



New York Health Benefit Exchange: Reducing Health Disparities

Prepared for:
The New York State Department of Health

Prepared by:
The Center for Popular Democracy (CPD)
Nisha Agarwal
Deputy Director

January 21, 2013

Introduction

How can New York State design its Health Benefit Exchange to address health disparities, such as those based on **race, ethnicity, gender, disability, sexual orientation and gender expression**? On September 7, 2012 over 100 stakeholders (including providers, patients, advocates, community groups, health plans, insurance brokers and others) came together at a stakeholder meeting held by the New York State Department of Health (“DOH”) in an effort to address this question. The meeting began with presentations from four expert panelists:

- Yvonne Graham, Associate Commissioner New York State Department of Health, Director, Office of Minority Health and Health Disparities;
- Dr. Lisa Iezzoni, Professor of Medicine, Harvard Medical School, Director of the Mongan Institute for Health Policy, Massachusetts General Hospital;
- Dr. Paula Johnson, Chief, Division of Women’s Health and Executive Director, Connors Center for Women’s Health and Gender Biology, Brigham and Women’s Hospital, Massachusetts; and
- Jay Laudato, Executive Director, Callen Lorde Community Health Center, New York.

Panelists provided examples of health disparities and suggested ways in which the Exchange could reduce them. Panelist presentations drew from the experience of Massachusetts’s implementation of its health reform law, which was a model for the Affordable Care Act, and from the unique context of New York State and its many diverse communities.

This report offers suggestions for ways in which the New York Health Benefit Exchange can reduce health disparities. The suggestions are drawn from the meeting’s presenters and from comments made by audience participants and comments submitted in writing to the DOH. This report focuses on three areas for reducing health disparities through the Exchange: **ensuring effective consumer service functions, ensuring network adequacy, and ensuring effective data collection.**

Background

Health disparities are differences between populations in rates of disease, health outcomes, and access to quality care. Despite improvement in the health of the American population, there remain health disparities between racial and ethnic minorities compared to whites; people with disabilities compared to those without; women compared to men; lesbian, gay and bisexual individuals compared to heterosexual individuals; people who are transgender compared to those who are not; and others. These disparities are not primarily attributable to biological differences between groups, but are strongly associated with social and economic determinants of health.ⁱ

The Affordable Care Act takes several steps to reduce health disparities. The creation of health benefit Exchanges, to increase access to high-quality insurance, is an important pathway to reduce health disparities.ⁱⁱ Access to health insurance is associated with increased access to and use of health care services, improved health status and reduced likelihood of incurring medical debt to seek treatment.ⁱⁱⁱ On April 12, 2012, Governor Cuomo issued Executive Order 42 establishing the New York Health Benefit Exchange (“Exchange”) within the Department of Health.^{iv} DOH is directed to work in conjunction with the New York State Department of Financial Services and other state agencies as necessary to effectuate the Exchange. An Exchange is a marketplace for consumers and small businesses to shop for health care coverage in a way that is easy to compare plans across price, benefits and quality. The New York Health Benefit Exchange is being developed in accordance with federal regulations. However, New York has significant latitude in designing many of the Exchange’s features.

Consumer Assistance Functions

Federal regulations require Exchanges to incorporate a number of consumer assistance functions, including:

- Operation of a **toll-free call center** that addresses the needs of consumers requesting assistance.
- An **up-to-date Internet website** that provides information on benefits, cost-sharing, enrollee satisfaction, plan ratings, among other elements;
- **Outreach** to educate consumers about the Exchange and encourage participation.^v

The regulations also require information to be provided to consumers in plain language, the provision of auxiliary aids and services to individuals with disabilities, and interpretation and the provision of translation services for people who are limited English proficient (LEP).^{vi}

In addition, Exchanges must create a **Navigator Program**.^{vii} Navigators are required to have expertise in eligibility and enrollment procedures, the needs of underserved and vulnerable populations, the range of Qualified Health Plan (QHP) options and Insurance Affordability Programs (IAPs), and privacy and security standards.^{viii} The Navigators selected by a state must provide their services in a manner that is accessible to people with disabilities and LEP individuals.

Exchanges must select at least one community and consumer-focused non-profit organization to be a Navigator. Exchanges must also select at least one entity to be a Navigator from any of the following: (1) Trade, industry, or professional organization; (2) Commercial fishing organizations, ranching and farming organizations; (3) Chambers of Commerce; (4) Unions; (5) Resource partners of the Small Business Administration; (6) Licensed agents and brokers that do not receive direct or indirect consideration from a QHP or non-QHP; and (7) Other public or private entities, such as Indian tribes, tribal organizations, urban Indian organizations and state and local human services agencies. Health insurers and their subsidiaries and, associations and their subsidiaries that include lobby on behalf of health insurers may *not* serve as Navigators.

Network Adequacy

Federal regulations define the minimum criteria for QHPs in the Exchange, including network adequacy provisions.^{ix} Under the rules, QHP issuers must ensure that their QHP provider networks have sufficient numbers and types of providers with experience in meeting the needs of medically underserved and vulnerable populations. The Exchange and health insurers must work together to make the provider information for each health plan option available on the Exchange's website and, if requested, in hard copy from the insurer. These directories must indicate if a provider is no longer accepting new patients.

Data Collection

The collection and reporting of data on race, ethnicity, language, gender, disability status, sexual orientation and gender expression is critically important to ensuring that disparities based on these characteristics are reduced. Accurate, comprehensive data can be used to assess and monitor disparities, and can help inform decisions about how to reduce disparities. Section 4302 of the Affordable Care Act requires that all federally provided or supported health care or public health programs, activities, and surveys collect and report data on race, ethnicity, sex, primary language, and disability status at the smallest geographic level practicable and to enable reliable estimates of health access and outcomes by each of these groups. In addition, Section 4302 also provides for the collection of "any other demographic data as deemed appropriate by the Secretary [of the Department of Health and Human Services] regarding health disparities."^x To that end, the Secretary of the U.S. Department of Health and Human Services (HHS), Kathleen Sebelius announced in June 2011 that HHS would begin collecting data in its population health surveys to enable identification of disparities experienced by people who are lesbian, gay, bisexual and transgender (LGBT).^{xi}

The New York Context

Health disparities continue to be a major challenge for New York, including disparate access to health insurance. Racial and ethnic minorities, for example, have lower rates of insurance coverage in New York and nationally because they are less likely to have employer-sponsored health insurance and have been found to be less knowledgeable about eligibility for public programs than whites.^{xii} Establishing the New York Health Benefit Exchange is a strong step forward to reduce unequal access to health care, but resources must also be targeted to underserved communities to ensure that groups with health disparities learn about and enroll in the Exchange.

New York State is taking additional steps to reduce disparities— most recently, through the Health Disparities Workgroup of the Governor's Medicaid Redesign Team, which involved a broad range of stakeholders in the development of a comprehensive slate of policy proposals to reduce disparities based on race, ethnicity, language, disability, LGBTQ status, and other factors, using reforms to New York's Medicaid program as the lever to drive change.^{xiii} Now, the development of the New York Health Benefit Exchange provides another opportunity for the State to devise strategies to reduce disparities.

Donna Frescatore, Assistant Secretary of Health for Governor Cuomo and Executive Director of the Health Benefit Exchange notes: "The Exchange offers us an opportunity to significantly

reduce the number of uninsured in our state. Most of these individuals are workers and their families; they earn too much to qualify for public programs currently; they don't receive insurance through their employer; and they simply can't afford to buy insurance on the direct-payment markets. We know that in New York, as in the rest of the nation, ethnic, racial, and other minorities are far more likely to go without insurance, which is often cited as one of the biggest barriers to getting care."^{xiv}

The recommendations provided below track the three core themes discussed during the stakeholder meeting on September 7: (1) consumer assistance; (2) network adequacy and (3) data collection. They derive from panel presentations, written and verbal comments provided by stakeholder, and research of models and approaches in other parts of the country.

Recommendations

Consumer Assistance Functions

Stakeholders provided a number of suggestions for the Exchange regarding the manner in which it communicates with consumers. In addition, stakeholders commented on specific aspects of the Exchange's consumer assistance functions, such as the call center, website, and community outreach. Each of these areas is discussed in detail below.

1. Facilitate Language Access & Communication Assistance

Several stakeholders emphasized the importance of the Exchange being accessible to LEP communities and to people with disabilities. Approximately 2.5 million New Yorkers are limited English proficient; 500,000 are deaf or hard of hearing; and 400,000 are blind or visually impaired. For these individuals, the provision of interpretation and translation services, auxiliary aids and alternate format materials (e.g. Braille, large print and audio) are critical to ensuring that they are able to understand, access and evaluate the information provided to them through the Exchange.

In addition to the regulations governing the Exchange, which require its consumer assistance functions to be accessible to LEP communities and people with disabilities,^{xv} federal law has long required that recipients of federal financial assistance, including health care providers and state and local governmental entities, provide the services necessary to ensure equal access for people with limited English proficiency and people with disabilities.^{xvi} The Americans with Disabilities Act prohibits discrimination on the basis of disability in places of public accommodation, state and local government, and other contexts, and requires covered entities to provide meaningful access for people who are deaf, hard of hearing or visually impaired.^{xvii}

With respect to language access, federal guidance recommends federal funding recipients to engage in a four-factor analysis to determine the extent of language assistance services they must provide, which requires a balancing of: (1) the number or proportion of LEP persons eligible to be served or likely to be encountered by the program or grantee; (2) the

frequency with which LEP individuals come into contact with the program; (3) the nature and importance of the program, activity, or service provided by the program to people's lives; and (4) the resources available to the grantee/federal fund recipient and costs.^{xviii} In addition, for translation of written documents, the guidance contains a "safe harbor", which provides that translation of vital documents for LEP language groups that comprise five percent or 1,000 individuals, whichever is less, of the population eligible to be served or likely to be affected is strong evidence of compliance with the written translation obligations of Title VI.^{xix}

The four-factor test and safe harbor provision are guidelines, not rigid requirements, and at the state level, different thresholds have been utilized to determine the languages for written document translation. (Virtually all state laws require oral interpretation regardless of language spoken, in part because the technology and modalities exist to provide oral interpretative assistance in virtually any language with relative ease.) The DOH patients' rights regulations, which include a right to language assistance services, require translation of significant hospital forms and instructions for LEP groups comprising more than 1% of a hospital's service area – a standard designed with New York's particular demographics in mind, where 1% of a hospital's service area may represent a large absolute number of people.^{xx} Executive Order 26, which was signed by Governor Cuomo in October 2011, requires translation of vital documents in the top six languages spoken throughout the state, which captures 70% of the LEP population statewide.^{xxi}

The key consideration in determining the accessibility of the consumer assistance functions of the Exchange would therefore be the diversity and particular needs of the population to be served in New York. To that end, commenters suggested that the Exchange:

- a) Provide important consumer information in a variety of languages and formats. For interpretation/oral communication, commenters recommended that the Exchange use a broad range of modalities, including bilingual staff, in-person/live interpreters, TTY, telephonic interpretation services etc. This is consistent with the approach taken in federal and state laws.
- b) For written documents, commenters recommended that the Exchange provide translations when at least five percent or 500 LEP individuals are included in the Exchange, with a minimum of 15 languages, using the federal Social Security Administration's "Multilanguage Gateway" as a model.^{xxii} According to stakeholders, using this guideline would better reflect the linguistic diversity of the State, and could capture Asian language populations that are often less likely to receive effective language assistance in the health care setting compared with other language groups such as Spanish.^{xxiii} However, the Social Security Administration's Multilanguage Gateway provides translations in 15 languages only of public documents like fact sheets and informational brochures; it does not provide full translation of its website or vital documents in all of these languages. Further, given that the Exchange will operate statewide, the 5% or 500 individuals threshold may be simultaneously under-inclusive and over-inclusive. Based on 2011 American Community Survey data, only Spanish,

Chinese and Russian are spoken by 5% of the statewide LEP population. Meanwhile, virtually every language is spoken by at least 500 LEP individuals statewide. The percentage standard would be inconsistent stakeholders' comments urging inclusivity in the range of languages for which translations will be provided, but an absolute number threshold may be administratively difficult for the Exchange to meet, at least in the short-to-medium term. An alternative approach that the Exchange could consider is to require translation in the top six LEP languages spoken statewide, which would cover the vast majority of LEP individuals in the state. In situations where vital documents are not translated into an individual's primary language, that individual should be entitled to oral translation of the document through the Exchange.

- c) Include translated taglines in at least 6 languages on all Exchange notices and vital documents with information on how to access translated materials and oral language or communication assistance services and on the consumer's right to access these services free of charge.
- d) Translate the website into at least 6 languages, and ensure that the website be compliant with the requirements of Section 508 of the Rehabilitation Act to enable equal access for people with disabilities.^{xxiv} The website should include a prominent button or section on the home page that directs LEP consumers to translated versions of the Exchange website and to translated materials and resources. Many state agency websites display the availability of Spanish-language resources and the Spanish version of their websites on their homepage, but are less successful in doing so with other languages.
- e) Have an immediate prompt on the call center hotline that allows the caller to choose a language preference, to avoid consumers hanging up the phone if they cannot get service in a language they can understand. Once prompted, consumers who need language or communication assistance can be directed to bilingual Exchange staff who speak their language, to a recorded message providing standard information in the consumer's preferred language, and/or to an interpreter who can help the consumer communicate with Exchange staff.
- f) Develop outreach and marketing materials—including handouts, newspaper and subway ads, billboards and radio announcements—in at least 6 languages.
- g) Create a "Language Access Unit" within the Department of Health or have dedicated staff responsible for creating and implementing compliance plans for language access and communication assistance for people with disabilities consistent with federal and state laws, including Title VI of the Civil Rights Act of 1964 and the Americans with Disabilities Act. The proposed Unit could also work with the Exchange to address complaints related to language and communication assistance services and auxiliary aids.

The language access recommendations offered by commenters are consistent with approaches New York State has taken in other contexts, including Executive Order 26:

Language Access Policy, which requires all executive state agencies that provide direct public service to translate vital documents and provide interpretation services.^{xxv} Importantly, the Executive Order requires state agencies to identify a language access coordinator, who can develop and implement compliance plans for the agency and who works to address complaints related to language and communication assistance. There are thus many examples of state-level agencies creating a dedicated staff or unit for language assistance that the Exchange can learn from and that can serve as resources if the Exchange were to create a similar function.

2. Require Insurers to Adhere to the same Language Accessibility Guidelines as the Exchange

Many commenters emphasized the need for the Exchange to require, through its contracting powers, that plans participating in the Exchange provide comprehensive language assistance services. One commenter highlighted the California Health Care Language Assistance Act as a model, which requires vital documents to be translated into threshold languages and requires interpretation services be made available to all enrollees at all points of contact with a health insurer.^{xxvi} Some stakeholders recommended that translation be required in languages spoken by 5% or 500 of the plan's LEP enrollees, whichever is less, with a minimum of 6 languages being required.

3. Use Plain Language

Commenters noted the importance of the Exchange ensuring that consumer-oriented information and materials be provided in plain language that is accessible to individuals with low health literacy. The New York City Mayor's Office of Adult Education and Office of Immigrant Affairs offers useful resources, including the development of an "Easy-to-Read NYC" guide for city agencies that outlines how agencies can achieve plain language goals in their materials.^{xxvii}

4. Provide Decision-Making Support Tools Through the Call Center and Website

Dr. Paula Johnson, a panelist for the stakeholder meeting, presented on the Massachusetts experience using both call center and website portals to facilitate consumer access to insurance products. Dr. Johnson recommends that the Exchange's call center and website actively guide and assist consumers, not merely provide information passively. New York stakeholders who participated in the September 7 meeting and who submitted written comments expressed general enthusiasm for this approach.

Some suggestions on the types of decision making support that should be available to consumers include:

- Information on all health insurance plan options and complete information about the services that are included or that are *not* included in the plan.
- Costs to the consumer in the form of premiums, deductibles and co-pays.
- Data on consumer satisfaction which may be particularly important for people with serious illness and disabilities who require access to specialized treatment and providers.

- Whether health plans include providers with staff who speak languages other than English or have staff of a certain gender available for an appointment.

5. Conduct Sensitivity Training for Consumer Assistors

Stakeholders emphasized the need for the Exchange to be sensitive to the needs and concerns of the many diverse consumers who will access insurance products through the Exchange. For example, call center staff should receive training on language and communication assistance policies and procedures, as well as training on how to handle questions from non-traditional families. Exchange call center staff should provide information about plan options and services in an unbiased manner.

6. Create an Inclusive Look and Feel of Exchange Website and Materials

Written comments submitted also recommended that the Exchange website visually reflect openness to diversity, depicting in photos and graphics the broad range of consumers who will access the website and the Exchange, including LGBTQ couples, people with disabilities and people of color.

7. Use Diverse Channels for Consumer Outreach

Commenters recommended that radio and targeted alternate media (e.g. *telenovelas*) be utilized to communicate information regarding the Exchange and its services. Commenters also recommended targeted distribution of outreach and marketing materials, such as through ethnic and local press and in neighborhoods and at locations and events where target communities gather (e.g. Pride Parade, cultural centers). Stakeholders cautioned that traditional written outreach materials would be insufficient to reach many vulnerable communities, where there may be low levels of literacy. Targeted outreach should also be conducted at provider sites where the uninsured and communities of color disproportionately seek services. One panelist suggested partnering with more prominent organizations and institutions in the state to reach populations that might not be accessed otherwise. For example, in Massachusetts, a partnership was formed with the Boston Red Sox and the state's Health Connector to reach a population of young men who were otherwise not touched by other outreach efforts.

8. Select Trusted Community Entities to Serve as Navigators

Stakeholders emphasized the importance of Navigators and in-person enrollment support for consumers seeking to access the Exchange. They noted, for example, that despite the promise of Internet- and telephone-based enrollment and access strategies, many consumers do not have access to or experience with personal computers or the Internet and over-reliance on technology can exclude hard-to-reach groups. People with disabilities may not be able to access computer terminals, and many vulnerable community members also do not have a telephone. These stakeholders emphasized the need for in-person consumer assistance. One commenter noted that during their coalition's recent listening session, participants "stressed the need to use 'established organizations that have become part of the local scenery and are known to be part of the community.' As an example of an assistance program that works, a participant who worked with a community-based eviction

prevention program, described how assistors will ‘take you by the hand and show you how to get what you need.’”^{xxviii}

In both the written comments and during the in-person stakeholder meeting, it was emphasized that the Exchange should make use of trusted community-based organizations, community health workers to conduct outreach and enrollment. Commenters, many of whom have been contracted to perform community outreach, lauded the New York State Facilitated Enrollment (FE) Program and Community Health Advocates (CHA) Program as models for the state to support and expand in the rollout of the Health Benefit Exchange. The FE program assists consumers in applying for public health insurance in community-based settings. Facilitated Enrollers are culturally and linguistically appropriate, provide service during non-traditional hours, and often perceived in the community as “safer” access points to coverage and benefits information for immigrants, LGBTQ individuals, and people with disabilities, among others. The CHA program similarly provides linguistically and culturally appropriate, community-based counseling and assistance on health coverage and care. Both the FE and CHA programs could serve as models for a robust community-based enrollment infrastructure for the New York Exchange.^{xxix} The New York Health Options program is also connected to regional “enrollment facilitators” who can be called to file complaints, verify plan-assisted enrollment, or receive referrals and resources, among other things, and can be leveraged for the Exchange.^{xxx}

In addition, some commenters emphasized the need for community-based health providers to be authorized under the Exchange to enroll consumers in health insurance plans. These community providers, like community-based organizations in the FE and CHA networks, are able to provide culturally and linguistically appropriate enrollment services, and often have the capacity to track and follow-up with consumers who may require multiple attempts to assemble required documentation and successfully enroll in coverage. In some cases, such as family planning or LGBTQ health services, community health providers may be the most trusted source for primary and preventative health care and information about coverage options.^{xxxi}

Network Adequacy

The New York Health Benefit Exchange will define the network adequacy requirements for health plans participating in the Exchange. Health plans must meet these requirements to be certified, and to be recertified each year as QHPs. Commenters offered a broad range of recommendations regarding the types of providers that should be required in QHP networks and what QHP providers should be obligated to provide to ensure that the needs of communities facing disparities are adequately addressed.

With respect to provider networks, stakeholders noted that health plans offered through the Exchange should have:

1. *Sufficient number of specialists.*

One commenter recommended that New York should require all Exchange-participating plans to contract with *all* willing family planning centers in a region. In addition, it noted that in some regions of the state there are shortages in some specialties. In these cases, plan networks should provide coverage of telemedicine and include as many providers as possible.

In addition, commenters caution against penalizing consumers if plans in the Exchange do not have sufficient providers to meet their needs, and recommend that out-of-pocket costs should be covered for consumers who are unable to locate a provider who is able to meet their needs should be limited to the amount they would have incurred for using a network provider.

2. Sufficient providers for AI/AN communities

Health plans should contract with all Tribal operated health clinics in the State.

3. Sufficient providers with accessibility accommodations

Health plans should contract with providers who can meet the accessibility needs of the communities they serve, including both physical access to buildings and sites but also access to exam tables and medical equipment. These providers should have protocol for identifying the need for auxiliary aids, mobility aids, case managers, and other supports for individuals with cognitive or mental disabilities.

4. Sufficient providers with linguistic ability

Health plans should contract with providers who can meet the linguistic needs of the communities they serve. This can be accomplished if plans contract with providers who have bilingual or multilingual staff, and/or commit to the provision of comprehensive interpretation and translation services for LEP patients.

Data Collection and Dissemination

The collection of data by the Health Benefit Exchange was the final, major area of focus at the September 7 stakeholder meeting and in written and oral comments. The Affordable Care Act contains a number of data collection provisions, as discussed above, and New York State, through its Medicaid Redesign Team, has committed \$2 million toward data collection efforts. The Exchange is an opportunity to further deepen New York's commitment to the collection of data related to race, ethnicity, language, gender, disability, sexual orientation, and gender expression, among other characteristics.

1. Collect Data

Commenters recommended that the Exchange collect data on disability status, sexual orientation and gender identity, in addition to race, ethnicity and language. In the case of data on race, ethnicity and language, some stakeholders recommend that this data be tracked at multiple points of consumer engagement with the Exchange, including application, enrollment, and appeals, to determine if there are disparities in each process

Stakeholders recommend that consumers be notified about the voluntary nature of providing data, and informed as to why questions regarding race, sexual orientation, language, and other demographic attributes are being requested as well as assured as to the privacy and security of data collected.

2. Disseminate Data

Stakeholders and panelists emphasized the need for data collected by the Exchange to be compiled and made available to the public. They also suggested that it be reported in a manner that is easy to understand and evaluate by non-experts. These data could then be utilized to identify disparities and develop targeted interventions. In a similar manner, if robust data related to a number of demographic characteristics are collected and analyzed for consumers' interactions at multiple points of the Exchange, it will be possible to identify unintended ways in which programs and practices of the Exchange may be unintentionally contributing to disparities.

Additional Recommendations

Beyond the feedback provided by stakeholders on the key issues highlighted for discussion at the September 7 meeting—consumer assistance, network adequacy and data collection—commenters provided the following additional recommendations for the Exchange:

1. Several stakeholders commended the Exchange for convening a meeting on disparities and urged continued engagement throughout the life of the Exchange.
2. Commenters recommended that the Exchange conduct periodic surveys and evaluations of consumers to understand how the Exchange's consumer experience can be improved.
3. Finally, several stakeholders emphasized the importance of addressing disparities through civil rights compliance efforts and the creation of a robust complaint and appeals process within the Exchange.

Conclusion

In the Health Benefit Exchange, New York State has a remarkable opportunity to build on the gains it has already made to address health disparities and expand it to another fundamental area of the health care infrastructure. Below is a summary of the key recommendations made by stakeholders.

Consumer Assistance

1. The Exchange must be accessible to LEP communities and people with disabilities. The following strategies can be used to achieve this goal:

- a. Provide consumer information in a variety of languages and formats, including interpretation in all languages using the range of modalities available and translation of written documents in at least 6 languages.
 - b. Include translated taglines in at least 6 languages for all Exchange notices and vital documents, informing consumers of their ability to access interpretation and translation services to understand the notices.
 - c. Have clear prompts and notifications on the Exchange website and through the call center that enable consumers to access language or communication assistance quickly.
 - d. Develop outreach materials in at least 6 languages.
 - e. Create a “Language Access Unit” or have dedicated staff responsible for creating and implementing language access and communication assistance plans.
2. Require plans participating in the Exchange to provide comprehensive language and communication assistance services.
 3. Consumer-oriented information and materials provided through the Exchange should be drafted in plain language so that it is understandable to a broad range of consumers. Information and materials, including outreach tools, should visually reflect openness to diversity, depicting in photos and graphics the range of consumers who will be access the Exchange.
 4. The Exchange should be sensitive to the needs and concerns of New York’s diverse consumers and provide training to staff on language and communication assistance policies, as well as training on how to handle questions from non-traditional or mixed status families.
 5. Consumer outreach should be targeted to reach diverse communities, including publication of information in ethnic and alternative media and distribution of outreach and marketing materials in locations where communities gather, such as cultural centers and events. Outreach should also focus on institutions that serve high numbers of uninsured people, such as emergency rooms and community health centers.
 6. The Exchange should make use of trusted community-based organizations to serve as Navigators, and leverage the successful Facilitated Enrollment and Community Health Advocates programs to build a strong community-based Navigator infrastructure. In addition, the Exchange should include community-based health care providers within its Navigator network.

Network Adequacy

1. The Exchange should contract with all reproductive health/family planning providers in a region, to ensure adequate access to key health services for women.

2. The Exchange should contract with all Tribal operated health clinics in the state and ensure that consumer protections afforded to American Indian and Alaskan Native consumers under federal law are honored by plans participating in the Exchange.
3. The health plans offered through the Exchange should have contract with a sufficient number of providers who can meet the physical accessibility, cultural, and linguistic needs of consumers.
4. Consumers who are unable to locate a provider who is able to meet their needs should be exempt from out-of-network costs.

Data Collection and Dissemination

1. Data collected by the Exchange should go beyond federal baselines and include collection of data on race, ethnicity, primary language, disability status, gender, gender identity, sexual orientation and English literacy levels.
2. Consumers providing demographic information should be notified as to the voluntary nature of the reporting, and assured as to the privacy and security of data collection.
3. Data should be reported, in a disaggregated manner, to enable analysis and understanding of disparities for particular communities within groups based on race, gender, disability, sexual orientation, or language.
4. Data should be published and reported in a manner that is easy to understand and evaluate.

Additional Recommendations

1. Stakeholders should be engaged throughout the process of Exchange implementation, not only at the outset.
2. The Exchange should conduct periodic consumer surveys and evaluations.
3. The Exchange should create a robust complaint and appeals process.

Working together, New Yorkers have the opportunity through the Health Benefit Exchange to dramatically reduce disparities in access to insurance and thereby reduce disparities in health outcomes. The strategies and recommendations provided by stakeholders are enormously valuable in ensuring that New York has a highly effective and inclusive Exchange, and that the state is a national leader in removing barriers to health care due to race, gender, disability, sexual orientation, language, and other factors.

Notes

ⁱ See, e.g.: Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care* (2003), available at: http://www.nap.edu/catalog.php?record_id=10260 (a comprehensive review of the literature on disparities on the basis of race, ethnicity and language); Agency for Healthcare Research and Quality, “Health Care Quality and Disparities in Women: Selected Findings from the 2010 National Healthcare Quality and Disparities Reports” (2010), available at: <http://www.ahrq.gov/qual/nhqrwomen/nhqrwomen.pdf> (overview of disparities in access and outcomes for women); Institute of Medicine, *The Future of Disability in America* (2007), available at: <http://www.iom.edu/Reports/2007/The-Future-of-Disability-in-America.aspx> (overview of health and related barriers faced by people with disabilities); and Center for American Progress, “How to Close the LGBT Health Disparities Gap” (December 21, 2009), available at: http://www.americanprogress.org/wp-content/uploads/issues/2009/12/pdf/lgbt_health_disparities.pdf.

ⁱⁱ See, e.g., Lee J. Hargraves and Jack Hadley, “The Contribution of Insurance Coverage and Community Resources to Reducing Racial/Ethnic Disparities in Access to Care,” in *Health Services Research* (June 2003), pp. 809-829.

ⁱⁱⁱ A. Finkelstein et al., “The Oregon Health insurance experiment: Evidence from the first year,” NBER Working Paper No. 17190.

^{iv} The text of Executive Order 42 can be viewed here: <http://www.governor.ny.gov/executiveorder/42>

^v 45 C.F.R. §155.205 (2012)

^{vi} 45 C.F.R. §155.205(c) (2012)

^{vii} 45 C.F.R. §155.210 (2012)

^{viii} 45 C.F.R. §155.210(e)(5) (2012). A Qualified Health Plan (QHP) is: “an insurance plan that is certified by an Exchange, provides essential health benefits, follows established limits on cost-sharing (such as deductibles, copayments, and out-of-pocket maximum amounts), and meets other requirements. A qualified health plan will have a certification by each Exchange in which it is sold.” See: <http://www.healthcare.gov/glossary/q/ghp.html>. Insurance Affordability Programs refer to programs such as Medicaid for persons under the age of 65, State Children’s Health Programs, and the insurance subsidy programs (such as Advanced Premium Tax Credits and Cost-Sharing Reducing Benefits) administered through the Exchange.

^{ix} 45 C.F.R. §156.230 (2012)

^x Patient Protection and Affordable Care Act, H.R. 3590, 111th Cong. §4302(a)(1)(D) (2010)

^{xi} Office of Minority Health, US Department of Health and Human Services, *Plan for Health Data Collection on Lesbian, Gay, Bisexual and Transgender (LGBT) Populations*, <http://minorityhealth.hhs.gov/templates/browse.aspx?lvl=2&lvlID=209>

^{xii} See Commonwealth Fund, *Racial and Ethnic Disparities in U.S. Health Care: A Chartbook* (March 13, 2008), available at: <http://www.commonwealthfund.org/Publications/Chartbooks/2008/Mar/Racial-and-Ethnic-Disparities-in-U-S--Health-Care--A-Chartbook.aspx>

^{xiii} See: http://www.health.ny.gov/health_care/medicaid/redesign/health_disparities_workgroup.htm

^{xiv} Comments of Donna Frescatore, Assistant Secretary of Health in Governor Cuomo’s Office and Executive Director of the Health Insurance Exchange, at the Health Benefit Exchange Stakeholder Meeting (September 7, 2012).

^{xv} 45 C.F.R. §155.205(c) (2012)

^{xvi} See Title VI of the Civil Rights Act of 1964, 42 U.S.C. §2000d, et. seq. and Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §701 et seq. and interpreting regulations, guidance and case law.

^{xvii} Americans with Disabilities Act, 42 U.S.C. §12101 et. seq.

^{xviii} Department of Health and Human Services, Guidance to Federal Financial Assistance Recipients Regarding Title VI Prohibition Against National Origin Discrimination Affecting Limited English Proficient Persons, 68 Fed. Reg. 47311 (August 8, 2003).

^{xix} Id.

^{xx} 10 N.Y.C.R.R. §405.7

^{xxi} N.Y. Exec. Order 26 (October 6, 2011), <http://www.governor.ny.gov/executiveorder/26>

^{xxii} See: <http://www.socialsecurity.gov/multilanguage/>

^{xxiii} Written comments of Project CHARGE (October 5, 2012). See also: Make the Road New York, New York Immigration Coalition and Korean Community Services of Metropolitan New York, *Now We’re Talking: A Study on Language Assistance Services at Ten New York City Public and Private Hospitals* (April 2008), available at:

http://www.maketheroad.org/pix_reports/Now%20Were%20Talking%20Report%20Final.pdf (finding that, despite improvements in language assistance provision at hospitals in New York City, Korean speakers continued to face great barriers based on language compared with Spanish speakers).

^{xxiv} 29 U.S.C. §794(d)

^{xxv} N.Y. Exec. Order 26 (October 6, 2011), <http://www.governor.ny.gov/executiveorder/26>

^{xxvi} California SB835 (February 21, 2003), available at: http://www.leginfo.ca.gov/pub/03-04/bill/sen/sb_0851-0900/sb_853_bill_20031009_chaptered.html

^{xxvii} New York City Mayor's Office of Adult Education and Mayor's Office of Immigrant Affairs, *Easy-to-Read: Guidelines for Clear and Effective Communication*, available at: <http://www.nyc.gov/html/oath/pdf/Easy-to-Read%20NYC.pdf>

^{xxviii} Written comments of Health Care for All New York (October 5, 2012)

^{xxix} One comment, from Project CHARGE, recommended that if the CHA program were to be expanded for purposes of the health benefit Exchange, that it award additional points during the RFP process for community-based organizations that can provide culturally and linguistically appropriate services. When the NYC Administration for Children's Services created such a weighted points scheme for a recent RFP, it resulted in better representation among contracted organizations of Asian-Pacific American, South Asian and Arab-American community groups with particular capacity to serve those communities.

^{xxx} See: http://www.health.ny.gov/health_care/family_health_plus/apply/application_centers.htm

^{xxxi} Written comments of Family Planning Advocates of NYS (September 26, 2012)