Community Perspectives

Proceedings from the Bronx Community Health Care Discussion

Obama-Biden Transition
January, 2009

Prepared by
The Bronx Health Link
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About the Sponsors

The Bronx Health Link, Inc.

Created in 1998, The Bronx Health Link is a clearinghouse of information addressing health issues in the Bronx. The mission of TBHL is to improve community health by identifying and organizing around emerging health issues, increasing communications, providing information and increasing access to available services and programs. Though TBHL serves the entire borough, our focus is on low-income neighborhoods with the highest risk for poor health outcomes.

The focus of our work is health education and promotion programs through the Comprehensive Prenatal Perinatal Services Network grant from the New York State Department of Health and the Infant Mortality Reduction Initiative funding from the NYC Department of Health and Mental Hygiene. We conduct a year-round outreach campaign, relying primarily on educational interventions that employ workshops, one-to-one contact with community residents and in the distribution of brochures, flyers, and other materials disseminated in the community and through our 45 Resource Centers. We conduct bilingual educational workshops in partnerships with health and social service providers. We sponsor an e-communication network where we post daily health-related information. We conduct community-based research such as surveys, focus groups, and interviews.

The Bronx Health Link Board of Directors
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Commission on the Public's Health System

The Commission on the Public's Health System (CPHS) is a city-wide, community-based membership health advocacy group organized in 1991. The mission of CPHS is to fight for equal access to quality health care services for everyone regardless of race, ethnicity, language spoken, or ability to pay. CPHS is committed to being:
* A strong advocate for the public health and hospital system;
* A strong voice for public health funding in state and city budgets;
* A strong supporter of community organizations organizing in their neighborhoods; and
* A strong advocate for health care services regardless of ability to pay, language spoken, race and/or ethnicity, or diagnosis.

Copies of this report can be obtained by calling The Bronx Health Link at (718) 590-2648 or emailing Lizette Santiago at lizette@bronxhealthlink.org.

January 2009
Introduction

In early December 2008, the Obama-Biden Transition Team issued a call for grassroots participation in local meetings around the country to provide input into the development of the President-elect’s health care plan. As the Transition Team explained, “Health care is a top priority for President-elect Obama and for Senator Tom Daschle, Secretary-designate for Health and Human Services (HHS). They both are committed to health care reform that comes from the ground up -- that's why this holiday season, we're asking you to give us the gift of your ideas and input.” Specifically, the Team asked people concerned about health care access to convene Town Meetings all over the country between December 15 and 31, based on a prescribed format, and to report the results promptly to the Transition Team.

At the Bronx Health Link, our work has made us acutely aware of the drastic health crises facing our borough, particularly the large number of residents who live in poor communities of color. According to 2007 census surveys, 27% of Bronx residents (and 38% of children) live in poverty; and in 2005, 29% of adults under 65 were uninsured. Rates of infant mortality, asthma, diabetes and HIV – to name just a few indicators – remain dramatically higher than those for the city and the country. Our agency has a long history of researching the health needs of these communities and gathering community experiences and recommendations for action. Besides producing annual community needs assessments on maternal and infant health since 2005, TBHL has in the past year participated in community surveys, focus groups, roundtable policy discussions, and formulation of a policy agenda for both the Primary Health Care Initiative (sponsored by the City Council Speaker) and the Child Health Policy Initiative (sponsored by a coalition of community organizations, coordinated by the Commission on the Public’s Health System).

Thus, our agency was enthusiastic about taking up the Transition Team’s challenge. TBHL partnered with the citywide Commission on the Public’s Health System to sponsor a Bronx Community Health Care Discussion, which was set for December 29. An email and flyer were prepared that invited both health care providers and consumers to attend and bring their ideas. The email and flyer were circulated by both organizations to their large lists.

The community discussion was held at the Bronx County office building on the morning of December 29, 2008. In all, 21 health professionals and consumers participated, primarily from the Bronx. Given the combination of short notice and the competing activities of the holiday season, the turnout was significant. The Transition Team’s Participant Guide (see Appendix) was used to direct the questions, and the prescribed survey was distributed and collected (discussion notes, attendance list, and survey results follow). Participants raised important concerns about inadequate health care and preventive services – both in terms of access and quality – and proposed a range of policy solutions. All of this information was forwarded to the Transition Team. We will continue to work with the Bronx community to assure that community perspectives are incorporated as policies to expand health access and quality proceed at the federal, state and local levels.
Bronx Population at a Glance

(Data is for 2007 unless otherwise noted.)

What the population is:
* Total population: 1,373,659
* Live births: 21,624 (a 21% decrease from 1990)
* Crude birth rate (number of births per 1,000 population): 16.6
* General fertility rate (number of births per 1,000 women of childbearing age, 2006): 70.9 (second highest borough, after Brooklyn)

Who lives in the borough:
* Median age: 31.8 (lowest of any borough)
* Race/ethnicity of mothers, % of live births (2003-5): African Americans, 35%; Puerto Ricans, 21%; other Latinas, 35%; Asians, 4%; whites 6%
* Immigrants in overall population: 32% (a 52% increase from 1990; 75% of the 2005 total are from Latin America)
* Immigrants among women giving birth (2005): 52% Countries of origin providing largest numbers: Dominican Republic (16%), Mexico (8%), and Jamaica (4%).
* Neighborhoods with more than 25,000 immigrants (2000): Norwood, University Heights-Kingsbridge, Wakefield, Morris Heights
* Residents who speak language other than English at home: 55% of those over 5 (700,401 people); 83% of those speak Spanish.

Why things are at a crisis level:
* Education level attained (% of those 25 and older): 31% did not graduate from high school; 30% only graduated from high school; 15% had some college; 7% had an associate’s degree, 11% had a bachelor’s degree and 6% had a graduate or professional degree (vs. Manhattan figures of 16% non-graduates from high school and 57% with bachelor’s degree or higher)
* Residents without high school diploma with incomes below federal poverty level: 38% (vs. 10% of those with bachelor’s degree or higher).
* Residents below federal poverty level: overall, 27%; families, 24%; women-headed families, 38%; children under 18, 38%
* According to the Citizen’s Committee for Children, African American and Latino households in NYC are more likely to have incomes less than $10,000 than are white and Asian households, and one fifth of Latino households are earning at or below this level
* Median household income: $34,156 vs. $69,000 in Manhattan
Who does and doesn’t have medical coverage:

**Medicaid Usage:**
In 2005, 12% (7.4 million) of the women of reproductive age nationwide utilized Medicaid for their care. Of the 128,961 births in NYC in 2007, approximately 52% were covered by Medicaid – and 68% of births in the Bronx (versus 39% in Manhattan and about a third nationwide). Districts with even higher proportions of delivering women on Medicaid are Mott Haven, Hunts Point, Unionport /Soundview, Fordham, and Williamsbridge. In NYC, the racial distribution of Medicaid-covered births was 9% Puerto Ricans, 32% other Latinos, 28% Blacks, 15% Asian/Pacific Islanders, and 15% whites.

**The Uninsured:**
According to 2005 data, the Bronx has a higher percentage of uninsured under-65 adults (29%) than the country at large (18%). Being uninsured threatens the health of the individual who often delays treatment because of a lack of access to care. In New York State, an estimated 20% of women of childbearing age are uninsured. Numerous studies have found that uninsured pregnant women are less likely to receive prenatal care than women who have private insurance.
Recommendations from the Bronx Community Healthcare Discussion

The following are the recommendations that emerged from the Obama-Biden Transition Community Healthcare Discussion held in the Bronx on December 29, 2008 by a range of health and human service professionals and consumers:

Overall Healthcare Financing System

1. There must be a national, universal, single-payer health care financing system, such as that embodied in the House bill, HR 676, with the following key components:
   - Coverage of all U.S. residents, including both documented and undocumented immigrants
   - No opt-out provision
   - Coverage of all medical services, mental health, dental and optical care, prescription medications, and such preventive services as screening tests, nutritional counseling, and case management.
   - Mandated bargaining with pharmaceutical companies to get the largest bulk discount rates
   - Identical rules and procedures for all states and cities, and a uniform set of administrative forms
   - Financing through income taxes and a tax on employers
   - The national system would replace private health insurance.

2. Federal health agencies should consistently circulate notice of all changes in policies and rules to state and local governments.

Healthcare Professionals

3. Provide adequate funding for need-based scholarships so that all who seek to enroll in schools for health professionals, including people from the full gamut of racial and cultural backgrounds, can do so.

4. Create a national plan to address the nursing shortage.

5. Expand the National Health Service Corps, including incentives for primary care providers.

6. Admissions criteria for professional schools – including medical, nursing, dental and MPH programs – should include measuring the applicants’ commitment to return to provide service to their communities.

7. Include information on health professional careers in school curricula, beginning in elementary school, to expand the pool of students prepared and motivated to enroll in health-profession training schools.

8. Provide funding for cultural competency training of all health professionals so they can provide better care for their multi-cultural patients.
**Access to Healthcare**

9. Expand funding of community health centers, particularly in underserved areas, and hire the full range of health professionals (e.g., social workers, health educators, mental health counselors) to provide patients with a medical home and help with navigating the system (in conjunction with recommendation #13 below).

10. Expand availability of medical services in the early mornings, evenings and weekends to make care more accessible to 9-5 workers.

11. Provide funding so that all schools of significant size have an in-house clinic for student care.

12. To encourage breastfeeding and make it more accessible, provide funding to mothers for breast pumps.

13. Create a well-funded cadre of visiting public health workers (nurses, social workers, and community health workers) to provide home care to populations with particular needs, such as women in prenatal and postpartum stages and people who need follow-up care after hospitalization, especially the elderly.

14. Provide consistent monitoring and enforcement of state, city and federal laws requiring hospitals to provide medical care to all, regardless of ability to pay, and to inform patients about their rights.

15. Stop reimbursing unnecessary and harmful medical care - such as unnecessary Cesarean sections and unwanted and intrusive end-of-life interventions.

16. Fund the training and placement of patient navigators/ombudspeople in all major medical institutions, including emergency rooms, who can provide coordination of care and advocate for patients’ rights and the full attainment of the services to which they are entitled.

**Prevention and Health Education**

17. Develop well-funded, integrated programs (i.e., not divided into separate silos), driven by community-based planning, for prevention education and services as a key priority for a national health care system.

18. Fund ongoing education programs both in the public schools and in communities (including billboards, public service announcements and Web-based venues), using linguistiically and culturally appropriate methods:

   - to make consumers/patients aware of their rights to obtain medical care and to be treated fairly, and what services are available. Popularize the slogan “Health care is a right.”
   - to raise awareness of major methods of preventing illness.
19. Provide ample funding to state and city health departments and community-based organizations to do outreach and public education about key health prevention concerns, including culturally appropriate education about nutrition, shopping, and food preparation.

20. As part of a prevention focus, increase support of local environmental programs such as parks and mass transit to encourage more physical activity.

**Community Role in Healthcare**

21. Communities must be fully involved in decisions concerning the distribution of health resources and the design of health prevention and care programs.
Notes of Presidential Transition / Bronx Community Healthcare Discussion

Monday, December 29, 2008, 10:00 a.m. – 1:00 p.m.
Place: 198 East 161st Street, Second Floor Hearing Room, Bronx, New York
Hosts: The Bronx Health Link and the Commission on the Public's Health System

Attended by 21 people from around New York City. [Note: Each item beginning with a bullet represents a comment by a different person.]

Each participant was given a packet including an agenda, a list of the Transition Team’s questions, the Participant Guide for Health Care Community Discussions, the Participant Survey for Health Care Community Discussions, and two booklets each from the sponsor organizations: *A Community Health Profile of Maternal and Infant Health in the Bronx* and *Programs and Services to Give You and Your Baby a Healthy Beginning*, both by The Bronx Health Link, and *Voices from the Community* and *Yes New York Can! A City-wide Child/Teen/Family Health Policy Agenda*, developed by the Commission on the Public's Health System and the Child Health Initiative.

Introduction by Joann Casado, Executive Director of The Bronx Health Link: The goal is to provide community input into the health care dialogue for the Presidential transition. They want ideas for an affordable, quality health care system. They want us to tell them about people’s stories of experiences with health care. Submissions will be made online. This is the only such meeting in the Bronx.

Meeting goals:
1) Discuss health care reform
2) Use a process that empowers people
3) Collect stories that exemplify the need for reform.
4) Provide community input to the new administration

[She read from the Transition Team document on health care discussions.] Everyone should fill out and return the Transition Team survey before leaving today. We want an open, honest dialogue.

All the participants introduced themselves and (where applicable) their organizations.

Ms. Casado then proceeded to ask the questions in the discussion guide.

1. Briefly, from your own experience, what do you perceive is the biggest problem in the health system?

   - Lack of health insurance and access to health care services, i.e., extraordinarily unequal access to services and same type of services; racial and ethnic disparities. Having an insurance card without access is a problem. It takes more than a plastic card.
   - The way insurance is, even if all had access to a middle-class norm, it would still be dreadful – providers spend their lives filling out useless forms for a profit-making model. We still use a capitalistic system for health care – the whole structure is wrong.
   - The huge complexity of the system. Example: state-by-state differences, such as for Medicaid, all systems are different. In New York we have good things and stupid things. We need a federal system that’s standardized.
• Also differences in insurance systems – the costs and complicatedness of the systems. We need one national system that’s the same throughout and portable, with one set of forms for everyone.

• We need no middleman, i.e., no insurance companies, and a healthcare financing system delinked from employers.

• Competition doesn’t work in healthcare. Even if all could get insurance cards, we need equality. Community needs have to be part of the discussion process, not just the needs of industry.

• Better distribution of resources and services, based on need, not on who has money or can get access to it. Example: Bed Pan Alley, the corridor of hospitals on the East Side [wealthy neighborhoods] of Manhattan, while immigrants and communities of color are losing services.

• Cost of health care. Insurance is just a symptom. If I can afford it, I can choose my insurance. If the costs were more reasonable for the average person, that would simplify it.

• The system denies access to those who think they can’t afford care. A 30-year-old musician called me on a weekend last summer. His son (age 8) had been vomiting blood for 8 weeks, but he had not brought him in for care. I said he should take him in right away to Einstein (when he did so, a top neurosurgeon operated on him). I asked: Why didn’t you bring him in sooner? He said his wife had lost her job and so the couple now had no benefits. Lessons:
  A) people aren’t aware that legally you can’t be turned down at an ER.
  B) people aren’t aware that there are public programs you can qualify for. For example, the hospital did get reimbursed by Medicaid (70% or more of their patients are on Medicaid). They have a great financial department that knows how to bill Medicaid correctly and so can expedite coverage. We need more patient education as to what programs they qualify for.

• This speaks to the complexity of the system. If everyone had a card, it’s got to be compulsory. For every family with a disabled child, you have to do case management to navigate the system. We need one simple system. Rhode Island has a system with a lot of coverage. Insurance companies have people who figure out what drug they’ll reimburse for – instead, we should have them do something useful.

• I visited Cuba – they have a doctor-patient ratio of 1-700 vs. 1-5,000 in U.S. They visit families at home three times a year and do a lot of preventive education.

• Access to primary care physicians is important. Based on the pay available, physicians don’t want to go into primary care because of debts accumulated from medical school. We need to expand the National Health Service Corps and make primary care more attractive. Yesterday my doctor said he can’t make a living off of Medicaid reimbursements. A national health insurance program must have incentives for primary care. A bill in the House, HR 676, with 95 sponsors, would set up a national program that would cover all residents. I’d like to see a groundswell for that bill – it’s been waiting for Congressional action for several years.

Moderator’s question: What if a policymaker tells you there are no funds available for such a universal coverage plan?

• There actually is a huge amount available – the current insurance system spends 20%-25% of revenue on overhead to administer insurance and managed care companies. Under the Canadian single-payer system, it only takes 8-10% overhead to run it – much lower than the
private sector. Eliminating these costs could cover a big piece of the costs of a universal system.

- I’m a person with a disability, and I like the idea of a federal system. My pet peeve: I’m not allowed to work by SSI – I have to sneak around. I want the freedom to work. A federal system should allow people with disabilities to work. I have sickle-cell anemia, but my brain works great. Every one of us is capable of working. Four years ago I lost my benefits because I worked “too much”—I was cut off Medicare. Then I had a crisis and had to go to Montefiore for care – but had no benefits because I worked “too much.” People with disabilities need more autonomy. If we work, they can take funds out for health coverage. I don’t want private insurance to restrict what we can get. I got a $32,000 bill from Montefiore for my medical emergency. We have to have economic autonomy. I’m angry, I want to work without restrictions. They’re killing people’s spirits and heart. I want to be a powerful, autonomous person in society.

2. **How do you choose a doctor or hospital?**

- Based on the health insurance you have. Some choose doctors from word of mouth by friends, family, etc., if they are under the insurance plan I have. Look to see if the doctor treats patients with respect. Does the doctor talk to you or write a prescription before listening? How well does he/she listen? Can you easily get information after your visit?
- I want advice on providers who have more experience with particular illnesses. I look up rankings on websites.
- But some people may not have access to the Internet.
- Cultural competency trainings should be provided to health professionals to provide better care for their patients.

**Moderator’s question: Hypothetical case: Doña Juana lives in the projects in the Bronx and has been diagnosed with heart disease. She went to a community hospital in the Bronx, but her family is not available to advocate for her. What should the system do for her?**

- We need an ombudsman to help patients navigate the system. Sometimes the secretary is the one who knows who the best doctors are. If it’s a teaching hospital, all attending physicians have academic appointments – the jobs are higher paying, so the doctors tend to have more experience and thus provide a higher quality of care.
- But there are two different measures of quality of care: a) academic credentials; b) how patients actually receive the care.
- I agree. There are doctors with no bedside manner.
- Providers must have cultural competency re: Doña Juana’s situation. Both the navigator and the provider must understand all of her needs. They must work in conjunction with each other – now the system is fragmented.
- In your packet are the results of a citywide survey done recently on health care access. On the face of it, most people have access. But then you find out that when people go to a teaching hospital, they go to a clinic and see a different provider each time. There may be no interpreters in their language and there may not be clear explanations. Academic credentials do not equal quality. There are huge gaps in access – even if you have a place to go. Only if you know someone, or know someone who knows someone, do you have real options – but many people don’t. Coordination of care, help and direction, is critical as part of the system, especially because that system is so complex.
I do public health education. Sometimes we use PSAs. There’s a high percentage of functionally illiterate people. People are afraid to come out to get care. People read newspapers, listen to radios, go to senior centers – that’s where we need to reach them. My experience is in workshops on immunization – people don’t realize that these are free or low cost, that you don’t need to have a health plan. Doing these workshops gives them more comfort. You need to look for people who advocate in the community. There are a lot of resources; it’s a matter of knowing how to get access to them.

In a new system, health departments should be well-funded to do outreach and public education. Community health centers are a good way to deliver culturally competent care, particularly in underserved areas. We need more and expanded centers – they would provide a medical home and help people navigate the system.

We need to make better use of the cheaper staff and systematize their role as advocates. It would be useful to place other health professionals in community health centers, i.e., social workers, health educators, mental health counselors, etc., to help make a medical home in communities. They can help play a role in providing access to care; they can make the patient feel welcome and hook them up with services. The system should routinely fund social workers. That way, the system can use the expensive services of doctors/midwives/etc. more efficiently.

How should public policy promote quality health care providers?

- Make sure education is available in all health professions – not just those with lots of money or those who happen to find scholarships. Admissions criteria for professional schools – medical, nursing, dental and even MPH programs – should include measuring the applicants’ commitment to go back to the community. The National Health Service Corp depends on money being appropriated. Recently the New York State Legislature cut back the New York State version of that program – makes it a half-baked program. We need training of health professionals to go back to their communities. This should be a criterion for acceptance by schools.

- For health provider training, start from the beginning: Go back to junior high level – if public schools aren’t providing students who can meet the entrance criteria, we won’t have the cadre of health professionals that we need, health professionals who represent the whole gamut of cultures in this country. In fact, we need education starting in kindergarten.

Moderator’s question: Should we ask for a national training program to include more underrepresented people?

- Sophie Davis at City College of New York has a good program in the first two years of medical school. They have a bridge to city high schools.

- We have to find ways so health professionals can do what they want to do. Now there’s a tendency that if they’re good, they get promoted to be further away from patients. Many nurses tell me that they don’t get to do the type of holistic care with patients that they used to. They shouldn’t have to spend their lives fighting with insurance companies to find coverage for the people they are serving.

- We have to teach people how to navigate the system. We have to go to the places where Doña Juana socializes. I work in the community, I give them common-sense ideas about health care.
• Bronx Community Health Network (BCHN) has such a program – based in the Einstein Hospital ER. The navigator talks about how to get a primary care doctor, but funds for that program are from community health center grants to BCHN – it’s not built in.
• We have to stop seeing such programs as frills.
• Health education, case management, and nutrition education must be reimbursable, not peripheral.
• In a national system under HR 676, such services would be included.
• Montefiore just announced it is closing its adult sickle-cell clinic – it’s the only one in the Bronx. I talked to a patient who didn’t think she had access to it. Montefiore should not be allowed to close the clinic. [Editor’s note: After the meeting, two participants checked with Montefiore, which said that the adult sickle clinic is not closing. It is being relocated to a building around the corner, and will have some staff changes, but will definitely continue in operation.]
• That’s the issue that brings me here.
• This goes to the question of equal access to care – one could have insurance, but have no place to go for care.
• We must make sure to distribute resources based on what’s needed in the community.
• “We” in health care decision-making has always been from the top down, not community-based.

3. Have you or your family members ever experienced difficulty paying medical bills? What do you think policy makers should do to address this problem?
• I work for the city, have good health coverage. But recently I needed surgery, and the surgeon recommended to me didn’t take any insurance coverage. My insurance did cover the hospital expense but I had to pay for his fee. Even if he had taken insurance, they would have only reimbursed one-third of his fee. Access is a problem wherever you are. The medical system is holding everyone hostage. You have to pay top dollar if you want the best care. The govt. should do a national system so that some charges to patients are offset by taxes – so costs aren’t so astronomical. I spent three days in a modest hospital room and the fee was $74,000. My son was born premature and spent 2-1/2 weeks in the NICU [neonatal intensive care unit] – thank God we had coverage – it would have cost $120,000.
• Even if you’re rich, you can’t afford catastrophic or chronic illness care. One obvious solution: stop throwing away money on bad care – such as unnecessary Cesarean sections and unwanted and intrusive end-of-life interventions.

Moderator’s question: If Ms. Doe goes to the ER without insurance and doesn’t qualify for coverage, what should be done?
• I just went to the ER and didn’t have the $50 deductible, so I didn’t get the care I needed.
• That’s an outrage, but there are little protections, hard-won, in New York State. When violated, we should let the system know. In New York State, hospitals are not allowed to turn away anyone from the ER. This is upsetting – it shows why we need someone in the ER to help patients navigate through the health care system.
• I wasn’t turned away, I was ignored for 7 hours. Conditions in Montefiore are horrendous – they stack patients in the hall like in a cattle corral. The ER needs more funding. When a doctor finally saw me, he said “Who are you? What do you want?” I said all the info was on my record, but they had no record of me in their system at all.
I’ve worked in health care for 10 years. My dad had a stroke and heart attack recently. The bill was $300,000 – he had no insurance. It took 3 weeks to find the program that covered it for him, and that’s even with the help of a social worker – but he had to provide bank statements, employer documents, etc. It’s impossible to meet the deadline to submit all the documents. I feel for those who don’t have caregivers. We need education from childhood about access to health care. The system is cuckoo. If my father didn’t have me to navigate for him, he probably would have paid the bill by depleting his savings. We need to tell everyone that payment programs are there. They didn’t give my dad information on these programs until we asked. The hospital admission process should include giving information on payment programs.

I grew up in public housing. When someone’s rights are violated in a hospital, the word gets around, and people back off. Education about rights and programs has to be ongoing – to repeat and reinforce the message.

Who is responsible for oversight of the hospitals to make sure they give out the mandated information?

The New York State Health Department is, but there are real problems getting them to check up on hospitals and enforce the rules. I’m part of a group working with them on this – last summer, they gave us two days to comment on a propose letter to hospitals and yet it’s still in limbo, six months later. There has got to be enforcement; regulations are meaningless unless they’re enforced.

My grandparents are both ill – they didn’t plan for their frail age. I’ve found that health educators and social workers are not always the best informed about programs available to people. Medicaid is extremely complicated. It’s frustrating that you do everything you’re told you’re supposed to do, then they come back and say “you have do this other thing.” They should make sure that health educators are fully educated. When federal agencies make policy changes, they’re not good about circulating that info to states, cities, etc.

Why don’t educators see this as a priority for their job? Because someone (their supervisors) are not telling them they should.

Sometimes institutions withhold information. My father was turned down for Medicaid to cover nursing home expenses. After he got that decision, the nursing home staff told him “Now I’ll tell you your payment options.”

A woman in a wheelchair asked me to read her letter (which she had already sent to the Transition Team) into the record. (In summary: She was diagnosed with sickle cell disease as an infant, and at age 43 caught sepsis in a hospital and landed in a wheelchair. Now it’s hard for her to find housing because of lack of wheelchair accessibility, she can’t purchase a home due to low income, says doctors aren’t willing to help her get back on her feet due to seeing Medicare and Medicaid as “poverty-level insurance” and lost her city job after being out sick for a year, but unable to qualify for disability retirement. She asked why “doctors and nurses still treat patients with sickle cell like drug addicts”, and asked “why must we fight to get Social Security, Medicare, Medicaid and perhaps Food Stamps when we need it” and why Social Security penalizes the disabled when they try to work.)

I have an experience with the ombudsman’s office of an elected official, referring someone who had a question about health services. Their staff is young, and there’s a huge learning curve – they don’t have adequate training. It’s a good starting point, but they’re usually political science grads, not social workers. We need to push to have social workers in these positions. It’s frustrating for me as a worker in local government – I don’t know where to send you to. People look to local government as a great place to get information out.
4. In addition to employer-based coverage, would you like the option to purchase private insurance through an insurance-exchange or a public plan like Medicare?

- I feel that question is like “have you stopped beating your wife?” It assumes we want to keep employer-based coverage. I’d like a public plan – Medicare for all.
- I’d also like a public plan for everyone.
- It must be a system of universal coverage where you can’t opt out. If people can, they’ll choose food and rent over insurance premiums.
- Medicare doesn’t do a good job with dental care.
- HR 676 is more than extending Medicare as it currently exists – it would cover mental health and dental services.
- For NYC, HR 676 is especially important because it doesn’t require you to be a citizen, just a resident, to be covered. In this city there are huge numbers of people without documents – federal policy currently doesn’t require them to be covered.
- HR 676 is the single-payer plan which has been introduced in at least 4 or 5 Congresses and has not moved forward.

5. Do you know how much you or your employer pays for health insurance?

- Prescriptions are a large part of the expense
- HR 676 would require the federal government to bargain with pharmaceutical companies to get the biggest possible discount
- I run a community-based organization – 3 employees are on the health insurance plan (Empire) and we pay $30,000/year for their premiums – it’s a non-contributory plan (for employees), although they have to pay deductibles and co-payments. It doesn’t cover glasses or dental care. It would cost $1500 per employee to cover their family – double the rate for single people – so we have no choice but to not offer that.
- HR 676 would cover dental and optical care.
- Small employers can’t negotiate with insurance companies – larger ones can. At an earlier job with 30 staff, we had to negotiate really hard to get a lower rate. At my current job, I had to have my wife put me on her dental plan. There should be no reason to negotiate something that’s your right.
- Other agencies pass their insurance costs on to employees, but it’s more and more difficult for employees to pay.
- We need a mantra for health care reform – “health is a right”. That should be a part of education campaigns.

What should an employer’s role be in a reformed healthcare system?

- In a national system, the employer’s role should not be to buy insurance but to pay taxes for a national health care system.
- The tax should not be regressive. The state and national personal income tax is regressive.

Screening mammography, flu shots and cholesterol screening are types of preventive services Americans should receive. Have you gotten the prevention you should have? If not, how can public policy help?
• I had to wait three months to get a mammogram, and I have Empire insurance. There aren’t enough radiographers available. There’s a lack of mammography services available in each area.

**How many people have gotten flu shots?** About 8 hands went up.

**How many people have had cholesterol screening?** About 8 hands went up.

• One problem is that if I take the day off from work for screening, I don’t get paid for that day I have to take off.
• My dad had to wait 7 months to get an appointment for a digital prostate exam.
• This list is incomplete. I would add diabetes testing, HIV testing, pap smears, and colonoscopies.
• It took me four months to get an appointment for a colonoscopy.
• My primary care physician is great – when he doesn’t take my insurance, he negotiates a rate with me. With national insurance, we wouldn’t have to travel to get a good doctor.
• Many people won’t see a doctor if it’s not mandated. Example: vaccinations – many only get them because they’re required to take a job or enroll in school. Everything has to start with education in the schools – they don’t give common-sense advice about how to take care of your body.
• We did a focus group with teenagers in the Bronx. We found that they won’t go to the doctor on their own – usually the mother is the gatekeeper. Even emancipated young people only go if they have to for their children.
• Even people who work in the health education field (where I work) don’t take advantages of services available to them.
• A problem is that the hours of many doctors are 9-5 – I can’t afford to take time off from work. Taking advantage of preventive services within working hours is extraordinarily difficult – I won’t get paid for a day off. There’s a lack of services before 8 am, after 5 pm, and on weekends, and on a walk-in basis.
• Some clinics will only take a maximum of 3 kids from each family.
• Some mothers, if they have several kids, have a hard time paying for travel costs, so they’ll wait to bring them in for services until it’s required.
• Every school should have a clinic to provide health care to children so parents don’t have to travel with kids.
• There should be employer-based clinics for larger employers, and smaller employers should coordinate with larger ones.
• I don’t like to hear blame put on people who don’t get preventive services. It’s true that some people don’t want to go – but for many others, there are lots of barriers. We need to move resources into prevention, make sure they’re paid for. Moving policy to that has been hard. Medicaid for children has a piece that covers preventive services – that’s because welfare rights organizations had to sue to get the law implemented that requires it to cover particular tests and services for children. But under Medicaid managed care plans, this is often not enforced. One study found that only 45% of children in Medicaid managed care saw a dentist in the previous year. Now the New York City Health Commissioner wants to close all the city’s dental clinics – it’s a crazy plan. We need to push this agenda – even if we have a national health plan, will prevention be a priority? Services must be available for people when needed in a culturally competent way.
• New York State has been doing good smoking cessation programs. I see it in the schools – kids know smoking’s bad, even if they don’t really know why. Having a consistent message
works. Bodegas get shut down if they sell cigarettes to minors. There’s a high cigarette tax. In a national plan, they have to go at prevention in the same way.

Moderator’s question: What is the level of access to preventive health services in countries with national health care such as Canada and Sweden?

- A Commonwealth Fund study reviewed studies finding that in those countries the level of health is better and people live longer than in the U.S.
- Also the level of self-efficacy in those countries is higher.
- We should look at those studies.

[Back to the earlier question about what prevention measures are needed]

- We need to support environmental programs – parks, mass transit to encourage more exercise – not just clinical programs, but programs that emphasize safety and the environment. Examples: We need to help people understand how to shop for food, where food comes from.
- Insurance has to cover breast pumps to make breastfeeding feasible.
- We should bring back visiting public health workers in people’s homes. We need a cadre that could be nurses, social workers, or community health workers. This could be done for women in prenatal and postpartum stages and also for people who need follow-up care after hospitalization, especially for the elderly – it’s much cheaper and better care than provided by nursing homes.
- A national plan should address the nursing shortage. The problem is that nursing schools don’t have enough capacity or enough faculty. There’s no shortage of applicants – in fact schools are now flooded with applicants.
- This visiting health worker cadre could see folks who either can’t come in for care at all or need assistance to get to the care they need.
- In Britain, a nurse comes to the home of every mother for a month after she gives birth. Studies show that health workers can do better assessments in the home.
- Security can be an issue for visiting nurses.
- When I worked for the Health Department, they sent people in pairs to tough neighborhoods.
- Let’s get away from stereotypes: There are some bad areas but don’t assume all poor neighborhoods are dangerous.
- Home health aides go into all communities without having to have security.
- The system should get community input on what works.
- We recently worked with community groups to develop a child and teen health policy agenda for New York City – these recommendations can spill over to adults. Plans for adult health care should be done like this – communities determining what they need.
- In certain parts of Brooklyn where I work, the lack of access to health services is worse than in some Third World countries.

How can public policy promote healthier lifestyles?

- Smoking cessation programs are a good example.
- But they shouldn’t have a punitive element.
- New York City’s HIV prevention campaign, including distribution of condoms, is another good example.
• There should be PSAs and billboards in every language.
• Latino radio and TV generally doesn’t discuss public health – they should be targeted. Constant repetition of messages is key for prevention.
• One good policy is that the City Department of Health now requires calorie counts to be posted in restaurants and there is education on how to use them. This should be made a national policy.
• Not everyone eats out, so culturally appropriate cooking information should be provided.
• Individual campaigns like these are a good means to reach people, but there needs to be an overall policy. In a redone system, there needs to be a focus on health and navigating through the health care system rather than just medical care. These issues (the ones cited earlier) would be a part of it and flow down from there.
• We need safe, usable outdoor space and playgrounds – kids are not allowed to move any more due to fears about safety.
• Campaigns have to be part of a continuum – now they’re done in separate silos. Communities have to be involved in creating policy for promoting healthier lifestyles.
• The system needs to provide an overall structure that starts with prevention and health education/promotion, primary care, access to diagnostics, specialties, hospitalization, and the whole gamut of health care.
• These services need a sufficient level of funding. The reason the smoking cessation programs have done well is that they got lots of funds from suits against the bad guys. You can’t do that with AIDS and other health issues.
• You have to look at the system and ask at each level how much funding do we need?
• We have to put out a simple message: prevention saves money. We need to have the statistics ready. Emphasize that an ounce of prevention is worth a pound of cure.
• A lot of the data is already out there – the problem is how to use it to push the issue with elected officials, who are beholden to insurance companies.
• Community organizations should let the community know that prevention is the best both for people’s health and their wallets.
• I am very concerned that Montefiore Hospital is closing its adult sickle-cell anemia clinic due to a lack of funding. There are lots of services for pediatrics but adults need care too. There have to be options other than a total shutdown.
• I’m outraged by the shutdown of the sickle-cell program. People like me with sickle-cell are considered non-entities. It’s a long-term condition. The program has over 400 patients. They say the clinic lost the NIH grant it had been getting for 20 years.
• This is the problem with private decision-making. I suggest we write to Montefiore and the state and city health departments. Montefiore is not a poor hospital.
• Even if they lost their grant, can’t they at least scale back the program rather than eliminate it? No one who knows about sickle-cell will be there on staff.
• It would be important to do letter-writing and media outreach.

(People who came late were asked to speak:)
• This community forum is an excellent way to hear about issues. Can you please ask if participants would be willing to share their contact information with everyone who attended?
• I know a woman who has a huge dental abscess – her face was horribly swollen. She had been a domestic worker who had worked for her employer for 30 years. She was just fired.
because her employer didn’t want to look at her with her face that way. She couldn’t get a dental appointment to deal with this until March 30. This is an outrage.

- Groups like this [those gathered here] can provide a force to be reckoned with. The Bronx has been underserved. We have representation without adequate funding from the federal government.
Results of Participant Survey
During Bronx Community Health Care Discussion

Note: Only 19 of 21 participants returned surveys. Some participants marked multiple items for each question.

1. What do you perceive is the biggest problem in the health system?
   a. Cost of health insurance
   b. Cost of health care services
   c. Difficulty finding health insurance due to pre-existing condition
   d. Lack of emphasis
   e. Quality of health care

   Survey results:
   a-11, b-10, c-8, d-10, e-11

2. What do you think is the best way for policy makers to develop a plan to address the health system problems?
   a. Community meetings like this
   b. Traditional town hall meetings
   c. Survey that solicit ideas on reform
   d. A White House Health Care Summit
   e. Congressional hearing on C-SPAN

   Survey results:
   a-16, b-7, c-9, d-9, e-7

3. After this discussion, what additional input and information would best help you to continue to:
   a. More background information on problems in the health system
   b. More information on solutions for health reform
   c. More stories on how the system affects real people
   d. More opportunities to discuss the issues

   Survey results:
   a-8, b-9, c-7, d-7
List of Participants

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Donnette Carroll, Sickle Cell Thalassemia Patients Network
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Executive Summary:
A Profile of Maternal and Infant Health in the Bronx (2007-2008)
Funding provided by the NYCDOHMH

Copies of the full-length report can be obtained by calling The Bronx Health Link at (718) 590-2648 or emailing Lizette Santiago at lizette@bronxhealthlink.org.
Executive Summary:  
A Profile of Maternal and Infant Health in the Bronx (2007-2008)  
The Bronx Health Link

Introduction: This is an Executive Summary of the Profile of Maternal and Infant Health in the Bronx for 2007-2008, prepared by the Bronx Health Link. The full report is a compilation of data from national, state and local sources highlighting the current state of reproductive and maternal health in the Bronx. The development and distribution of this document was made possible by funding from the New York City Council Infant Mortality Reduction Initiative and the New York City Department of Health and Mental Hygiene (NYCDOHMH).

Overview: While advances have been made across the country in the field of maternal and infant health, the Bronx lags behind on all key indicators. The borough’s rates of infant mortality, maternal mortality, and percentages of prematurity, low birth weight, teen pregnancy, and late or no prenatal care exceed—in some cases substantially—those of the city and country. Several of the poorest neighborhoods are hit particularly hard. This year’s Profile of Maternal and Infant Health in the Bronx attempts to go deeper than previous reports, beginning to analyze the underlying causes of these distressingly high rates.

The key thread running through almost every measure of maternal and infant health is the presence of stark racial disparities between whites and people of color (who constitute 94% of the women giving birth in the Bronx), particularly African Americans and Puerto Ricans. What might explain this? According to Ronald David, a physician, professor and co-author of the recent research on infant mortality by the Joint Center for Political and Economic Studies, “For many years, the operating theory in the health community has been that the high incidence of infant deaths among African-Americans is attributed to higher teen pregnancy rates, single motherhood, lower education levels, poverty and, most recently, genetic causes. However, we found that infant mortality for Blacks remained high even when all these factors were controlled.” And last September, the NYC Health Department reported, “The race gap persists even when poverty is taken out of the equation. Infants born to higher-income Black women died at nearly three times the rate of those born to higher-income white women.” What, then, might be the hidden cause? According to Dr. Michael Lu, an obstetrician-gynecologist and professor at UCLA and a leading researcher on racial disparities, “We know that stress is an important risk factor [for infant mortality], and it initiates the release of stress hormones leading to preterm birth and increase susceptibility for infection.”

There are several likely mechanisms by which the stresses of daily life in a disenfranchised, impoverished community damage the health of women of color and their developing fetuses:

- One study found that “African American mothers who delivered very low birth weight (VLBW) preterm infants were more likely to report experiencing interpersonal racial discrimination during their lifetime than African American mothers who delivered non-LBW infants at term.”
• Research by Dr. Lu and his colleagues found that, as one summary put it, “the disproportionately higher number of fast-food restaurants and liquor stores, lower number of grocery stores and the higher cost of fresh produce in many urban, predominately Black communities caused poorer pregnant Black women to make stressful choices about what to eat and where to live. So did…worries about sending children to poorly equipped, understaffed schools.”

• Stress is one cause of gestational hypertension (high blood pressure during pregnancy). One research team found a strong link between that condition – disproportionately present among Black women -- and adverse birth outcomes.

• Another likely mechanism is stress leading to vaginal infections, which Black women experience at higher rates. One study found that “African Americans were…more likely than women in other groups to deliver preterm if any of these infections were present.” It also noted that “individual and community-level stressors” such as housing density and poverty “all influence the likelihood of acquisition of STIs [sexually transmitted infections].”

There are also economic barriers to high-quality care which have a disproportionate effect on people of color. Two-thirds of Bronx births are to women on Medicaid, and many remain uninsured. According to a 2005 report by Bronx Health REACH (Racial and Ethnic Approaches to Community Health): “Even within the same institutions, the uninsured, people covered by Medicaid, and sometimes, even those enrolled in Medicaid Managed Care, Family Health Plus and Child Health Plus, receive poorer quality care in different locations, at different times, and by less trained physicians than those who are privately insured – a practice that is prohibited by the Patient Bill of Rights and Medicaid Managed Care contracts…the discrepancies virtually ensure unequal access to care.” In addition, there is often inadequate transportation and child care for poor women to obtain these services. There are also many barriers to applying for and renewing Medicaid coverage.

The failure of many doctors and other care providers to communicate vital health information to patients in an understandable and culturally appropriate manner constitutes yet another barrier to high-quality care.

Notwithstanding the poor health indicators documented in this profile, thousands of women and infants are surviving and thriving in the borough. The methods that can enlarge their numbers are well known. Prenatal care, a key to maintaining maternal and infant health, needs expansion, as do supportive prenatal, birthing and postnatal services. Programs for education, counseling and direct services concerning many of the issues identified in this report need to be created, funded, and implemented, or -- where they exist – greatly expanded.
Infant Mortality: The rate of infants dying before the age of one year continues to be shockingly high in the Bronx (7.1 infant deaths per 1,000 live births in 2006)—exceeding the city (5.9) and national rates (6.8) (which themselves are far worse than those of most industrialized countries) and the federal Healthy People 2010 goals. In 2006, within the Bronx, the highest infant mortality rates are in Mott Haven (12.7), Williamsbridge (11.6) and Morrisania (9.6). Mirroring national trends, the infant mortality rate in New York City among African Americans continues to be double that of whites, with Puerto Ricans close behind.

Sudden Infant Death Syndrome (SIDS): SIDS – sudden unexplained infant deaths despite thorough investigations – have declined dramatically in recent years, both nationwide and in the Bronx. This may be partly due to educational campaigns emphasizing the importance of putting infants to sleep on their backs, which greatly reduces the risk of SIDS. Maternal smoking and second-hand smoke are other important risk factors for SIDS, and there are campaigns against these exposures as well.

Prematurity: Babies born before 37 weeks of gestation are at extremely high risk for serious, sometimes lifelong illness, disability, and possibly death. Percentages of babies born prematurely have been increasing nationally and in the city. Many premature babies also have low birth weight. As with other maternal and infant health problems, African American/Black and Latino infants have much higher risk of being born preterm than white infants. In 2005, 10.2% of babies born in the Bronx were premature. Bronx districts with the highest percentages were Morrisania (12.8), Williamsbridge (11.1), Concourse/Highbridge (10.6), University/Morris Heights (10.5), East Tremont (10.5), and Unionport-Soundview (10.4).

Low Birth Weight: Infants with low birth weight (less than 5 pounds, 8 ounces) are at much higher risk of serious health problems and SIDS. Factors such as maternal smoking and use of alcohol play key roles in causing low birth weight. In 2006, 10.2% of infants born in the Bronx were born with a low birthweight, a higher percentage than that of any other borough or the NYC total (8.9%). Citywide, African American/Black babies (closely followed by Puerto Rican babies) were almost twice as likely as white babies to have low birth weight.

Prenatal Care: Prenatal care is key to healthy pregnancy and childbirth, and must start early to be fully effective. In recent years, higher proportions of pregnant women nationally have obtained timely prenatal care. In 2005, 24% of pregnant women in the Bronx obtained late or no care, a higher percentage than for the whole city. Higher still were such percentages in the following Bronx neighborhoods: Mott Haven (32.6%), Hunts Point (30.3%) and Concourse/Highbridge (29.6%).

Teen Pregnancy: Teenage mothers are much less likely to obtain prenatal care, and are at especially high risk for serious illnesses; their babies are at a higher risk of low birth weight and preterm delivery. The Bronx, like the city and country, has seen a drop in the percentage of teen births over the past decade, but in 2006, 11.9% of all live births in the Bronx were to teenagers (age under 20), the highest of the five boroughs in NYC. This rate was about two times higher than the percentage of live births to teenagers in Manhattan (5.9%), Queens (6.1%), and Staten Island (5.9%). Within the Bronx, percentages are even higher in Mott Haven (15.8%), Hunts Point (15.8%), East Tremont (14.9%), Morrisania (14.7%), University/Morris Heights (13.0%), and Concourse/Highbridge (12.1). In 2006, 79.2% of the women under age 20 who had live births in the Bronx were on Medicaid.
**Breastfeeding:** Breastfeeding is key both to the full health and development of the baby and to the mother’s health. Numerous studies have correlated this practice with lower levels of infant diarrhea, ear infections, pneumonia, meningitis, obesity, and asthma, as well as several maternal illnesses. It is now the standard recommended for at least the first six months of life. Percentages of mother who breastfeed have increased steadily over the past decade and a half nationally and in New York City, with the highest percentage increase among African Americans. Nonetheless, exclusive breastfeeding (breastfeeding only and not utilizing formula) remains uncommon, particularly among low-income women and women of color. This is due to such factors as employers’ refusal to make accommodations, lack of social support, and social stigma.

**Maternal Illness and Mortality:** Among the more common illnesses faced by pregnant women are hypertension, hemorrhage, ectopic (tubal) pregnancy, and infection. Other health risks come from domestic violence, smoking, and drug abuse. For the period of 2003-2005, the maternal mortality rate for the Bronx (at 29.9 maternal deaths per 100,000 live births) continues to greatly exceed the citywide rate (23.1). Citywide, Black women die at a rate over 15 times higher than do white women.

**Domestic Violence and Pregnancy:** Three to four million women in the United States are beaten in their homes each year by their husbands, ex-husbands, or partners. Pregnant women are especially vulnerable. Studies have found that pregnant women subjected to violence are far more likely to suffer from high blood pressure, vaginal bleeding, and hospitalization during pregnancy, and to deliver preterm and/or low-birth-weight babies.

**Cesarean Sections:** Cesarean section has become the country’s most common surgery, at levels far above the recommended maximum of 15% of all deliveries set by the World Health Organization (WHO). Nationwide, 30% of all births are by C-sections, and the New York City level is nearly as high, 29%. The percentage of births by C-sections at Bronx hospitals was 27.5 -- far above the WHO upper limit. The NYC Public Advocate has recommended “an initiative that prioritizes reducing the cesarean rate, emphasizes continued research into the risks associated with the procedure, and establishes ‘best practice’ procedures for all health care facilities and providers in New York City.”

**HIV/AIDS:** Rates of HIV infection among women continue to rise nationwide, with unsafe heterosexual sex now the predominant risk. In 2006, the Bronx had a rate of HIV diagnoses was 62.4 per 100,000 population, second to Manhattan at a rate of 70.5; particular Bronx neighborhoods had high rates such as Hunts Point-Mott Haven (102.5), Highbridge-Morrisania (95.4), and Crotona-Tremont (82.2). Despite availability of powerful antiretroviral drugs, women with AIDS continue to die at higher proportions than men. However, NYC cases of perinatal HIV transmission declined from 334 in 1990 to 13 in 2005 (7 of which were in the Bronx).

**Postpartum Depression:** Estimates of postpartum depression incidence among new mothers nationally range from 5 to 25%. Depression has significant effects on women’s relationships, their ability to nurture their newborn, and their overall quality of life. Effective treatments exist for depression, but because many women are unable to define their feelings as depression or because of the social stigma of depression, many women do not disclose their symptoms to their medical provider. There is some evidence that routine depression screening of women in obstetric or in pediatric settings can increase the detection of mental illness and referrals for services.
Risk Factors for Maternal and Infant Health

Nutrition: Maternal weight can profoundly affect infant health – underweight mothers are at risk of birthing an underweight baby, and obese women are at risk for pregnancy complications, birthing a malformed baby, and contracting various diseases later in life.

Alcohol: Drinking alcohol—even small amounts—during pregnancy can cause physical and mental birth defects. Each year, more than 40,000 babies are born with some degree of alcohol-related damage, and 1,300-8,000 have Fetal Alcohol Syndrome (FAS), a combination of physical and mental birth defects.

Illicit Drug Use: A range of illicit drugs (particularly heroin, cocaine, Ecstasy, crystal meth) poses risks for both unborn babies and their mothers. A nationwide survey of pregnant women found that 4% used illicit drugs, mostly marijuana, plus another 1% who made non-medical use of prescription drugs. There can be barriers for pregnant women drug users in obtaining prenatal care and drug treatment. For example, some drug-using women, fearing loss of custody if detected, are deterred from seeking care. Thus, the women most in need of services are often alienated from prenatal care.

Exposure to Environmental Pollutants

Air Pollution: Research by Columbia University in the South Bronx, Washington Heights and Harlem found that all mothers and newborns studied had been exposed to a type of hydrocarbon – a particle formed by burning substances like diesel fuel – which easily enters homes and was linked to low birth weight, slowed mental development, asthma and cancer. The Bronx has especially high levels of slow-moving, diesel-fuel-burning truck and bus traffic due to: numerous waste transfer and recycling plants; large wholesale produce markets; and the heavily-trafficked Cross Bronx Expressway. In addition, the borough houses a huge sewage-into-fertilizer treatment plant that emits dangerous heavy metals such as lead, iron and zinc.

Chemicals: Some four million-plus chemical mixtures are in homes and businesses nationwide. While little information is available on the effects of most during pregnancy due to the lack of government-mandated testing by manufacturers, many are known to be harmful to an unborn baby. A pregnant woman can inhale these chemicals (such as from household cleaning products), ingest them in food, drink or the containers holding them (such as tin cans and certain plastic baby bottles), or, in some cases, absorb them through the skin (such as through lotions and shampoos). In addition, pregnant women are advised to avoid pesticides, since studies have suggested that high levels of exposure may contribute to miscarriage, preterm delivery and birth defects.

Cigarette Smoke: The percentage of pregnant women who smoke has been steadily dropping for many years, currently around 10% – lower among Latinas and African Americans/Blacks than whites. Cigarette smoke, whether from the mother’s smoking or second-hand smoke, endangers both the mother’s and infant’s lives. Infants born to smoking mothers are 65% more likely to have low birth weight and 70% more likely to die in infancy than infants born to nonsmokers, and children of mothers exposed to smoke during pregnancy were found to have postponed development.
Lead: Exposure to high levels of lead during pregnancy contributes to miscarriage, preterm delivery, low birth weight and developmental delays in the infant. Lead toxicity in children – found at higher levels among African Americans and Latinos -- is characterized by behavioral and learning problems and anemia.

Mercury: Mercury is a metal that mainly gets into our bodies by the fish we eat. Prenatal exposure to high levels of this metal can severely damage the nervous system of developing babies, leading to brain damage, learning disabilities and hearing loss, or death.

Health Insurance Status

Medicaid Usage: In 2005, 12.0% of the 7.4 million women of reproductive age nationwide utilized Medicaid for their care. Of the 125,506 births in NYC in 2006, approximately 53% were covered by Medicaid – and 68.2% of births in the Bronx (versus about a third nationwide). Districts with even higher proportions of delivering women on Medicaid are Mott Haven, Hunts Point, Unionport/Soundview, Concourse/Highbridge, Fordham, and Williamsbridge. In NYC, the racial distribution of Medicaid-covered births was 43% Latinos, 28% Blacks, 14% Asian/Pacific Islanders, and 15% whites.

The Uninsured: The Bronx has a higher percentage of uninsured under-65 adults (29%) than the country at large (18%). Being uninsured threatens the health of the individual who often delays treatment because of a lack of access to care. In New York State, an estimated 20% of women of childbearing age are uninsured. Numerous studies have found that uninsured pregnant women are less likely to receive prenatal care than women who have private insurance.

In conclusion, this Health Profile is not merely an academic report – it is a call to action. The conditions facing many Bronx women and children – particularly African Americans and Latinas – are atrocious, producing a catalogue of shamefully unnecessary suffering and death in stark contrast to the outcomes in many wealthier and whiter communities. But many of the barriers to improved health identified in these pages can be dismantled by concerted policy changes and institutional improvements. Achieving that will take organized advocacy efforts through a partnership of health professionals and consumers in these communities. We intend this report to be a useful tool for such an effort, a catalyst for change.
Voices From The Community
Acknowledgements

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The **borough coalition leaders:**
- Brooklyn Perinatal Network (Brooklyn) – Denise West
- El Centro del Inmigrantes (Staten Island) -- Gonzalo Mercado and Rev. Terry Troia
- Make the Road New York (Queens) – Juanita Lara
- Northern Manhattan Improvement Corporation (Manhattan) – Jules Douge
  - IndoChina Sino-American Community Center (Lower East Side/Chinatown) – Peter Cheng
- The Bronx Health Link (Bronx) -- Joann Casado


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Executive Summary

The Child Health Clinics in New York City have a long and proud history. For 100 years, they have served large numbers of immigrant children and children of color. The clinics grew out of Free Milk Stations started by philanthropists that distributed “clean milk” to ensure that low-income infants did not die because of diarrhea. Doctors and public health nurses were added to these milk stations to provide health care services. At one point, public health nurses from the clinics made home visits.

The Child Health Clinics are a model of community-based, locally accessible primary care services for children. The clinics emphasize provision of preventive and primary care services in an era when specialization and technology are more prevalent. An early focus was on keeping babies well. The clinics later shifted to caring for all young children and eventually expanded services to incorporate all children and young people up to age 19.

To celebrate the 100th Anniversary of the Child Health Clinics, the Commission on the Public’s Health System (CPHS) organized a Planning Committee including children’s organizations, advocacy groups, and public unions. This Child Health Initiative was developed to:

- Develop broad-based coalitions in each borough;
- Organize three events in each borough to celebrate the anniversary, at or near child health clinics;
- Provide outreach to “unaffiliated families” to attend the celebrations;
- Survey parents about their children’s health status and their access to health care services;
- Arrange discussion groups with young people to hear directly from them about their health status and access to services;
- Ask parents at the events if their children had health insurance coverage, and if they did not, offering to have them enrolled on the spot or refer them to a Facilitated Enroller; and
- Talk to parents and young people about the importance of ongoing access to comprehensive primary care services – “a medical home.”

Recognizing that New York City does not have a Child Health Policy, a plan was developed to hold celebrations in each borough and in the process gather the voices of community residents about their children’s health care. The survey was developed to learn more about what parents were thinking about children’s health care and to gather direct information about problems, gaps in services, and barriers to health care services.

A community-based organization was chosen to lead a coalition effort in each borough. These organizations, along with CPHS, and a Policy Committee spent several months developing a survey instrument that could be used to gather voices from parents, and also as a guide for use in focus groups with young people. After testing of the survey, changes were made to capture the types of information we believed was important. The survey was also translated into and administered in twelve languages: English, Arabic, Bengali, Chinese, French, Haitian Creole, Korean, Polish, Serbo-Croatian, Spanish, Tagalog, and Urdu.

The survey contains thirty nine questions along with three open-ended questions at the end. Information gathered in this confidential survey included:
- Demographic data about the parent
- Demographic information about the children;
- Health status of children;
- Health access issues for children;
- Insurance issues; and
- Information/Communication.

The voices of the 659 parents of 1,376 children interviewed and the 114 young people who participated in twelve focus groups are captured in this report. This is a convenience sample that does not necessarily represent all populations in the city. The surveys were administered primarily at Child Health Clinic events though the survey respondents were not usually families who used the Child Health Clinics. The population drawn to these events was overwhelmingly immigrants and persons of color largely because of the location of these clinics in low-income communities of color.

New York is a city of vast contrasts, with extraordinary wealth and intense poverty. Health care services are not evenly distributed across the city, with concentrations of medical care in the more upscale communities of the city. There are also vast differences in the health of the population, and access to services, based on income, race, ethnicity, language spoken, disability, and ability to pay for services. Some of the racial and ethnic disparities in access to care and outcomes of care will be portrayed and discussed in the companion Child Health Initiative publication, the Child/Teen/Family Health Policy Agenda.

Results of the Surveys and Focus Groups

Results of the Surveys
The picture drawn from the surveys is somewhat complex, particularly as the responses from the close-ended questions are contrasted with the responses to the open-ended questions. The picture at first looks rosy.
- Almost all children are covered by health insurance – 601 families (93%) had insured children.
- Almost all children have a “regular” source of care – 618 families (95.3%) said their children have a regular doctor or clinic.
- Many children were able to get “regular” check-ups – 525 families (80%) said their children get check-ups all of the time.
- Many children were able to have an appointment in less than a week’s time – 443 families (73.1%) were able to get appointments for their children in less than one week.
- Parents were able to ask and get their questions answered about their child’s medical care – 484 families (73.6%) always get their questions answered.

But the picture appears less rosy when looking at the responses to other questions.
- Overwhelmingly in the surveys, children were reported as having specific health problems, including: asthma; overweight/obese; dental problems; and attention or behavior problems.
- When asked what medical problems of children they see in their community – the most frequent mentioned concerns were: asthma, overweight, and diabetes.
Children in 95 families (14.5%) were hospitalized in the last twelve months. The percent of hospitalizations was higher in Queens and in Staten Island.

Children in 243 families (37.2%) used an Emergency Room in the last twelve months. The percent of Emergency Room visits was very high in the Bronx (49.6%) and in Staten Island (50%).

Parents in 69 families (10.5%) reported that they had to travel one or more hours to medical care for their children.

Parents in 124 families (25.9%) who speak a primary language other-than-English were not able to find a doctor or clinic that spoke their language. This is more of a problem in the Bronx (28.4%); in Queens (26.2%); and in Staten Island (48%).

Parents in 144 families (32.2%) who speak a primary language other-than-English were not provided with interpreters. Based on the number of parents that responded to this question in each borough, this was a large problem in Brooklyn (34.4%) and in Staten Island (63.4%).

The picture is bleaker when reviewing the parents’ responses to the open-ended questions at the end of the survey. Some examples of the quotes include:

- “Sometimes the doctor or nurse has problem to understand me because of the language barriers and the cultural differences.” (Bronx)
- “They should have more clinics for children that suffer asthma, obesity, diabetes, or cancer in our community and also they should hire more staff in those clinics that speak our language.” (Brooklyn)
- “Have health community to go to sensitivity training to understand culture and language barriers.” (Manhattan)
- “HMO taking too many children – like a bakery. And have to wait too long and little time with patients. Like commercials – see you take a number.” (Queens)
- “More clinics. Doctor take more time with the patient. They need more equipment in the clinics so they don’t have to travel too far to see the specialist.” (Staten Island)

The Focus Groups

Twelve focus groups were convened with 114 young people participating. Young people were involved to ensure that their voices were also heard because of the belief that parents do not always know what their teenagers are thinking. Questions for these focus groups were drawn from the parent survey and slightly altered to the interests and perceptions of young people.

Most important health problems: The health care problems and concerns of the young people differed from their parents, with a greater focus on HIV, AIDS, STD’s (Sexually Transmitted Diseases), pregnancy and other consequences of unprotected sex. Pressures on young people, particularly for new immigrants, led to concerns about mental health issues and stress. In the Staten Island focus groups, concerns centered more on access to care and attention from medical staff. Some of the participants felt there is a “need to treat immigrant youth with dignity and attention.”

Definition of being healthy: Most teens stated that good nutrition, good hygiene, and exercise meant being healthy. There was some discussion about access to preventive care to maintain good health. A few of the focus groups discussed how spiritual health or spirituality contributed
to the quality of their overall health. Some participants did not believe that they live in a healthy community, but rather in a “hood” where mostly Black and Hispanic people live.

**Regular doctor or clinic:** Most of the participants had access to a regular doctor or clinic in their neighborhood, with one group in the Bronx able to access healthcare in their school. In one Manhattan focus group and one in Staten Island healthcare was accessed through the Emergency Room.

**Travel to access care:** About 25% of the participants had to travel for healthcare services. Young people in Staten Island, Brooklyn, and the Bronx reported having to travel far to get medical care. Some Brooklyn participants did not like the way they are treated in teaching hospitals – groups of staff walked into their room without permission, and some felt “like it was an experiment.”

**Communication during medical exam:** Most participants said they were able to communicate well with their doctors, although some cited a problem because “the doctor doesn’t speak good English, sometimes it is hard to understand him.” Some participants raised concern about the doctor communicating more with the parent rather than the young person.

**Understand what is happening during medical exam:** Responses to this question varied widely. One group in Staten Island felt rushed and not listened to in Emergency Rooms. Focus group participants in Brooklyn felt empowered to ask questions. One Brooklyn participant said that “doctors are not like the olden days. Man you got these interns coming in from college ad stuff like that. Before back in the day, the doctors would take the time you know and handle you as a patient you know, talk confidentially with you. Now you go there and you could hear the doctor in the next room telling the patient what’s wrong with him.” Some participants looked for alternate sources of information through brochures or looking up information online.

**Health insurance coverage:** A majority of the participants had health insurance cards or had access to health care in a clinic.

**Changes if you had power for a day:** Some groups wanted to see their communities changed, some wanted to change the availability of health care, some wanted to change how they received treatment at their medical facilities, some wanted more information about sexually transmitted illnesses, and others wanted to make changes to the health care system as a whole. A large majority of participants wanted to have universal health coverage and care in the United States, citing other country’s programs. Brooklyn participants wanted improved patient services. There was a call from some focus groups for having clinics which opened according to students’ schedules, after school and on the weekends, so that students can access services (from the Bronx) or to have school-based clinics (from Queens).

**Conclusions & Recommendations**
Making the effort to obtain voices from residents is an important way to learn about health status, access to health care services, and the problems, gaps, and barriers people faced when they go for care. In *Voices From The Community* we learned some good news and some troubling news. The picture is not all bleak, but there are definite problems that need to be addressed. Many children have health insurance coverage in New York City, but services are not always available and accessible, or provided in a way that is acceptable. A focus on improving health care services
and health care status in low-income, medically underserved, immigrant and communities of color is an important undertaking.

*Voices From The Community* should be read in conjunction with the Child/Teen/Family Health Policy Agenda. The borough coalitions have reviewed and discussed a summary of the findings from the surveys and focus groups for their borough. The priorities and recommendations for the Agenda come in part from the report of the surveys.

As noted above, some of the problems normally associated with health care barriers and gaps in services appear to have been addressed for children in New York City. In this survey, almost all children had some form of health insurance coverage. Their parents also told us that they have a “regular” source of health care services, but some families have to travel far to access this care.

Yet this survey and the focus groups also tell us that there is a great deal of dissatisfaction in the delivery of care and services. We also know from other sources of information that there are wide disparities statistically in health status and in the availability of health care services in low-income communities. Based on these statistics, and the concerns raised by parents in the survey and from young people in the focus groups, we have determined that it is the content and the quality of the care and visits that are the problem. Based on this conclusion, the Child Health Initiative has the following recommendations:

- Every child needs a “medical home” where comprehensive, ongoing, coordinated care is provided, and referrals are made for additional needed care. Having a “regular” source of care where these elements are missing cannot be considered quality care. Having rotating physicians in hospital clinics serve as primary care practitioners does not ensure the elements of a “medical home.”
- Health care services must be culturally and linguistically competent. This requires a “sea change” and serious training efforts within health care provider settings that involves all levels of employees. Training must also include the need for all staff to interact with patients in a professional and respectful manner.
- Reimbursement for primary care services must be changed to ensure that health care providers are able to spend the appropriate amount of time with each patient. Primary care providers must be incentivized to ensure they are providing all of the elements of good primary and preventive services for children. It is not always the physician that is needed to provide information and answers to questions. However, it would mean an adequate staffing level of nurses, or others well-trained, to spend teaching time with patients. In this study, were heard from parents and from young people about the 5-10 minutes spent with the doctor in which the exam feels rushed, questions go unanswered, and problems are not thoroughly explained.
- Health care standards of care for periodic screening and testing for children found in Medicaid Law should be expanded to be the standard for all children. In addition, there needs to be greater accountability for, and close monitoring of reporting and implementation of these standards (EPSDT, see footnote 8).

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1 *A Primary Care Capacity Shortage in New York City & the Potential Impact of Hospital Closures*. September 2006. Primary Care Development Corporation & Health & Hospitals Corporation.
• Quality care standards for children’s health care need to be developed with the involvement of the community whose children will be affected by them.
• Families should be provided with education on their rights on what they should expect when they access care and on how to navigate the health care system. This information must be provided in a comprehensive way that is acceptable and usable for families.
• Navigators should be available to assist patients when there are problems.

The Child Health Initiative, coordinated by CPHS with its’ borough coalition partners, is proposing to continue to work together to implement these recommendations and the recommendations found in the Agenda. Along with the Initiative’s Policy Committee, we are recommending the following principles:

• The voices found in this report are an important part of understanding health care issues in New York City. They need to be heard and heeded.
• Follow-up is needed on a number of the issues raised in Voices including, a review of access to care in communities in which respondents identified problems.
• A needed linkage between community planning efforts and institutional proposals for expansion or contraction of services.
• A focus on planning to address particular illnesses and environmental problems that confront many of the city’s immigrant and communities of color.
• A need to address the concerns of teenagers and young people, separate and apart from the efforts on behalf of younger children.
YES

NEW YORK

CAN!

A Child/Teen/Family Health

Policy Agenda

For New York City
Executive Summary

Change is in the air, in our hopes, in our dreams, and in our actions. Yes New York Can! is part of that change in the air. It is a community-led, community-driven organizing and planning effort that identifies and promotes a new paradigm for making New York a city filled with Healthy Children living in Healthy Communities.

Yes New York Can!, along with Voices from the Community, are two products of a year-long Initiative to celebrate the One Hundredth Anniversary of the city’s Child Health Clinics, which represent a distinguished model of community-based, locally accessible primary care services for children. One hundred years ago was an extraordinary era for public health in the city. It was a time when free clean milk was distributed, children first received immunizations, nurses made visits to homes, and children’s health and development were assessed and recorded. These activities were guided by a clear and consistent vision for children, based on the recognition of their developmental needs.

In recent years that vision has dimmed and faded; today we cannot find a vision for children’s health in New York City. Yet as we look ahead to the next 100 years, we believe that such a vision is sorely needed. This 100th Anniversary provides the occasion for us to propose a new vision for the city’s children. This vision has informed the development of a Health Policy Agenda for children and teenagers that is presented here, an Agenda that will be unique because its content will reflect the priorities of the community itself, expressed through borough child health coalitions led by community organizations.

For the past year, the Child Health Initiative has brought together community organizations in all five boroughs to work with CPHS and a Policy Committee in a pioneering project focused on the health needs of New York City’s children and teenagers.

The Child Health Initiative recognizes that the current reality for children is:

- There are racial and ethnic disparities in access to health care services and in outcomes of health care.
- There are also geographic problems in the distribution of health care services and access to those services. These disparities can be seen, measured, and documented in services such as access to prenatal care and in outcomes of birth.
- There are wide variations in infant survival and in birth weight, depending on community of residence, race, and ethnicity.
- There are huge variations in the rate of children’s hospitalizations for conditions that could be prevented or treated in the community, such as asthma, acute respiratory infections, and pneumonia.
- Some diseases, such as asthma, are much more prevalent in underserved communities.
- Children in New York City are more likely to use Emergency Room care than older adults – the opposite of what would usually be expected.

To address these and numerous other deficiencies and disparities that stunt the health of our children and young people, representatives of community organizations, professional organizations, child-serving agencies, advocacy groups, unions and others, came together to begin the process of building a Children’s Health Policy Agenda.
The Child Health Initiative — comprised of CPHS, five child health borough coalitions, and a Policy Committee with health and policy experts and children’s advocates — was organized to celebrate the Child Health Clinics, to gather voices from the community, and develop a Policy Agenda. *Yes New York Can!* is the Child/Teen/Family Health Policy Agenda developed by the Child Health Initiative. Over the past year, the Policy Committee helped to design a survey of parents about their children’s health status and access to care. Similar questions were also used in focus groups with young people. The surveys and focus groups were administered and organized by the borough coalition leaders.

The two major principles guiding our vision is the need to works toward 1) Healthy Children and Young People and 2) Healthy Communities. Health care must emphasize primary and preventive care to ensure that children and young people are developing appropriately for their age and that potential problems are caught before they become more serious. The focus on children and young people is important because the early years are the time when healthy development, good nutrition, and the other components of health can form the rest of our years. It is also important for parents and children to live in healthy communities with satisfactory housing and a clean environment, the availability of parks and open spaces, access to nutritious food, and schools that educate children and young people. Each of these items is an integral component of a healthy community.

We also believe that it is important to involve the whole community — community organizations, schools, houses of worship, and families — in the development of recommendations for improving their communities and neighborhoods. The involvement of organizations and residents is critical in developing how needs can be met, and what is required to ensure a healthy community.

*Yes New York Can!* is our Agenda for the future direction of health care for children, young people and their families in New York. The results of the surveys and focus groups (*Voices from the Community*) helped inform the development of this Agenda. Each of the borough coalitions determined their priorities. They then decided on strategies for meeting those priorities. There is one citywide priority — to fix the school health program so that it can work more effectively for the many children enrolled in both public and private schools in the city.

*Yes New York Can!* provides the following: A Vision Statement for Healthy Communities; Health Status of Children & their Communities; A Summary of *Voices from the Community* and A citywide Policy Initiative looking at the School Health Program; and Policy Initiatives for each of the five boroughs:

- The Bronx: Asthma; Obesity; and Mental Health – submitted by the Bronx Health Link.
- Brooklyn: Lack of quality care; Access to care issues; Lack of service coordination – submitted by the Brooklyn Perinatal Network.
- Manhattan – Nutrition – submitted by the Northern Manhattan Improvement Corporation. Asthma -- submitted by IndoChina Sino Community Center.
- Queens – Asthma, Obesity/Overweight, and Access to care – submitted by Make the Road by Walking.
- Staten Island – Access to treatment, Treatment for special needs populations, and Coordination and Access to Care – submitted by El Centro del Inmigrantes.
The President-elect believes that every American should have high quality and affordable health care, and to reach this goal, we must modernize our health care system in order to:

- Improve health care quality and cut costs;
- Expand coverage and access; and
- Increase the emphasis on primary care and prevention.

As we work to revamp our health care system, we need to hear from you. There is no problem that we cannot solve together—and it is out of our collective wisdom and experience that we will identify potential solutions to the many health care challenges that we face. We need to hear your ideas and your stories so that we can report them to the President-elect. What follows is brief background information to help you start a discussion and a set of key questions. Your answers to them will guide our collective effort to reform the U.S. health system.

I. OVERVIEW OF THE PROBLEM

The potential of health care in America is enormous and ever expanding. Diseases that once were life-threatening are now curable; conditions that once were devastating are now treatable. We have the knowledge to extend and improve lives.

But, as the stories of those who participated in the recent on-line discussion at www.change.gov testify, our system is flawed and fails to deliver affordable, high-quality health care to all Americans. Our system faces three interrelated problems.

First, health care costs are skyrocketing, hurting our families as well as our economy:

- Health insurance premiums have doubled in the past 8 years, accompanied by increasing co-pays and deductibles that threaten access to care.¹
- Large medical bills have contributed to half of bankruptcies and foreclosures.²
- Rising health care costs place a burden on American businesses, as they try to balance health benefit costs with job growth and competitiveness. American manufacturers are paying more than twice as much on health benefits as most of their foreign competitors (measured in cost per hour).³
- Problems with health care quality and administrative “waste” contribute to these costs:
  - Medical errors result in as many as 100,000 deaths per year in U.S. hospitals.⁴
  - On average, American adults received just 55 percent of recommended care for the leading causes of death and disability.⁵
- The U.S. spent $412 per capita on health care administration and insurance in 2003—nearly 6 times as much as other developed countries.⁶
Second, over forty-five million Americans have no health insurance:

- Nearly 160 million Americans have job-based insurance, but many are just a pink slip away from joining the ranks of the uninsured. For every 1 percentage point increase in the unemployment rate, over one million people become uninsured.\textsuperscript{7}
- Being uninsured leads to delayed care—late diagnoses for cancer when it is harder and more expensive to treat, and preventable complications due to untreated diabetes. It also leads to denied care—a child without health insurance is less likely to receive medical attention for recurrent ear infections or for asthma. Uninsured trauma victims are less likely to be admitted to the hospital and are 37 percent more likely to die of injuries.\textsuperscript{8}
- Even people with coverage are increasingly finding that it is insufficient or simply not there when needed. Nearly one in five Americans either delay care or have unmet needs despite having health insurance.\textsuperscript{9}

Third, our nation’s investment in prevention and public health is inadequate, leading to rapid spread of chronic diseases, many of which could be prevented entirely or managed:

- One in 3 Americans—or 133 million—have a chronic condition,\textsuperscript{10} and 5 chronic diseases—heart disease, cancer, stroke, chronic obstructive pulmonary disease, and diabetes—cause over two-thirds of all deaths.\textsuperscript{11}
- Approximately 1 in 3 children born today will develop diabetes in their lifetime.\textsuperscript{12}
- Only four cents out of every health care dollar is spent on prevention and public health.\textsuperscript{13}

II. The President-elect’s Health Care Plan

President-elect Obama presented a framework for health reform to achieve three goals:

Modernize the Health Care System to Improve Quality and Reduce Costs:

- Invest in a national health information technology system that will allow us to coordinate care, measure quality, reduce medical errors, and save billions of dollars;
- Reward health providers that provide high quality care and coordinated care;
- Expand disease management programs and self-management training to help patients;
- Lower drug costs by increasing the use of generic drugs in public programs, and taking on drug companies that block cheaper generic medicines from the market;
- Require hospitals and providers to collect and report health care cost and quality data.

Expand Coverage to All Americans:

- Build upon and strengthen employer coverage;
- Allow people to keep the coverage that they have and maintain patients’ choice of doctor;
- Establish a National Health Insurance Exchange that offers a range of private insurance options as well as a new public plan option;
- Require insurance companies to cover pre-existing conditions so all Americans regardless of their health status or history can get comprehensive benefits at fair and stable premiums;
- Expand Medicaid and SCHIP and provide sliding-scale premium assistance for low-income people.

Improve Prevention and Public Health:

- Require coverage of clinical preventive services such as tobacco cessation services and cancer screenings, in public programs and private health plans;
- Invest in community-based prevention that will lead to healthier schools, worksites, and communities;
- Tackle the health and public health workforce shortage and bolster the public health infrastructure.
III. Questions

1. Briefly, from your own experience, what do you perceive is the biggest problem in the health system?

2. How do you choose a doctor or hospital? What are your sources of information? How should public policy promote quality health care providers?

3. Have you or your family members ever experienced difficulty paying medical bills? What do you think policy makers can do to address this problem?

4. In addition to employer-based coverage, would you like the option to purchase a private plan through an insurance-exchange or a public plan like Medicare?

5. Do you know how much you or your employer pays for health insurance? What should an employer’s role be in a reformed health care system?

6. Below are examples of the types of preventive services Americans should receive. Have you gotten the prevention you should have? If not, how can public policy help?

7. How can public policy promote healthier lifestyles?

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**Examples of Recommended Preventive Screenings**

**Screening Mammography:**
- All of the major professional societies that make recommendations about breast cancer screening recommend that women by age 50 and older get a routine annual screening mammography for breast cancer. Many of these societies recommend that women should undergo such screening at age 40.  
- Yet, only 71.8 percent of women age 50-64 and 63.8 percent of women 65 or older received a screening mammogram in 2005.

**Flu Shots:**
- The Centers for Disease Control and Prevention recommends that all adults over the age of 50 receive an annual vaccine against influenza.  
- Yet, in 2006, only 45.9 percent of adults over the age of 50 received a flu shot.

**Cholesterol Screening:**
- The U.S. Preventive Services Task Force recommends that doctors routinely screen men ages 35 years and older and women ages 45 years and older for high cholesterol.  
- Yet, according to data from 2007, only 74.9 percent of adults in the U.S. had their cholesterol checked within the past five years.
PARTICIPANT SURVEY FOR HEALTH CARE COMMUNITY DISCUSSION
(Please Give Your Survey To Your Host—Thank You!)

1. What do you perceive is the biggest problem in the health system?
   a. Cost of health insurance
   b. Cost of health care services
   c. Difficulty finding health insurance due to a pre-existing condition
   d. Lack of emphasis on prevention
   e. Quality of health care

2. What do you think is the best way for policy makers to develop a plan to address the health system problems?
   a. Community meetings like these
   b. Traditional town hall meetings
   c. Surveys that solicit ideas on reform
   d. A White House Health Care Summit
   e. Congressional hearings on C-SPAN

3. After this discussion, what additional input and information would best help you to continue to participate in this great debate?
   a. More background information on problems in the health system
   b. More information on solutions for health reform
   c. More stories on how the system affects real people
   d. More opportunities to discuss the issues
References

4. Linda T. Kohn, Janet M. Corrigan, and Molla S. Donaldson, Editors; Committee on Quality of Health Care in America, Institute of Medicine, To Err is Human, Washington, DC: National Academy Press (2000).