may also result in decreased adherence with medication regimes, poor appointment attendance, and decreased satisfaction with services. (Cites omitted.)³⁴

Many states already collect language data on all applicants pursuant to requirements in Medicaid managed care regulations so only collecting language data from a household contact would actually reduce rather than expand data collection. And in California, all private health plans subject to the provisions of S.B. 853 must also collect this data.

While the household contact may assist with an initial application, applicants and non-applicant household members likely will interact with the Exchange on an ongoing basis to get information, submit renewal applications, and file complaints. Thus, the Exchange will benefit from having language data on all applicants and non-applicants to appropriately identify and plan for needed language services. For example, once an Exchange determines eligibility, applicants and other non-applicant members of the household – rather than (or in addition to) the household contact – may contact the Exchange with questions about selecting a QHP, accessing services, finding support, or to report changes in status/income. Further, the Exchange is the most centralized source for many newly eligible individuals to obtain insurance and thus its goal of one-stop shopping is equally effective for data collection – if the Exchange collects this data and ensures its availability to others who need it, it can preclude multiple requests for the same information and improve language services.

According to the Institute of Medicine,

While a range of health and health care entities collect data, the data do not flow among these entities in a cohesive or standardized way. Entities within the health

³³ American Community Survey, 2006-2008, *Selected Social Characteristics in the United States: 2006-2008*; also American Community Survey, 2008, *Language Spoken at Home by Ability to Speak English for the Population 5 Years and Over*, Table B16001, available at <http://factfinder.census.gov>.

³⁴ Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health*, at 17 (2002).

care system face challenges when collecting . . . language data from patients, enrollees, members, and respondents.³⁵

Many insurers historically have expressed the inability to collect language data from enrollees since most enrollees interact with their employers (during enrollment) and health care providers (when seeking services). The Institute of Medicine notes that health plans may have limited opportunities for direct contact with enrollees during which the data can be collected and the need for the data explained.³⁶ Aetna, which was the first national commercial plan to start collecting race and ethnicity data for all of its members, has only been able to collect language data from 30-35% of its population.³⁷ As the IOM recognized, the:

limited success of Aetna with data collection. . . after several years of concerted effort suggests that the upper limit of data collection by health plans with presently known direct methods may be far below the level necessary for identifying disparities in quality of care through stratified analysis. . .³⁸

We have the ability to fix this problem and ensure that going forward we have comprehensive collection of language data that is critical to access and prohibiting discrimination across all sectors of the healthcare arena on over 32 million individuals. To ensure that QHPs have comprehensive language data on those it serves, it is essential that the initial streamlined application collect and share it. Given our experience in expanding demographic data collection generally, seeking the addition of new fields to existing data collection instruments and changing systems in the future would likely involve significant costs that can be avoided when we have the historic opportunity to include collection of preferred language at the initial concept and application build. As one example, the Social Security Administration collects data from Medicare applicants but does not collect language data. We have learned from HHS and SSA staff that for SSA to begin collecting this data and upgrade its data systems would require hundreds of millions of dollars. The lack of readily available centralized language data on Medicare enrollees inhibits HHS from identifying disparities in Medicare based on language barriers and Medicare providers from identifying language needs of patients in advance to ensure adequate planning and compliance with civil rights laws.

The other benefit of the Exchange collecting language data is the ability to set national standards which can ensure the ability to analyze and compare across Exchanges and QHPs. For example, current CMS policy for Medicaid allows states to collect race and ethnicity data of enrollees using state-determined categories. This has created widespread variations and an inability to effectively use this data for cross-state

³⁵ Institute of Medicine, [Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement](#) (2009), at 127.

³⁶ Institute of Medicine, [Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement](#) (2009), at 133.

³⁷ *Id.* at 134.

³⁸ *Id.* at 134-135.

comparison. Regarding language data, some states collect “primary” language, some states collect “preferred” language, and some collect information both on preferred spoken and written information. If HHS sets one standard for collecting language data on the single, streamlined application, we believe this will increase consistency and comparability of this data, a critical element to analyzing and comparing data. We recommend that Exchanges collect language data using the standards put forth by the Institute of Medicine in its 2009 report, *Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement*. Exchanges should use this data to determine the nature and types of language services that it needs to provide. For example, the data may document trends in language needs that identify new languages into which the Exchanges should translate materials and provide oral communication. Without this data, it will be more difficult for Exchanges to conduct strategic planning to meet the needs of its LEP consumers. And Exchanges should share this data with QHPs and navigators and encourage them to use this data for service planning and stratification of quality data by demographic data. Further, if any Exchange seeks Secretary approval of an alternate application, HHS should require the Exchange to use the same data fields/standards to allow comparison among and between Exchanges. Without having the same data fields, comparison is near impossible, as we have seen with HHS’ allowance of state Medicaid programs to determine their own fields for collecting race and ethnicity.

The benefit of an Exchange collecting and providing language data to QHPs is for the QHP to appropriately plan for needed language services, ensure compliance with ACA § 1557 and Title VI, identify whether certain language groups meet thresholds for translating documents, and provide customer service in a culturally and linguistically appropriate manner. Further, QHPs can use this data to stratify its own quality and claims data to identify and correct healthcare disparities. QHPs can also use stratified data to indicate on which areas market-based strategies to reduce health and health care disparities should focus.

Healthcare providers and navigators need this data to plan for needed language services, ensure compliance with ACA § 1557 and Title VI, identify whether certain language groups meet thresholds for translating documents, and identify any potential discrimination or healthcare disparities. If an Exchange collects this data and an insurer makes it readily available to its network providers, a healthcare provider can identify patients’ language needs in advance of a patient visit and ensure needed language services are in place. This will reduce wasteful inefficiencies for both provider and patient when a new patient may arrive and an interpreter or bilingual staff is not available because the provider did not know the patient needed language services.

Further, collecting this data on all applicants and non-applicants will ensure Exchanges (and QHPs and navigators) will have the information necessary to ensure compliance with Title VI of the Civil Rights Act of 1964 as well as § 1557 of the ACA.

viii. Taglines

We also urge HHS to ensure that the application – both paper and electronic versions – effectively informs LEP individuals how to obtain assistance in completing the application. We also recommend that HHS translate the application into multiple languages.

In its earlier regulations, HHS requires that Exchange Websites must provide meaningful access to information for LEP individuals and the same should apply to the application itself. This will ensure that Exchanges comply with Title VI and Section 1557. The taglines should explain to LEP individuals how to access information that is not translated and direct individuals to call the Exchange to access oral communication of the application content and assistance with submitting an application.

The development of the tagline is an easy process and should not involve significant cost or time. In fact, HHS could adopt existing taglines from other agencies or organizations for use by the Exchanges. For example, California has a tagline is available in 13 languages. As another example, the Arizona Department of Economic Security has a “Language Notification Flyer” that states – “If you need this notice translated into your language, please call xxx-xxx-xxxx or xxx-xxx-xxxx.” The notice includes 23 languages – 9 of which are included in SSA’s 15.

RECOMMENDATION: We suggest that the tagline for the application could state:

IMPORTANT: You can get an interpreter at no cost to talk to you about getting health insurance. To get an interpreter or to ask about written information in (your language), call 1-XXX-XXX-XXXX. Someone who speaks (your language) can help you. If you need more help, call the State Ombuds Office at XXX-XXX-XXXX.

HHS should translate the tagline into other prevalent languages or require the Exchanges to translate the tagline into the top 15 language groups in its service area likely to use the application, using state Census data or other relevant data. Preferably the entire tagline should be on the opening webpage of the Exchange as well as the application. But if it is not, then the homepage should include a direct link to the taglines and could use the name of the language as the link. For example, SSA’s “Multilingual Gateway” (<http://ssa.gov/multilanguage/>) includes the names of 15 languages in English and the non-English language and when an individual clicks on the language, the individual is taken to a webpage with information in that language. For the paper application, HS should ensure the taglines are clearly visible in a prominent location so applicants and potential applicants understand how to seek assistance. This is a small price to pay to ensure meaningful access to the Exchanges for LEP beneficiaries.

OVERALL RECOMMENDATIONS FOR BASELINE APPLICANT INFORMATION:

- Ensure the application and application process complies with existing federal civil rights laws (including ACA § 1557, Title VI, and § 504 and § 508 of the

Rehabilitation Act) and collects sufficient data for Exchanges, QHPs, navigators and providers to document compliance with these laws.

- Collect preferred language data from household contact, **all** applicants and, for applicants who are minors or incapacitated, from any non-applicant parent and guardian.
- Utilize IOM standards for collecting race, ethnicity and language.
- Require any Exchange seeking approval of an alternate to the single streamlined application to collect demographic data using the same standards as the model application and comply with transparency requirements during development.
- Include taglines in 15 languages on the application – both paper and electronic versions – informing LEP individuals how to access help applying for assistance.
- Collect data on sex assigned at birth, as well as optional data on gender identity and sexual orientation, from **all** applicants.
- Collect data on relationship status that includes the option of domestic partnerships and civil unions, and refer to “Parent 1” and “Parent 2” rather than “Mother” and “Father.”

IV. Income and Additional Information, CMS–10440

a. Income Information

Perhaps even more so than determining their tax-filing household, gathering income information will be difficult for applicants. As such, the questions should be straightforward and require reporting only what is available to the applicant, for example, by allowing reporting of income as it appears on a paystub, regardless of how frequently one is paid. Additionally, it will vital to provide clear guidance to applicants regarding which wage information (i.e., pre-tax) to report, perhaps by referencing a particular location on the paystub or common terms used to reference the appropriate income amount, such as “gross income.” However, HHS should avoid technical terms if at all possible and provide concise, easy-to-understand definitions to any terms that are outside common parlance. HHS should also consider those who may not be paid in the typical fashion – such as those who are self-employed, those working for multiple employers, those who do piece work, and those who receive cash income. They may not have access to a pay stub that allows for easy reference, so HHS must provide accommodations, both during the application and verification processes, so these individuals are able to provide accurate information without undue burden.

It will also be essential to communicate why accurate income information reporting is important. For example, HHS needs to provide clear information to the individual that the tax payer may have to pay back a portion of the premium credit if income ends up being higher than projected and conversely, that if income is below what was projected, the tax payer could also be eligible for a refund. HHS should communicate this information clearly, but also in a manner that does not discourage applicants from seeking financial assistance to pay for health insurance coverage. HHS should repeat these reassuring yet cautionary messages during the enrollment process when the applicant decides how much of the premium tax credit to take in advance.

We believe that other, more accurate, methods exist to determine income for a particular time period than asking someone to provide their currently monthly income. To determine income, for whichever time period is appropriate for the health insurance affordability program, applicants should provide income as reported on their paystub and the frequency of payment. The receiving agency can then make the appropriate calculation.

In an online environment, the application could provide a smart tool or worksheet for the applicant to enter basic wage data that then makes the calculation to determine monthly income. HHS could also devise a smart tool or worksheet to help seasonal workers or contract workers provide accurate income information. For example, a smart tool could provide a drop down box showing multiple pay frequencies such as weekly, bi-weekly, monthly, quarterly or allow the individual to insert a specific date range. Such a tool should allow applicants to enter multiple jobs that accumulate to calculate a monthly income.

In this same section, HHS suggests it will also ask specifically about sources of income other than employment income. Inquiring about these various income sources, such as Social Security benefits and unemployment benefits in a similar fashion to how we propose asking about earnings would simplify the process for applicants and result in a more accurate overall assessment of an applicant's income. Additionally, in an online application, HHS should program any more detailed questions (regarding amount and frequency) to appear only if the applicant reported a particular source of income.

An online environment, tied to a data hub, provides some additional benefits for collecting income information. As the applicant works through the process, the health insurance affordability program could verify critical information as the applicant completes the application. If discrepancies are found, the applicant could be alerted and asked to provide clarification or additional information that may resolve the difference. Alternatively, the eligibility system could, to some extent, pre-populate the application form. For example, the system could begin by informing applicants of the income information on file in quarterly wage databases and asking if it is accurate. Such approaches will likely speed the application process and minimize the amount of follow-up required to resolve any inconsistencies, especially if such verifications are done in a real-time fashion. Extensive focus group testing will be critical to determining what works best in asking applicants to provide or validate income information.

With specific regard to "Current/Monthly Income", we support the flexibility in the application design to skip this question. Individuals who have infrequent income may not be able to accurately describe the frequency of their income. People with non-traditional income sources may not be able to accurately report adjustments to income.

Assuming that HHS has provided the data elements in the order they will fall on the application, we suggest asking for data on "Current/Monthly Income" prior to "Projected Annual Income." Many individuals may not accurately know their projected annual

income but determining the monthly income first can inform the determination of annual income.

We also appreciate that the data element for “Projected Annual Income” includes an option for “don’t know.” We believe this is critical given the inability of many individuals to provide this information. Asking applicants to “project” forward what they anticipate earning in any given year will be extremely difficult and HHS should avoid this if at all possible. For example, estimating how much your weekly paycheck will total at the end of the year may be a complicated task for those with limited math skills. Additionally, trying to account for any changes the family may experience, such as a change in their job or increase in salary, will be an added burden. However, other ways exist to arrive at projected annual income without requesting such a top-line figure from applicants.

To start, the application should not ask applicants to calculate their annual incomes. They should instead report what appears on their paystub and how frequently they are paid, with the health insurance affordability program doing the actual math. This will help minimize any errors and result in more reliable data.

Following these questions, applicants could be asked whether they anticipate any changes in the next year. The application could tie these questions in with the questions designed to account for any discrepancies and tailored to elicit information that could be easily factored into the calculation. For example, if an applicant expects a raise or a decrease in hours, she could be asked how much her paycheck will increase or decrease and when it will occur. While not every applicant will be able to provide these details, those whose pay increases in routine increments may readily supply them. For others, the answers could be vaguer or open ended. For applicants who are clearly Medicaid-eligible, it is not necessary to ask follow-up questions regarding future income. Any of these reported or anticipated changes should be factored into income for the applicable time period for the health insurance affordability program (i.e., monthly or annual income), without the applicant having to make any such projection.

At minimum, if HHS retains questions pertaining to projected annual income in the application, these questions should appear following the other questions related to income so that applicants have something to work off of. This also coincides with the approach to eligibility determinations that begin with Medicaid (using current monthly income) prior to proceeding with an eligibility determination for APTCs (using projected annual income). Additionally, HHS should retain the proposed option of “don’t know” for applicants who have difficulty calculating their projected annual income. It will also be important for the application to provide toll-free help lines, including competent bilingual staff and/or interpreters for LEP individuals, and encourage applicants to call as they encounter questions at this and other difficult points in the application.

Under no circumstances should HHS require applicants to do math in determining an answer to an income question. As noted above, in an online environment, the application should provide a smart tool or worksheet for the applicant to enter basic wage data that then makes the calculation to determine annual income.

b. Disability Information

We do not think that the general population is trained or adept at understanding when they may have a disability or impairment that may qualify them for state health care benefits, and should not be called upon to make this determination unaided. As such, we think it is best to ask a broadly inclusive question first, and allow trained state employees to make a later determination on whether someone does or does not have a disability for the purpose of state benefits. The point in the application is simply to flag those individual or family applicants who may qualify and therefore should be directed toward a state benefit determination first before obtaining private insurance through the Exchange.

The application should focus on functional impairments rather than asking an individual to indicate that they have a “disability.” People will often resist the label of “disability,” but recognize that they have reduced functional capacity. For example, someone who is aging may readily acknowledge that they are having trouble hearing or seeing, but will not check that they “have a disability.”

We thus support asking all applicants the relevant questions to identify those who may be eligible for programs based on a finding of disability such as traditional Medicaid. We want to make sure the questions are sufficient to fully identify individuals with disabilities since the scope of benefits for “traditional” and “expansion” Medicaid may be different, depending on the state. The questions must be sufficient to truly identify the full scope of individuals and the notice of eligibility provided to individuals should also clearly state that an applicant can request a full Medicaid eligibility determination beyond MAGI.

First, the application should incorporate the following questions into information requested of the person applying on their own and/or a family member/child’s behalf to enable eligibility workers to provide reasonable accommodations or modifications needed during the application process:

- *If you have difficulty hearing spoken language or speaking, what translation assistance do you need for effective communication?*
- *If you have difficulty (even with glasses) seeing, reading, or understanding written language, what alternative format do you need for effective communication?*
- *Do you have difficulty concentrating, remembering, or making decisions due to a physical, mental, emotional, or developmental condition?*

Second, the application should include a non-exhaustive list of examples of “translation assistance” and “alternative formats” as accompaniments to the above questions, as a page link or accessible “drop down menu” from the online application and in the accompanying instructions in paper applications. Representatives taking applications by phone should also be trained to provide the examples when assisting individuals with making a phone application. Examples of “translation assistance” include: Qualified

sign language interpreters, qualified notetakers, computer-aided transcription services, written materials, telephone handset amplifiers, assistive listening devices or systems, telephones compatible with hearing aids, closed caption decoders, telecommunications devices for deaf persons (TDD's), videotext displays, speech-to-speech relay services, or other means of making oral interactions available to individuals with hearing or speech impairments. Examples of "alternative formats" include: qualified readers, taped texts, audio recordings, Brailled materials, large print materials, electronic formats, or other effective methods of making visually delivered materials available to individuals with visual or print comprehension impairments.

We also recommend that the instructions explain the kinds of accommodations that can be provided for someone who indicates cognitive processing difficulties due to a physical, mental, emotional, or developmental condition (e.g., appointments for in-person consultation, extended timelines for, or assistance with, gathering needed reference materials or documents, etc.).

With regard to eligibility determinations, we also recommend certain mandatory questions. Instead of asking whether the applicant and/or a family member/child has a "physical, mental, emotional or developmental disability", we suggest framing the question as follows:

Does the person have "difficulty hearing or seeing, or difficulty performing the following functions at an age appropriate level: concentrating, remembering, making decisions, engaging in common social interactions and conversation, walking or climbing stairs, maintaining motor control or holding still, dressing or bathing, or doing errands alone.

The above questions are derived from the six 2011 American Community Survey (ACS) questions relating to disability that have also been proposed in the HHS Notice of Proposed Rulemaking concerning the data collection requirements in Section 4302 of the ACA. The "ACS six" describe the functional limitations that accompany disabilities rather than use the unexplained term "disability," which has untoward connotations and stigma for many individuals. The ACS questions have been federally tested as a means of data collection on disability status, and are written out in the disability status section of the April 28, 2011 data collection letter prepared by The Leadership Conference, at pp. 12-13. At the same time, the ACS questions have some recognized limitations for capturing certain groups of people with speech, developmental, learning, neurological, and mental health disabilities (see August 1, 2011 letter from DREDF to HHS Secretary Kathleen Sebelius concerning data collection standards under Section 4302 of the ACA for additional information). The above questions recommended here are modified in recognition of these limitations in the ACS questions, as well as the fact that application forms require brevity.

Moreover, if the application seeks to identify a potential length of disability, we recommend asking:

Impairment expected to last?

Finally, we suggest HHS consider the various options for ensuring accessibility, including breaking the form up into steps and displaying additional optional or related lists on a new page. This may be more accessible than a drop-down menu, particularly for those with visual impairments or manual impairments who have difficulty using a mouse. If HHS chooses to use drop-down menus, they must be navigable using the keyboard only and the menu selections must also be labeled in a logical manner. WebAim.org: (<http://webaim.org/techniques/forms/>) has some helpful information on ensuring accessibility. The state may also be able to use a DHTML menu like this one (<http://www.udm4.com/menu/>).

c. Pregnancy Status

Also under “Additional Information,” we support asking all applicants for information about disability status to identify those who may be eligible for traditional Medicaid. We want to make sure the questions are sufficient to fully identify individuals with disabilities since the scope of benefits for “traditional” and “expansion” Medicaid may be different, depending on the state. The questions must be sufficient to truly identify the full scope of individuals eligible for Medicaid eligibility determination beyond MAGI.

Further, we support asking for information on pregnancy status since this could affect a woman’s potential eligibility options. The insurance affordability program a pregnant woman enrolls in could impact the scope of benefits and cost-sharing protections available to her. The disclosure of pregnancy on the application is also important since a woman’s pregnancy impacts the size of the household for Medicaid eligibility purposes and thus can have a distinct impact on which program she and certain individuals in her household are eligible.

We urge HHS to provide further guidance to states to ensure that pregnant women are given timely notice about the most comprehensive health benefits package for which they are eligible with the least cost-sharing. A pregnant woman’s ability to take advantage of such coverage requires that she has the information necessary to make informed decisions about the program in which she will enroll; the system should not impede her choice through administrative hurdles or the potential for discontinuity of care if her eligibility status for insurance affordability programs changes due to her pregnancy. HHS should therefore require that a state provide notice to women about potential eligibility options that could impact pregnant women’s coverage to all pregnant applicants for and enrollees of insurance affordability programs. A state should provide such notice not only at the point of initial application and at redetermination, but also if the state has reason to know that a pregnant woman might be eligible for additional or different scope of benefits, or cost-sharing protections. Regardless of whether a woman’s eligibility status changes, HHS should require states to ensure that pregnant women are not forced to sacrifice continuity of care, including by requiring coordination and alignment of programs.

d. Other Issues

We question the reason for asking residency questions of all household members, both applicants and non-applicants. However, the application should ask applicants if they are a resident of the same address as the household contact so that eligibility can be determined for the appropriate location. For example, a student could be a resident of another state, but be part of his parent's household and the eligibility determination would need to take into account this disparate residency. There is no need to ask applicants or non-applicants whether or not they intend to remain in the state, as recipients are required to report any changes, including moving to the health insurance affordability program. The notice of eligibility determination should notify applicants of this and other requirements in the notice of eligibility determination.

To ask non-applicants for their address and whether they intend to change residency may be unnecessary since the operative issue is whether the applicants are eligible for assistance and insurance now, regardless of whether they may intend to move in a few weeks or months. Otherwise, individuals may be left in a Catch-22 where State A refuses to provide insurance since the applicant has current residency but intends to shortly move out-of-state while the applicant cannot apply for insurance in State B until the applicant actually establishes residency. Further, the regulations prohibit asking unnecessary questions of non-applicants.

V. Program Specific Questions, CMS–10440

Medicaid will cover medical expenses that occurred in the three months prior to an eligibility determination, if the applicant would have been eligible for coverage at that point in time. While these data are important to collect to assist families in covering costs that may be beyond their means, the exact amounts can be asked post-eligibility, with applicants simply indicating on the application whether they have incurred any recent medical expenses through a simple checkbox. If so, the agency can then follow up for the details. It will be important to convey to families, perhaps in the eligibility notice, that assistance with past bills is available so that they provide the information needed for the costs to be picked up by Medicaid.

We also urge HHS to seriously consider how to frame the data element about an absent parent and to make this information optional. Many situations exist where identifying an absent parent may cause difficulties or even harm to the family. For example, a parent may be absent because of domestic violence and an individual's application should not be held up or denied because an absent parent is left unidentified. Other situations likely exist where identifying an absent parent can have adverse consequences to the applicant and thus HHS must identify a way for individuals to opt-out of this question for certain documented reasons.

VI. Confirmation and Eligibility Determination, CMS–10440

a. Application Summary

We strongly support providing families with the ability to review and make changes to their applications prior to submission. The design of any of the application modalities should provide individuals with final control over their application information, allowing them to investigate any other options and potential consequences before formally submitting their application. This control would encourage participation among many applicants, but especially by mixed-status immigrant families who may want to research the potential immigration consequences of applying for health care after they have learned the extent of personal information they must provide.

Applicants should also have the ability to print and save a copy of their application for reference. This protection should not be accessible solely online and through the paper application, but copies should be available to those who submit over the phone or through some sort of assistance mechanism. In the online application environment, we reiterate our support for a federal requirement that states establish a personal account to facilitate the review and return to an application at any time throughout the process.

The amount of information needed to complete an application is substantial, complicated, and in some cases will require individuals to track down documents and other information not readily available. Regardless of the manner of application, individuals should be able to submit partially completed applications so that they can get the appropriate level of assistance and gather any relevant information. Individuals, should not, however, be forced to risk their date of eligibility to do so.

The ability to start and stop would also encourage participation by mixed-status immigrant families. These families may want to research immigration consequences of applying for health care after familiarizing themselves with the health care application and benefits, but before actually submitting the application on behalf of their household.

RECOMMENDATION: Inform the household contact of options and methods for controlling the information entered on the application, including for deleting, changing, or saving for possible submission in the future.

The data elements note that this is the section that provides an “opportunity to make edits if needed.” The agency must accept any documentation required to establish eligibility, see 42 CFR § 435.907(a). This is essential for immigrants and others who have evidence of eligibility that is not verifiable electronically. The lawfully present immigration status of some applicants will not be verifiable by the DHS SAVE program, only by submission of documentary evidence. In an online environment, applicants should have the capability of uploading a document. In a paper or phone application, or the filer will need the opportunity to bring or mail a document. Whether this place at the end of the application is best, or the point where immigration status is requested, will depend on when in the process the electronic verification is to occur.

RECOMMENDATION: if the immigration status of an applicant family member will not be verifiable through SAVE, provide the application filer with an option to

upload a copy of an immigration document that can verify eligible status, or to bring it or mail it to the agency office. While the individual obtains the document, the individual should be found eligible and provided services for a reasonable period of time.

RECOMMENDATION: In this section or the next (see recommendation below), provide notice that an applicant whose eligibility cannot be determined immediately, though all information is provided, can receive benefits pending verification.

It is also critically important to establish a separate web portal for navigators and assisters that not only tracks their activity for audit and evaluation purposes, but also provides them with status and other information needed to assist the individual on an ongoing basis.

b. Rights and Responsibilities and Signatures

To best serve all applicants, the application needs to communicate the rights and responsibilities in clear and simple language that is non-threatening. On both the application and the notice, families should receive information on how to appeal the agency's decision as well as file a complaint if they believe they have suffered discrimination.

As discussed above, online applicants should have the ability, once a core set of questions are completed, to navigate to this page to sign and submit the application. Applicants should understand that by not completing the full application, processing could be delayed as additional details and/or verifications are sought, but should not be precluded from submitting an application that has questions that have not been answered. These "date of application" protections are vital and HHS should ensure them in all modalities. Processing of the application should continue while any inconsistencies or missing data issues are resolved, and where allowable, coverage extended during this period.

In addition, as required under the ACA, individuals must be able to apply for, enroll in, and renew coverage using electronic, including telephonic, signatures. Such an option is also available for applicants applying over the phone or through an application assister.

Also see the comment above recommending providing notice of civil rights protections with the notice of privacy protections at the beginning of the application, to encourage participation of immigrant families. A clear and strong statement of civil rights protections could also be included here, along with information on how to file a complaint of discrimination.

RECOMMENDATION: To best serve vulnerable populations, the application should communicate responsibilities in clear and simple language that is also friendly and without any threatening tone or content.

States are prohibited from denying or delaying services to an otherwise eligible individual pending issuance or verification of an SSN by the Social Security Administration, an important protection for vulnerable families including immigrant and LEP families who often face problems with obtaining Social Security numbers. The Medicaid rules incorporate due process protections to help individuals correct inaccuracies in their records without forfeiting critical coverage. 42 CFR §§435.910(a), 435.952, 435.956, 457.340(b); 457.380(f); 45 CFR §155.315(f)(4).

RECOMMENDATION: Provide notice in this section that Exchanges may not deny or delay services pending issuance or verification of an SSN, or on the basis of any information received unless they have sought additional information from the applicant, and have provided the individual with notice and hearing rights.

c. Date of Application

Allowing individuals to complete an application to the best of their ability and to sign and submit the application with missing information is an important protection. It will also likely lead to fewer errors as applicants will not feel they must guess even when the data points are unknown. HHS should establish a minimum level of information or core data elements that constitute a “valid” application, which could potentially include only minimal information about the applicants and signature. Once an applicant completes these elements, an applicant can sign and submit the application to preserve their date of application while they continue to gather additional information. If HHS does not establish a limited set of core elements having a check box for applicants to say “I don’t know” to questions that are not required could be helpful.

The submission of a partially completed application (regardless of whether an applicant provides all data needed to establish an official application date) should trigger follow-up procedures to assist the applicant in gathering missing information and provide a set timeframe for providing such information. Individuals should be informed that delays in completing and submitting the application may have an effect on the start time of their benefits and that they may complete the application to the best of their ability and submit it while gathering additional information or seeking help in understanding questions. If an Exchange can make an eligibility determination without the missing data, or while verification is pending when allowed by law (e.g., citizenship), it should proceed and coverage should begin during this period.

We believe “date of application” should refer to the calendar date that an individual submits an application to one of the insurance affordability programs including at least the minimally required data elements. The application should provide an exception to any address requirement for any individual who lacks an address. If an insurance affordability program requires additional information from the applicant to finalize an

eligibility determination, the program may request that information, but this shall not be considered a new application, the date of application does not change, and the timeliness standards apply based on the date of application. Further, an individual should be allowed to submit an application even if all information is not included and the Exchange should follow-up with the individual to obtain any additional information while the initial submission date remains the same.

We recommend that the timeliness clock begin running on the calendar date an individual submits an application, regardless of whether subsequent steps are necessary to complete the application. This standard is in keeping with customary Medicaid practice and has been reaffirmed in other recent regulations. See e.g., Medicaid Citizenship Documentation regulation discussion at 42 Fed. Reg. 38670. We recommend that CMS use the same date of application standard used by the SNAP program, which defines date of application based on the date an individual submits an application including name, signature, and address. See 7 C.F.R. § 273.2(b)(1)(v), (c)(1), and (c)(3). This standard will maximize enrollment of individuals and create uniformity between state and federal programs.

d. Determination and Notice(s)

Families should receive a full and complete eligibility notice, regardless of whether or not the members are all eligible for the same program. The notice should clearly lay out what each family member is eligible for, as opposed to starting with what they are ineligible for, and should also provide the basis behind the determination. Additionally, if families are split between various programs, the notice should provide an explanation of each. The notice could begin with a summary page that provides an overview of the coverage determination (e.g., children Mary and Alice are eligible for CHIP; parents Bill and Jan are eligible for APTCs), followed by more detailed information about each applicant on subsequent pages. These appendix-like pages could then explain more specifics about the benefits and cost sharing requirements of each of the relevant health insurance affordability programs. In situations where eligibility has been determined for some, but cannot be determined for all family members, the same type of notice could be used, highlighting whose eligibility is pending and the reason for it. The notice should then list any additional verification or documentation requirements on the person-specific sheet. All notices should include information on the right to appeal an eligibility decision, including the ability to request a full Medicaid determination, which is discussed more below.

As HHS develops the application, it should also develop model eligibility and renewal notices, or at minimum, language that has been field-tested among potential beneficiaries that states could then use in their own notices. Any alternative notices that states develop should be subject to Secretarial approval, similar to the alternative application. The same standards that apply to an application, such as the use of plain language and reassuring statements, should be required of notices.

The data elements specify under “Determination and Notice” the “withdrawal of a Medicaid application, Request for a full Medicaid application.” As we have stated in previous comments, we do not support allowing withdrawal of a Medicaid application due to the legal rights at issue and believe a request to treat this application as an application for all affordability programs should be automatic, or have an opt out, rather than opt in option.

HHS should eliminate this data element because it implicates rights that are too essential for individuals to forfeit by a process that is subject to manipulation. Even without such a provision, individuals who are wrongly denied potentially life-saving Medicaid coverage often abandon applications and appeals based on misinformed or biased or coercive agency personnel. Individuals would never benefit by withdrawing their Medicaid applications and foregoing due process rights and the potential of more comprehensive coverage at a lower cost. NHeLP has serious concerns that if the application notifies applicants that they can withdraw their Medicaid applications, many applicants will unnecessarily forgo a complete eligibility screening and receive Exchange coverage although actually qualified for Medicaid or CHIP. Further, the level of education that Exchanges would have to undertake to ensure an applicant is truly informed about his or her options and affirmatively chooses to withdraw, understanding all the potential legal and financial repercussions would be significant. We are concerned that an individual’s choice to withdraw will often be ill advised and undertaken without understanding the consequences. To codify such a policy, particularly where states may have a financial interest in minimizing Medicaid enrollment, would be a significant set-back to due process in the Medicaid program.

If, contrary to our recommendation, HHS allows this withdrawal policy, it is important that states must design this “opportunity for withdrawal” in a manner that is carefully controlled and monitored to ensure only fully-informed applicants withdraw their applications. And the application must accurately capture this process. If withdrawal exists, we recommend that HHS provide states with model language they can use in presenting this option. HHS should work with beneficiary advocates to develop the language for this notice, and test it with low-income individuals before states begin using it. A mechanism should also exist to allow applicants to restore their applications, if they later determine they were withdrawn in error, and preserve their initial application dates so they are not harmed by this error.

To further mitigate the harm that will result from suggesting that applicants withdraw their Medicaid or CHIP applications, NHeLP recommends that if HHS allows withdrawals that it only permit Exchanges to suggest withdrawals to those applicants whose income is above a threshold that makes it highly unlikely that they are eligible for these other programs and include this in the data elements/application. A reasonable threshold would be 250% FPL (or higher if a state has higher Medicaid and CHIP eligibility) as applicants with incomes above that level would not likely have Medicaid or CHIP eligibility. Since families with individuals eligible for multiple programs are likely to be confused by a withdrawal policy, we recommend HHS prohibit withdrawals where

any individual may be eligible for Medicaid of applications regarding that individual's and other family members' applications.

We also express our concerns because this element likely would fail to clearly address situations where applicants may be eligible for non-MAGI based Medicaid. The assessment that an applicant is not potentially eligible for Medicaid cannot be made on the basis of MAGI rules alone. HHS must gear the application and the assessment standards toward determining whether the applicant is potentially eligible for non-MAGI based Medicaid. Exchanges should not ask applicants who meet those screens to withdraw their applications. When an applicant is determined to be potentially eligible for non-MAGI based Medicaid, HHS should require the Exchange to promptly (within one business day) transmit all information obtained and verified by the Exchange concerning this individual to the Medicaid agency.

Further, for the assessments to be as accurate as possible and for there to be as few instances as possible where Exchanges assess potentially eligible applicants as ineligible for Medicaid or CHIP, the Exchange and state Medicaid and CHIP agencies should have access to all the information available to the other entity or agency, such as information used to determine eligibility for SNAP.

In addition, some individuals, including persons in immigrant families, will not be eligible for coverage under the Exchanges, full-scope Medicaid, or CHIP. Maintaining a connection to care for undocumented parents is critical for them and also will help promote a connection to care for their citizen and lawfully present children. Some states and counties cover all children regardless of status and policy makers must ensure continuation of this coverage. The Exchanges should help ease administrative costs by screening and enrolling for State and local programs, as required by ACA §1311(d)(4)(F). HHS allows states to contract with other entities such as federally-qualified health centers and public hospitals, to carry out one or more Exchange functions, as the safety net providers currently do with Medicaid functions.

RECOMMENDATION: After eligible family members have been determined eligible, it is important to screen and enroll ineligible family members who may qualify for emergency Medicaid, pre-natal care through CHIP, state and local coverage, and care at community health centers and public hospitals.

VII. Qualified Health Plan Enrollment, CMS-10440

If HHS designated the data elements in the order they will appear on the application, we strongly recommend providing the "Amount of APTC applied toward premium" **before** "Plan Selection and Confirmation." An individual's selection of a plan is likely dependent on the amount of APTC and thus providing this information earlier to individuals will assist them in making an informed selection of an affordable plan.

And while we appreciate the desire to have an eligible individual select and confirm a plan as part of the application process, we also recognize that some individuals may

need additional time to evaluate their options to select the plan that best meets their overall health and financial needs. This may be due to a number of factors including the services provided by each plan; prescription drug formularies, coverage and co-pays; coverage for certain special conditions or treatments; scope of pregnancy-related coverage; and continuity of care with a particular or existing provider. We suggest that HHS include information in the application process that an individual determined eligible for coverage may delay plan selection if the individual wants additional time to investigate plan coverage and services. If an individual chooses to delay the choice, the Exchange must provide the individual with detailed information on how to select a plan at a later date and how the individual can do this by mail, phone, in-person or website. If the person is eligible for Medicaid or CHIP, the state should provide fee-for-service coverage unless or until a person chooses a plan. For Exchange enrollees, the Exchange should establish interim procedures to provide coverage for services until the individual selects a plan.

VIII. SHOP Application, CMS-10438 & CMS-10439

We support the proposal that employees and employers can complete and submit SHOP applications over the phone, online, or in person, as it is vital the consumers have an option to select the mode that best meets their needs. As mentioned above, the use of an online application that uses dynamic questioning to reduce the number of questions that consumers will have to answer to complete an application for enrollment will help speed the process. It appears that the in-person option is limited to services provided by an agent, broker, or navigator. We believe that HHS should not restrict in-person assistance to these entities, particularly because HHS has recently highlighted the opportunity and need for other types of “application assisters” to serve individuals and small employers in need of support.

The strong privacy regulations, which apply to both individual market exchanges and to SHOP exchanges require a SHOP to restrict any use and disclosure of the personally-identifiable information they collect or create to only those purposes necessary to carry out specified functions, and to never use such information to discriminate inappropriately. A privacy statement should appear at the beginning of the application and make it clear what information will be collected, how it will be used, who it will be shared with, how it will be stored and for how long. HHS should also include a strong civil rights statement, as explained above, on the application.

In addition to helping many small businesses access coverage for their employees, the SHOP exchanges will link many uninsured immigrants and their children to care through family coverage. Small businesses employ a large number of immigrants and many immigrants are also small business owners and entrepreneurs. We appreciate the separate applications for individual market exchange and employee and employer applications for the SHOP exchange. The ACA allows for a merger of the two exchanges but because the immigrant restrictions are confined to the individual market, HHS should clearly distinguish and separate the two with regard to verification of eligibility.

a. SHOP Employee Application

Options for coverage. SHOP employee applications should inform consumers that they may qualify for subsidized health coverage through health insurance affordability programs, including Medicaid and CHIP, and link employees to the relevant state resources where they can get additional information and apply for coverage.

Race and ethnicity. To aid in protecting civil rights, as mentioned above, we support asking for the race and ethnicity of applicants, as well as their dependents. The application should notify applicants that this data are being collected to ensure that everyone gets the same access to health insurance and that the information is confidential and will not be used to decide which program they are eligible for.

Language preference. As with the individual Exchange application, the SHOP application should request data on the preferred language of applicants. As employees will need to communicate with the Exchange, as well as their chosen QHP, knowing their preferred language, both spoken and written, will help facilitate this interaction.

Dependent information. We appreciate the careful limiting of information gathering on dependents to focus primarily on name, gender, birth date, and relationship to employee. However, we support collection of information from all family members on their preferred language, race, and ethnicity. See above for rationales for collecting such data from all family members, including dependents of employees, to promote and protect civil rights.

Additional information. Any subsequent information request should only ask applicants to include changes in information or additional information that is specific to their enrollment (for example, regarding their dependents). It should not require submission of any information pertaining to non-applicants or resubmission of any previously provided information.

b. SHOP Employer Application

Language preference. Many small business owners are immigrants and many are limited-English proficient (LEP). It is imperative to collect data on the preferred language of the employer, as is currently proposed. Without knowing which employers are LEP, the SHOP cannot serve those individuals and cannot adequately plan to provide them with meaningful access to services as required by law.

Multi-site employer. The employer application should also include a question allowing applicants to indicate if they have work-sites in other states served by a different SHOP(s) and which SHOP shall be serving each worksite. If this is the case, the employee application should also allow indication of work-site address so employees seek coverage under the appropriate location.

Employee list. Employers will also be asked to submit a list of employees who are eligible to purchase coverage through the SHOP Exchange, including their tax identification number (TIN). TINs include SSNs as well as Individual Tax Identification Numbers (ITINs), under which people without SSNs file their taxes. It is well documented that the collection of SSNs by benefit programs discourages participation of immigrant families and should be carefully limited to uses that are strictly necessary for program administration and specifically authorized by law. Understanding these serious implications for participation, the ACA requires issuers to report to the IRS the TINs (rather than SSNs) of covered individuals, with the final regulations mirroring the language in the statute. As such, the employer application should ask for a TIN and not a SSN and provide a clear definition of “Taxpayer Identification Number” to ensure that the employer understands that the term includes both a SSN as well as other TINs.

Benchmark reference. We support the inclusion of a question on the employer’s selection of a benchmark reference plan, as well as the contribution the employer will provide towards coverage for employees and their dependents. Using a benchmark reference plan will allow employers to provide an age-adjusted premium contribution that protects older employees from facing a disproportionately higher employee share for coverage, while still maintaining the option of employees to choose from multiple plans.

IX. Conclusion

We greatly appreciate the opportunity to comment on the Data Elements. The streamlined application has significant potential to increase equity in our health care system by improving access and insurance coverage. However, unless efforts are made to ensure the application collects all essential information, we may lose significant opportunities to ensure all low-income and underserved populations are enrolled and do not face discrimination or health care disparities. We hope HHS will consider our suggestions regarding the Data Elements to improve your significant work on the application. If you have any questions about these comments, please contact Mara Youdelman at youdelman@healthlaw.org.

Sincerely,



Emily Spitzer
Executive Director