Voices from The Community

CHILD HEALTH CLINICS 1908-2008 100 Years

Child Health Policy in NYC
The Next 100 Years

cphs*

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Voices From The Community

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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

Policy Committee: includes CPHS, the five borough coalition leaders; Socrates Aguayo, *Health and Hospitals Corporation*; Ellen McHugh, *Parent to Parent in New York State*; Swapna Reddy, *Children's Defense Fund – New York*; Jennifer March-Joly and Joan Siegel, *Citizens Committee for Children of New York*; Dr. Katherine Lobach, *American Academy of Pediatrics – New York Chapter 3*; Dr. Harold Appel, *Doctors Council*; Dr. John Brunetti, *ACS Head Start of New York*; Noilyn Abesamis-Mendoza, *Coalition for Asian American Children & Families*; Jenny Rejeske, *New York Immigration Coalition*; Ana Garcia, *New York Academy of Medicine*.

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Participating Surveyors:
Citywide: Council of Peoples Organizations; South Asian Council for Social Services; Korean Community Services of New York; African Services Committee; and Commission on the Public's Health System.
In the Bronx: The Bronx Health Link; Bronx Community Health Network;
In Brooklyn: Arab American Family Support Center; Center for Law and Social Justice, Medgar Evers College; School Health Program, Lutheran Health Center; Catholic

Charities of Brooklyn; Caribbean Women's Health Association; Brooklyn Perinatal Network
In Manhattan: Northern Manhattan Improvement Corporation; 129th Street Prayer Alliance; PS 368 ; Children's Aid Society; IndoChina Sino American Community Center; RACCOON.
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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[1] and in the availability of health care services in low-income communities.[2] 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).
- 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.

[1] *Keeping Track of New York City's Children.* 2008. Citizens' Committee for Children of New York City. Also New York City Department of Health & Mental Hygiene *Vital Statistics.*

[2] *A Primary Care Capacity Shortage in New York City & the Potential Impact of Hospital Closures.* September 2006. Primary Care Development Corporation & Health & Hospitals Corporation.

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.

Introduction

Beginning in 2007, a small idea -- to plan a celebration for the 100th Anniversary of the city's Child Health Clinics -- developed into a large initiative. With the organizing of a Planning Committee, the Child Health Initiative grew into a research, planning and policy development, organizing, and advocacy effort. The goal of the Child Health Initiative is to celebrate the Child Health Clinics' anniversary while highlighting the need for all children to have coverage and access to comprehensive health care services. In New York City today, there are wide disparities in health status and access to care dependent on race, ethnicity, country of origin, primary language, community lived in, income, education, immigration status, and insurance coverage.

The Commission on the Public's Health System (CPHS) has long advocated for the Child Health Clinics as an important source of locally accessible services. These small clinics oriented to primary and preventive care have served generations of low-income, medically underserved immigrant and communities of color.[3] Beginning as Free Milk Stations, these facilities have evolved into a network of important local health services for children up through age nineteen.

Launching the Initiative

Funding was raised for the Child Health Initiative for a program that covers all five boroughs. A community-based organization for each borough was selected to organize a coalition that would implement the components of the Initiative. The five organizations are: Brooklyn Perinatal Network; El Centro del Inmigrantes; Make the Road New York; Northern Manhattan Improvement Corporation (with a Lower East Side/Chinatown subcommittee headed by IndoChina Sino-American Community Center); and The Bronx Health Link. Each borough coalition was charged with:

- Organizing three events at or near child health clinics to celebrate the anniversary;
- Providing outreach to "unaffiliated families" to attend the celebrations;
- Doing surveys of parents about their children's health status and their access to health care services;
- Arranging discussion groups with young people to hear directly from them about their health status and access to services;
- Asking 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
- Talking to parents and young people about the importance of ongoing access to comprehensive primary care services – "a medical home."

[3] The studies include: *Healthy Children – Keeping Needed and Well-Used Services Alive.* Commission on the Public's Health System. June 1998. Also, *New York City's Child Health Clinics – Providing Quality Primary Care to Children in Low-Income and Immigrant Families.* Citizens' Committee For Children of New York City. January 2000. Also, *Survey of Child Health Clinic Patients.* Draft May 18, 2005. NYC Health & Hospitals Corporation.

A Policy Committee consisting of CPHS, the borough coalition leaders, and other leaders and health experts developed the survey form for parents and worked on the development of a Child/Teen/Family Health Policy Agenda. The survey results are an important component of the Policy Agenda – but not the only component. Each of the borough coalitions is reviewing the survey results from their borough and tapping into the wealth of experience gained from living and working in the borough to develop priority recommendations for their neighborhoods. This community-led, and community-driven effort is unique in its planning model. The Policy Agenda builds on the collection of real-time, unfiltered perceptions and experiences of high-need health consumers through the surveys, the teen discussion groups, and the involvement of a wide diversity of people/organizations in the borough coalitions.

Surveys and reports done in New York City have focused on adults and/or entire families. No other survey in New York, with the exception of the Youth Risk Behavior Surveillance Survey, has focused specifically on children and youth in gathering important health care information. This report is thus unique in its concentration of information on children and young people in all five boroughs.

The Need

Almost one-million of the two million city residents under the age of 19 live in "at-risk communities."[4] There are many low-income, medically underserved, immigrant and communities of color in the city. These are the communities that the Child Health Initiative focused on for this survey. They are the communities where there are: more babies born at low-birth weight and higher infant mortality rates; higher rates of children with asthma; higher rates of children hospitalized with asthma, pneumonia, and respiratory infections; more lead paint violations; and a higher percentage of pregnant women receiving late or no prenatal care services. It is in these same communities where health care services have closed or been reduced over the years, and where there are not enough services focusing on primary and preventive services.[5]

The Surveys and Teen Focus Groups

Voices From The Community was designed to create a snapshot of children's health experiences in the many diverse populations in the city. It is not a scientific sample of the population – but rather a qualitative picture of the 'health reality' faced by children and young people in this city.

The participants in the Child Health Initiative agreed to interview parents about their children, and young people so as to bring their voices directly into the project. Initially, the Initiative committed to interviewing 200 parents and organizing ten teen discussion groups. Ultimately, in order to get a broader picture, 659 parents of 1,376 children were interviewed and 12 teen focus groups were held with 114 participants. Young people

[4] Keeping Track of New York City's Children. 2008. Citizens' Committee for Children of New York City. www.cccnewyork.org
[5] Primary Care Initiative Community Health Assessment. August 21, 2008. http://council.nyc.gov/downloads/pdf/PCI%20Final%20Report.pdf

were directly involved to ensure that their voices were also heard, as parents do not always know what their teenagers are thinking.

CPHS, the borough coalition leaders, and members of the Policy Committee spent several months developing, testing, and finalizing the survey format. A training manual was also developed and used for training staff and volunteers in administering the survey. The questions used for the Teen Discussion groups were taken from the survey, and adjusted to reflect the reality and interests of this age group.

In order to capture the diversity of the city's population, the survey was translated from English into: Arabic; Bengali; Chinese; French; Haitian Creole; Korean; Polish; Serbo-Croatian; Spanish; Tagalog; and Urdu. Through the borough coalitions and other avenues, organizations and individuals were recruited who had the language and cultural competence to relate to immigrant communities and administer the survey.

A majority of the surveys were administered at the Child Health celebration events where an effort was made to attract "unaffiliated families" – those who are not necessarily linked to any community networks. Additional surveys were administered at other events organized by borough coalition members and some were specifically targeted to various racial and ethnic populations to ensure the diversity of the representation. Examples of other survey sites: hair weaving salons; ethnic food market; ethnic festivals; and farmers' markets.

A surveyor asked the questions and wrote the responses on the survey form. Questions were asked in the primary language of the person being interviewed, but responses were written in English.

The surveys contained thirty-nine questions along with three open-ended questions. The survey responses will be reported under several categories:

- **Demographic data about the parent** including: race/ethnicity; country of origin; primary language; age; sex; years living in zip code; number of people living in the household; and the number of people for which the surveyed are financially responsible.
- **Demographic information about the children** including: age; state of health; country of birth.
- **Health status of children** including: types of illness/conditions; parental concerns about medical problems; stays overnight in a hospital; medical problem that keeps child from school, day care, or babysitter; visit to an Emergency Room for care.
- **Information/Communication** issues including: does the parent get their questions answered; is the parent able to communicate or understand what is happening; has the parent ever been asked to sign something they do not understand; if the parent speaks a language other than English, are they able to find a doctor that speaks their language; is an interpreter provided; have they ever been asked to have the child interpret for them.

- **Insurance issues** including: does the child have health insurance coverage; how does the parent pay for the child's health care; is the child in a managed care plan; has the parent ever applied for coverage for their child; was there a problem in applying for coverage; would the parent like help in trying to apply again.
- **Health access issues for children** including: child able to get regular check ups; child get all needed medical care; what the parent does when a child feels sick; what would make a parent wait to take the child for care; child has a regular doctor or clinic for medical care; how long it takes to get an appointment; parent knows a doctor or clinic where they can take the child for care; child received all needed medications; do they have to travel far to get to care; how long does it take to travel for care; how do they travel to get to care; and how long is the wait in the Emergency Room.

Information from the Surveys

Not all of the questions were answered by all the respondents. The results given below reflect only the number and percentage of actual responses. The survey instrument is at Appendix A.

Demographics about the Parents:

Number of Surveys:

659 parents were surveyed who had a total of 1,376 children under the age of 19 living with them. By borough:

- 149 parents were surveyed in Brooklyn;
- 186 parents were surveyed in Manhattan (119 in Northern Manhattan and 67 in the Lower East Side/Chinatown);
- 93 parents were surveyed in Queens;
- 86 parents were surveyed in Staten Island; and
- 145 parents were surveyed in The Bronx.

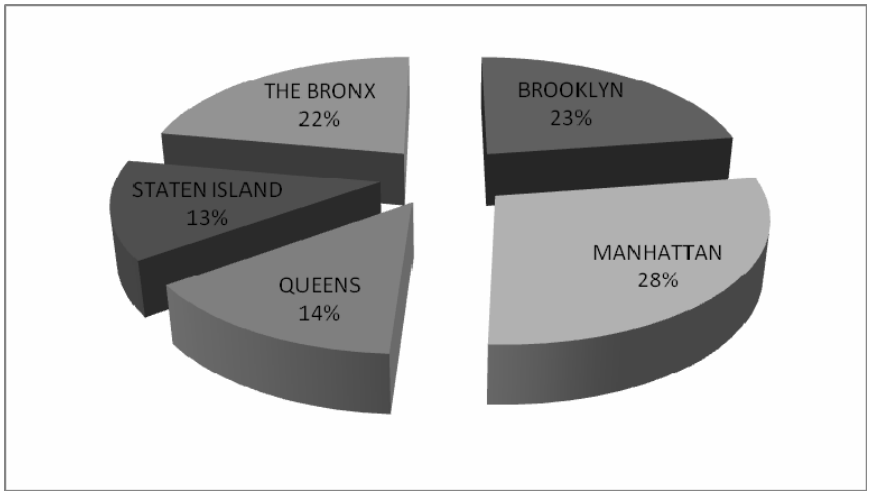

Figure 1: Borough Breakdown of Surveys

Sex/Gender

Of the 656 responses, the large majority (530, 80%) were women and 125 (19%) of the parents were men. One parent self-identified as Lesbian/Gay/Bisexual/Transgender.

Age

Of the 658 responses from parents surveyed, the large majority was between the ages of 26-35 (222 or 33.6%) and 36-50 (270 or 40.9%). Eleven of the parents were teenagers between the ages of 14-18 (1.6%) and 65 parents (9.9%) were between the ages of 19-25. Sixty-six parents (10%) were between the ages of 51-65 and 24 (3.6%) were 65 years of age or older. Although not specifically asked this question, in some families, because of the age of the respondent, we assumed that the grandparent is the guardian of the child.

Zip Code of Residence
Parents were asked the zip code of their residence. Of the 647 parents that responded to "How many years have you lived in that zip code?", a majority of the parents surveyed had lived in their current zip code for 14 years or less – 507 (77%). Sixty-nine of the parents (1.3%) lived in the current zip code for 21 years or more.

- 0-3 years - 197 (29.8%)
- 4-9 years - 200 (30.3%)
- 10-14 years - 110 (16.6%)
- 15-20 years - 71 (10.7%)
- 21+ years - 69 (1.3%)

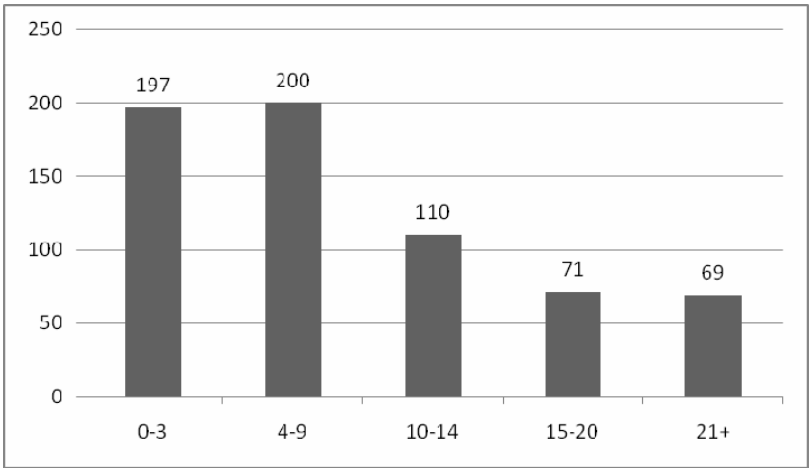

Figure 2: Breakdown of Years in Zip Code

Race/Ethnicity
Parents were asked to identify their race and ethnicity from a list that was read to them. Because the Child Health Clinics are primarily located in low-income, immigrant and communities of color, there was a larger majority of these populations surveyed than live in New York City.

- African 25 (3.7%)
- African American 121 (18.3%)
- Caribbean 34 (5.1%)
- Asian/Pacific Islander 114 (17.2%)
- White 32 (4.8%)
- Latino/Hispanic 275 (41.7%)
- Mixed Race 43 (6.5%)
- Other 15 (2.2%)

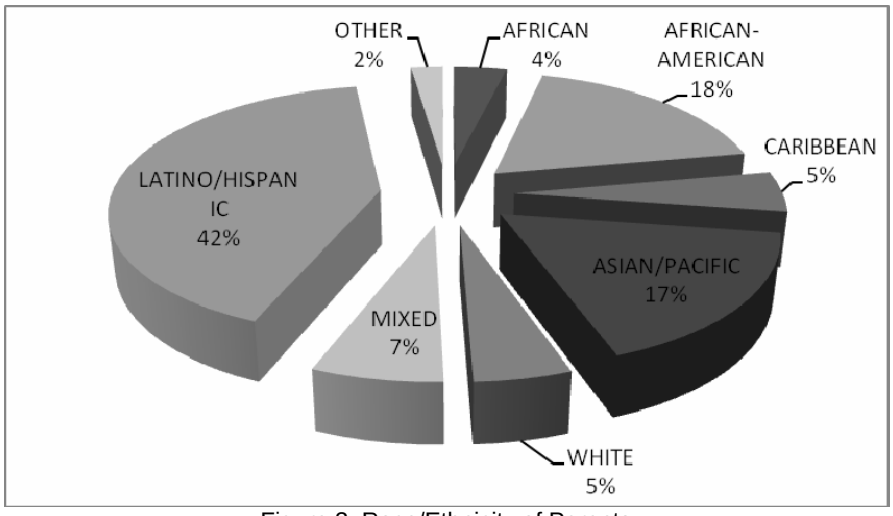

Figure 3: Race/Ethnicity of Parents

Country of Origin

"*Were you born in this country?*"

Two hundred and fifty-seven parents said they were born in this country (39%) and 398 were not born in this country (60.3%). Only on Staten Island were there more parents born in the United States (45 parents vs. 40 parents).

The next question asked the parent to identify "If you were not born in this country, in which country were you born?" The responses from each borough showed a wide range for country of origin:

- In Brooklyn, 88 of the 149 parents (59%) were not U.S. born. Twenty-one countries of origin were listed, with the largest numbers from: Bangladesh (9); Haiti (15); Mexico (12); and Pakistan (11).
- In the Bronx, 82 of the 145 parents (56.5%) were not U.S. born. Twenty-two countries of origin were listed, with the largest numbers from: Bangladesh (22); Dominican Republic (16); Puerto Rico (7); and Mexico (10).
- In Manhattan, 110 of the 186 parents (59.1%) were not U.S. born. Twenty-two countries of origin were listed, with the largest numbers from: China (29); Dominican Republic (32); Mexico (12); and Puerto Rico (11). Parents from Puerto Rico self-identified as born outside of the U.S.
- In Queens, 78 of the 93 parents (83.8%) were not U.S. born. Twenty-four countries of origin were listed, with the largest numbers from: Dominican Republic (5); Ecuador (16); Korea (4); Mexico (16); Philippines (9); and South Korea (6).
- In Staten Island, 40 of the 86 parents (46.5%) were not U.S. born. Twelve countries of origin were listed, with the largest numbers from: Mexico (16); Dominican Republic (3); Honduras (3); and Poland (7).

Primary Language

"*In what language do you feel most comfortable talking about your child's health?*"
The survey was administered in twelve languages based on the parent's indication of comfort in speaking that language. In response to this question, some parents indicated their comfort in more than one language, for example, 45 parents said they were comfortable in English and Spanish. There were 633 responses to this question.

- English 269 (42.4%)
- Spanish 175 (27.6%)
- Arabic 7 (1.1%)
- Bengali 27 (4.2%)
- Chinese 30 (4.7%)
- Haitian Creole 8 (1.2%)
- French 8 (1.2%)
- Korean 10 (1.5%)
- Polish 4 (0.6%)
- Serbo 1 (0.1%)
- Tagalog 1 (0.1%)
- Urdu 11 (1.7%)
- English/Spanish 45 (7.1%)
- English/Chinese 4 (0.6%)
- Other (mixed answer) 33 (5.2%)

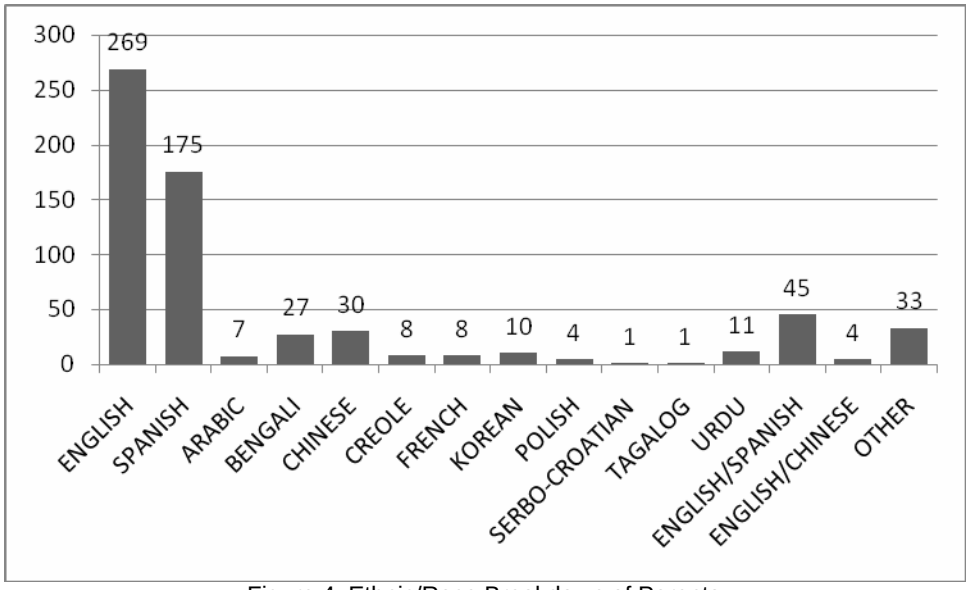

Figure 4: Ethnic/Race Breakdown of Parents

Household Size

"*How many people live in your household?*"
"*How many people in your household are you financially responsible for?*"
In all of the boroughs, the number in the household was typically larger than the number the parent said they were financially responsible for. This data indicates generally that

more than one immediate family is living together. Family was described as parents and/or guardian and their children.

- 184 families (27.9%) lived in households the same size as the family unit.
- 150 families (22.8%) lived in households with one additional person.
- 292 families (44.3%) lived in households with at least two additional persons.

Demographics of Children

The following demographic information was collected for the 1,376 children in the 659 families surveyed: age of child; status of health; place of birth; and illness/conditions.

Age of Children

Parents were asked to list the age of each child under 19 living with them. The ages listed were clustered: 0-5; 6-13; 14-19; and 22 of the listed children were 20 years or older. Since children under the age of five tend to visit the doctor more frequently than older children, it is important to know the ages of the children.

- Children aged 0-5 - 457 (32.2%)
- Children aged 6-13 - 605 (43.9%)
- Children aged 14-19 - 314 (22.8%)

There was a higher percentage of families with children aged 0-5 living in Brooklyn (36.3%); and families living in Queens (41.8%). Families living in Brooklyn (2.21) and Staten Island (2.24) had slightly more children than the surveyed city average of 2.09 children per family.

Place of Children's Birth

In 499 of the 604 surveys (81.6%) with a response, the children were all born in the U.S. In 57 surveys (9.4%), the children were not born in the U.S. In 48 of the surveys (7.9%), the country of birth for the children was mixed, with some born in the U.S. and others born outside of the United States.

Health Status of Children

"*For each of your children 19 years or younger, please tell us their age and whether their health is excellent, good, fair, or poor*."

There were 633 responses to this question. The majority of children were listed in good health, 366 (57.8%). On 48 of the surveys (7.5%), parents listed the children in fair health, and for 134 (21.1%), parents listed the child as in excellent health. For 85 of the surveys (13.4%), the answer was other, where different responses, or mixtures of responses, were written into the survey. There were seven families where the health of the children was listed as "poor to good" by the parent.

Children's Illnesses/Conditions

"*Have you ever been told by a doctor or other health care professionals that your child/children has any of the following conditions?*"

Surveyors were asked to write the number of children who have that illness/condition. A listing of conditions was then read to the parents. Surveyors were asked to check all of

the conditions that any child in the family had. Not all children were listed with a disease/condition, but there were 600 responses noted. The specific conditions are listed below, followed by a category of "Other" where the parent could name an illness/condition.

- Asthma 217
- Diabetes 26
- Hearing/Vision Problems 57
- Overweight/Obesity 67
- Lead Paint Poisoning 8
- Dental Problems 64
- Bone, joint or muscle problems 21
- Attention or behavior problems 52
- Autism 11
- Physical Disability 7
- Developing behind for his or her age 21
- Other 49*

*In the Other category, there is a list of different conditions, some of which could actually have been listed in one of the categories above. Some listed very specific diseases/conditions, such as: anemia and underweight; heart problems; migraines; Downs Syndrome; sickle cell and sickle cell trait; epilepsy; neurofibromatosis; speech delay; learning and mental disability. Typically these conditions were mentioned no more than twice.

In this survey asthma is clearly the leading health condition for the families and children surveyed, affecting large numbers of families with children in Brooklyn (47 out of 226 children, 20.8%); Manhattan (70 out of 375, 18.7%), Staten Island (36 out of 190, 18.9%); and The Bronx (49 out of 294, 16.7%).

Parental Concerns about Health Conditions

"*If you think about the children and young people among your friends or other family members in your neighborhood, what are some of the health or medical problems that they have?*"

There were three blanks left for parents to name the conditions. Again, as above with the parents' own children, asthma was cited most often as a condition to be concerned about:

- The top three concerns listed in the Bronx in the 145 surveys are: asthma (61); obesity/overweight (20); and diabetes (10).
- The top three concerns listed in Brooklyn in the 149 surveys are: asthma (56); diabetes (21); obesity/overweight (17).
- The top three concerns listed in Manhattan in the 186 surveys are: asthma (106); obesity/overweight (46); diabetes (34).
- The top three concerns listed in Queens in the 93 surveys are: asthma (21); obesity/weight (16); and allergies (7).

- The top three concerns listed in Staten Island in the 86 surveys are: asthma (33); obesity/overweight (29); diabetes (15).

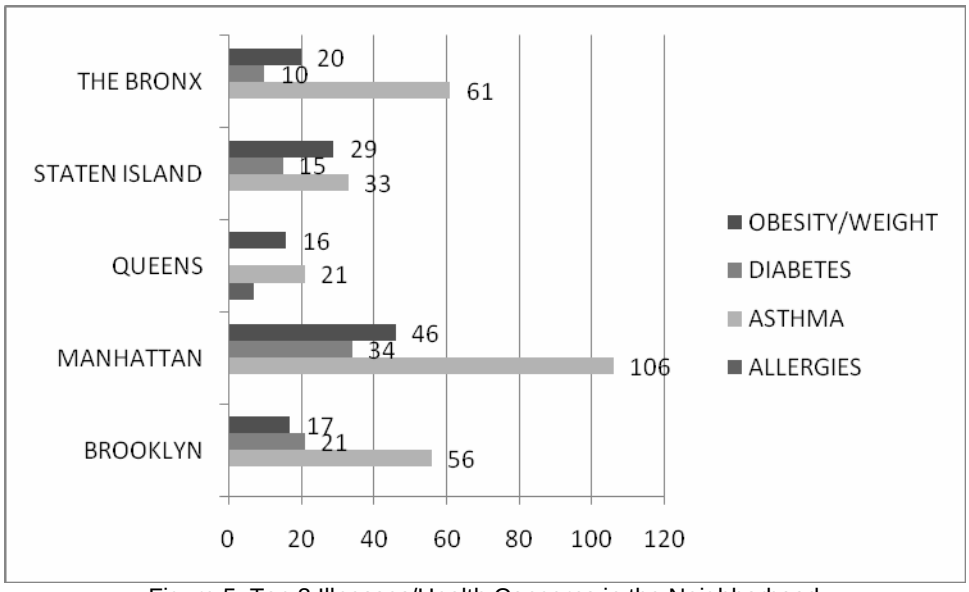

Figure 5: Top 3 Illnesses/Health Concerns in the Neighborhood

Health Problems

"*Do any of your children under 19 have a medical problem?*"

Although many of the parents surveyed had identified particular illnesses/medical conditions in an earlier survey question, when asked in this general way, the responses were quite different with fewer parents identifying a problem: 639 of the 659 parents who responded to this question yes or no. One hundred and eighty four or 28.8% said Yes, while 455 or 71.2% said No. Fourteen parents said they were "not sure".

Medical Problems Most Concerned About

"*Which of your children's medical problems are you most concerned about?*"

In response to open-ended questions, there appeared to be more of an affirmative response showing concerns about specific illnesses:

- In the Bronx surveys of 67 specific responses, 25 parents listed asthma and an additional 7 parents listed asthma in conjunction with other illnesses/conditions. Fifty-nine parents said not applicable, none or no conditions.
- In Brooklyn surveys of 65 specific responses, 29 parents listed asthma and an additional 5 listed asthma in conjunction with other illnesses/conditions. Forty-nine parents responded not applicable or none.
- In Manhattan surveys of 79 specific responses, 33 parents listed asthma and an additional 4 listed asthma in conjunction with other illnesses/conditions. Thirty-one parents responded not applicable or none.
- In Queens surveys of 41 specific responses, 7 parents listed asthma. Seventeen parents responded not applicable or none.

- In Staten Island surveys of 47 responses, 17 parents listed asthma. Thirty-one parents responded not applicable or none.

Medical Problems Keep Children from Daily Activities

"*Does this medical problem often keep your children from going to school, daycare or a babysitter?*"

In the 659 surveys, there were 477 yes or no responses. 100 parents said yes (20.9%) and 377 said no (79%). Nineteen parents said they were not sure; in 122 surveys this response was left blank; and 37 parents said not applicable. Four parents said "sometimes."

Hospitalizations

"*In the last 12 months, did you children have to stay in a hospital bed?*"

Of the 654 responses 95 said yes (14.5%), 544 said no (83.1%), and 15 (2.3%) said they were not sure. The percent of hospitalizations for children in Queens (22.5%) and in Staten Island (18.6%) were higher compared to the other boroughs which were each closer to 12%.

Emergency Room Use

"*In the last 12 months, did your children have to go to an Emergency Room for medical care?*"

Six hundred and fifty-three parents responded to this question: 243 said yes (37.2%) and 408 said no (62.4%), and 2 parents said they were not sure. The percent of Emergency Room visits was high in each borough, with Brooklyn, Manhattan, and Queens at about 30%. Most troubling was the percent of ER visits in the Bronx (49.6%) and in Staten Island (50%).

Waiting Time in the Emergency Room

"*How long do you usually have to wait in the Emergency Room?*"

The responses were then clustered into time categories of: up to 1 hour (60); 1-2 hours (86); 3-4 hours (44); 5-12 hours (30); and 13 or more hours (9). The majority of wait times was indicated as 4 hours or less (78.2%). The longest indicated wait times in the Emergency Room were in the Bronx (18%) and Manhattan (24%).

Emergency Room Use and Hospitalizations

Looking at responses to two questions reported above, Emergency Room use and Hospitalizations, showed that of the 243 parents who said their children had used the Emergency Room in the last 12 months, 73 (30%) were hospitalized. The questions do not ask if the specific ER use is related to the hospitalization, or for what condition the child was hospitalized. On the other hand, of the 371 parents who said their children did not use the Emergency Room in the last 12 months, only 22 of the children (5.9%) were hospitalized.

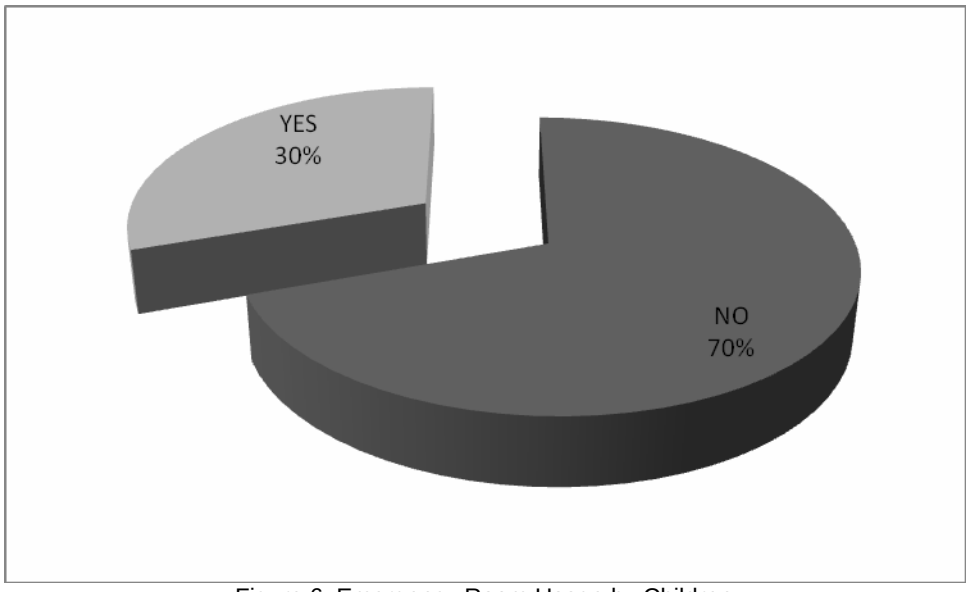

Figure 6: Emergency Room Usage by Children

Emergency Use and Asthma

In the section on demographic information about children, it is noted that a large number of children have asthma; 185 families indicated that they have asthmatic children (28.1%). Ninety-one families that have 104 children with asthma did not report use of the Emergency Room in the last twelve months (49%). Ninety-three of the families which had 111 children with asthma reported use of the Emergency Room in the last twelve months (50%). One family with 2 asthmatic children did not know if their child needed use of the ER in the past twelve months (1%). The numbers of children with asthma using Emergency Room services appears to be highest in the Bronx, Brooklyn and Staten Island.

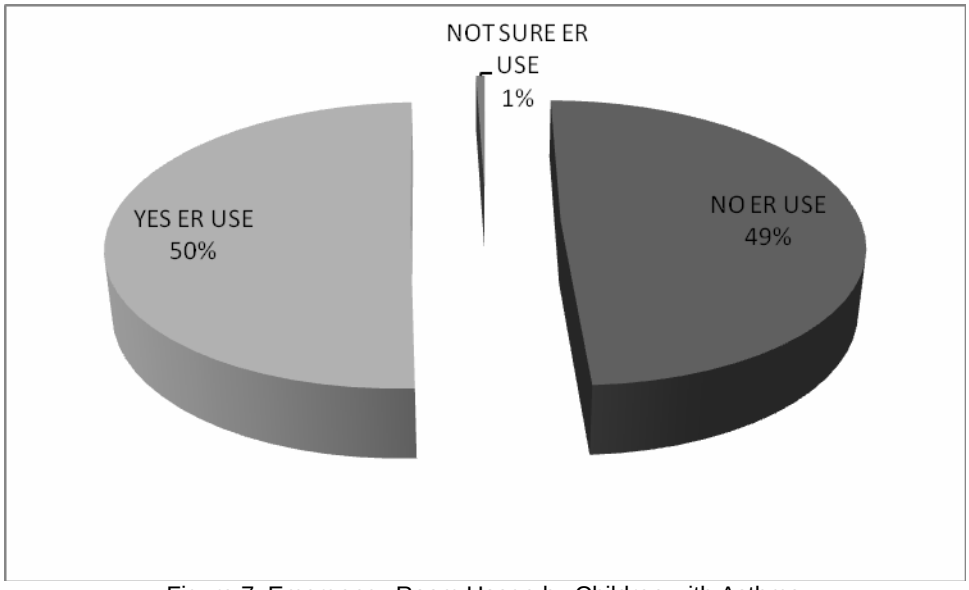

Figure 7: Emergency Room Usage by Children with Asthma

Information/Communication

A series of questions were asked about the parents' ability to communicate with health care providers and get answers to their questions. Some of the questions were related to language access, others related to the communication and understanding process.

Ask and Get Questions Answered

"*When you take your children for medical care and ask questions, do you get your questions answered?*"

The four possible responses were then listed: all the time; most of the time; sometimes; and never. An overwhelming number of parents, 484, responded that they always get their questions answered (73.6%); 145 parents said sometimes (22%); and 26 parents said not very often or never (3.9%). The last category of "not very often/never," appeared more frequently in Brooklyn (6); Manhattan (9); and Staten Island (5).

Communicate or Understand What is Happening in the Medical Exam

"*Have you gone for medical care and not been able to communicate or understand what is happening in the medical exam?*"

The responses were: yes, no, and not sure. In the 554 surveys with a response to this question, 162 parents said yes (29.2%), 377 said no (68%); and 14 said they were not sure. When the question is asked in this way, a somewhat larger number of parents indicated problems in understanding and communication. This was particularly true for parents in the Bronx and Brooklyn where 34% and 30% responded no to this question, indicating a communication/understanding problem during the medical examination.

Understanding of Written Documents

"*Have you ever been given something in writing, or asked to sign something that you were not able to understand?*"

This was a yes, no, not sure question. Of the 586 parents that responded to this question, 102 said yes (17.4%) and 471 said no (80.4%), and 13 said they were not sure. The percent of parents in Brooklyn with this problem was much higher, 32 parents out of 141 (22.6%).

Language Access/Interpreters

"*If you speak a language other than English, are you able to find a doctor or clinic that speaks your language?*"

Of the 478 parents who responded to this question, 124 (25.9%) said no and 315 said yes (65.8%), 30 indicated that they were not sure, and 9 had other responses, including: sometimes (5) and never tried (3). The inability to find a doctor or clinic that speaks the parent's language was most evident in the Bronx (28.4%); in Queens (26.2%), and in Staten Island (48%).

Interpreter Provided

"*Is an interpreter provided to help you talk with a doctor and other health care workers?*"

Of the 447 parents that responded to this question, 258 said yes (57.7%), 144 said no (32.2%), and 45 said they were not sure (10%). Based on the number of parents that

responded to this question, a large percentage of parents said that interpreters were not provided in the Bronx (31.7%), Brooklyn (34.4%), Manhattan (23.8%), Queens (25.5%), and Staten Island (63.4%).[6] Particularly troubling, is the percent of parents in Staten Island who were not provided with an interpreter.

Children Interpreting

"*Have your children ever been asked to interpret for you?*"

There were 483 responses to this question; 103 parents said yes (21.3%), 368 said no (76.1%), and 12 who said they were not sure[7].

Children's Insurance Coverage

There was a series of questions about health insurance coverage, managed care, and applying for coverage. Almost all of the children are insured, and nearly half of the children are covered by Medicaid, so the special periodic screening program for children (Early and Periodic Screening Diagnosis and Treatment - EPSDT) would apply.[8] EPSDT is a Medicaid required program of regular preventive, primary, and follow-up care.

Insurance Coverage

"*Does your children have health insurance?*"

Of the 646 responses, 601 said yes (93%), 42 said no (6.5%), and for three families not all of the children had coverage. Thirteen families surveyed in Brooklyn had no coverage for their children (9%); and in Staten Island 9 families had no coverage for their children (10.4%).[9]

Of the 42 families where the children did not have health insurance coverage, we looked at their race/ethnicity, and found: 2 were African; 4 African American; 4 Caribbean; 5 Asian/Pacific Island; 3 White; 3 Mixed Race; 19 Latino; and 2 identified as "Other."

In the 42 families where the children had no health insurance coverage, 28 of the parents interviewed were not born in the United States, 66%. In the 601 families where the children do have health insurance coverage, 60% of the parents were born in the United States. The birthplace of parents is not necessarily a determinant of the child's insurance status, although immigration status may have an impact on the parents' willingness to apply for public health coverage for their children.

[6] New York State law requires that Article 28 providers (hospitals and clinics) provide free interpreter services.
[7] New York State requirements prohibit a child under the age of 16 from acting as an interpreter in a health care setting. This question did not ask the age of the child that was asked to act as an interpreter.
[8] Early and Periodic Screening Diagnosis and Treatment (renamed Children's Health Assessment Program in New York State) is a table of required visits and testing, under federal law (Social Security Amendments, sec. 302(a), P.L. 90-248) for children insured by Medicaid.
[9] In New York City, an estimated percent of children have no health insurance coverage.

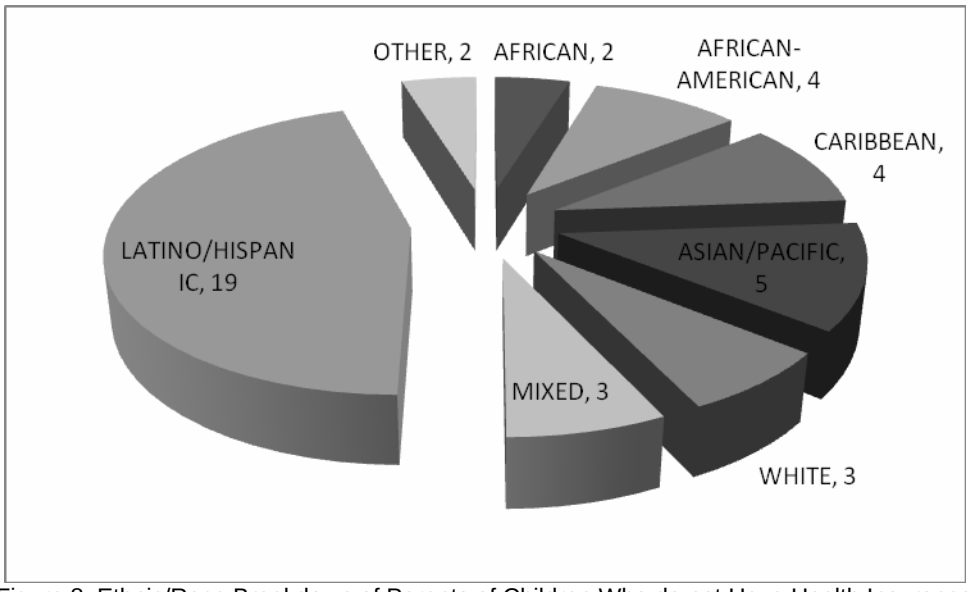

Figure 8: Ethnic/Race Breakdown of Parents of Children Who do not Have Health Insurance

Paying for Children's Health Care

"*How do you pay for your child's health care?*"

The parents were read various self-pay and coverage options. Six hundred and thirty-nine parents responded to this question, and for 16 surveys another response was written in which typically was the name of a managed care company. More than one response could be checked off.

- 8 parents indicated that they self-pay out of pocket.
- 246 parents indicated their children were covered by Medicaid
- 51 parents indicated Medicaid and Child Health Plus
- 4 parents said Medicaid and Medicare
- 4 parents said Medicaid and private coverage
- 104 parents said Child Health Plus
- 7 parents said Medicare
- 141 parents said private insurance coverage.

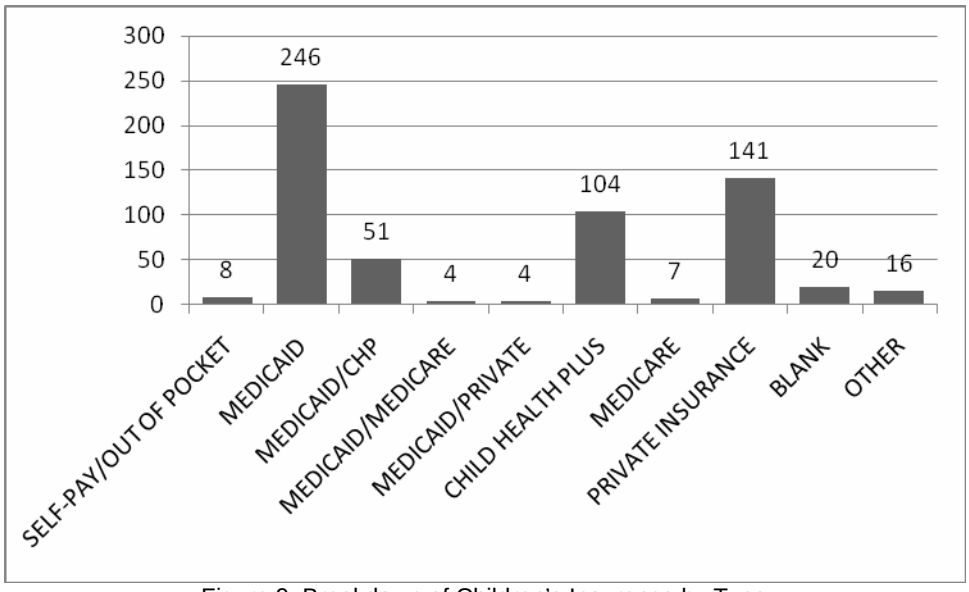

Figure 9: Breakdown of Children's Insurance by Type

Managed Care Plans

"*If your children have health insurance, are they in a managed care plan?*"
Of the 601 families where the parents indicated their children have health insurance coverage, 381 said yes (67.3%), 96 said no (16.9%), and 89 had other responses (15.7%). The other written in responses ranged from not sure to the name of a specific managed care plan.

Ever Applied for Insurance Coverage

"*If any of your children do not have health insurance, have you ever applied?*"
There were 47 responses to this question: 32 parents said yes, 14 said no, and 1 was not sure.

Problem Applying for Insurance Coverage

"*Did you have a problem applying for health insurance?*"
Five hundred and forty-six parents responded to this question; 60 said yes (10.9%); 476 said no (87.1%); and 10 said they were not sure (1.8%).

A follow-up question asked if the parent had problems in applying for coverage, "*can you tell me about the problem?*" Brooklyn had the highest number of people (16) who had problems applying, with the issues ranging from getting the run-around from enrollers to a recent release from incarceration hindering the application process. Similarly Manhattan had 15 people with problems applying for health insurance, ranging from documentation difficulties to receiving the run-around from enrollers. For the other boroughs Queens had seven and Staten Island and the Bronx each had 11 people who had difficulties applying for health insurance. Part from the survey parents were referred for assistance in applying for health coverage for their children.

Help Applying for Coverage

"*Would you like help in trying to apply again?*"

Only 60 parents indicated that they had a problem applying for insurance coverage. Yet when they were asked if they would like help applying again, there was a larger response. This could be a request for help in recertification for coverage.

Of the 329 responses to this question: 154 said yes (46.8%), 157 said no (47.7%) and 18 were not sure (5.4%). After completion of the survey, these families were referred for assistance.[10]

Children's Access to Health Care

A number of questions were asked to determine if children were having a problem accessing health care services. The questions included: regular doctor; get all the medical care needed; wait to get an appointment; receive all medications; travel time to get to care. The responses to these questions will also be reviewed in conjunction with responses to three open-ended questions that were asked at the end of the survey.

Children Able to Get Regular Check-Ups

"*Have your children been able to get regular checkups, including shots, tests?*"

The surveyor then read the possible answers: all the time; most of the time; sometimes; never. 525 parents (79.9%) responded all of the time; 84 parents (12.7%) said most of the time; 42 (6.4%) said sometimes; 5 (0.7%) parents said never. The sometimes and never responses were highest in Manhattan (22) and in Brooklyn (11).

Based on the responses to later questions, it is unclear if parents understood what we meant by the term "regular checkups."

Children Have a Regular Doctor or Clinic

"*Do you children have a regular doctor or clinic that they go to for medical care?*"[11]

This was a yes, no, not sure question and one parent responded "sometimes." Six hundred and eighteen parents (95.4%) said their children have a regular doctor or clinic; 25 said no (3.9%); and 5 said they were not sure (0.8%).

How Long to Get an Appointment

"*How long does it usually take to get an appointment?*"

The surveyor then gave the parents options of different periods of time. The responses are based on the 618 parents who said that their children have a regular doctor or clinic that they go to for medical care. With 45 non-responses, the rest of the parents reported that it took:

[10] The surveys were confidential. Surveyors were instructed to complete the entire survey, put it aside, and ask the parent if they would like assistance with their health insurance coverage. If the survey was done at a Child Health event, a Facilitated Enroller was available to assist the parent on-site. If not, surveyors were asked to make referrals to a community organization capable of helping the parent.

[11] For all children enrolled in Child Health Plus and Medicaid Managed Care, there is a requirement to have a Primary Care practitioner responsible for the child's health care. All children enrolled in Medicaid (305) are eligible for EPSDT services as described in another footnote.

- 1-2 days 324 (52.4%)
- 2-5 days 119 (19.3%)
- More than a week 63 (10.2%)
- More than 2 weeks 67 (10.8%)

The surveyors were asked to note any comments made by the parents. Twenty-two parents noted that they get an appointment on the same day. Two said they walked-in to see the doctor. One parent in Brooklyn said that it took two months.

It took longer to get appointments in several boroughs. For the responses more than a week or two weeks to get an appointment: In the Bronx, 39 parents said that it took more than a week to get an appointment; in Manhattan, 34 parents said more than a week; and in Brooklyn it was 23 parents.

Children Receive All Needed Medical Care

"*In the last 12 months, did your children get all of the medical care they needed?*" There were 651 responses to this question. 576 parents (88.4%) said yes their children received all the care needed; 63 said no (9.6%); and 12 said they were not sure (1.8%). The number of parents saying that their children had not received all of the care they needed was highest in: Brooklyn (18); Manhattan (14); and the Bronx (15).

What Parents do When Child Feels Sick

"*What do you usually do when your children feel sick? (e.g., treat an asthma attack, check blood sugar). Do you take care of the problem by yourself, go to an Emergency Room, or other?*"

For the 581 responses to this question, the written responses were then placed into categories as reported below. The categories of responses are:

- Visit the Emergency Room 155 (26.6%)
- Call/Visit Doctor 147 (25.3%)
- Call/Visit Clinic 31 (5.3%)
- Self Treat 66 (11.3%)
- Self Treat/then visit ER or doctor 136 (23.4%)
- Visit Doctor and/or ER 20 (3.4%)
- Do Nothing 12 (2.0%)
- Other Responses not categorized 14 (2.4%)
    - Some of the "Other" responses included "depends"

Reasons Parents Wait Before Going to Doctor

"*Did any of the following ever cause you to wait before taking your children to the doctor?*"

Surveyors were asked to read a list to the parent and to check all of the answers that applied. Three hundred and seventy-three parents (56.6%) parents responded "none" (271), "not applicable" (29) or left the answer blank (73). There were 825 responses on the 286 surveys where the parents indicated some problem that would make them wait

before going to the doctor, since more than one response could apply in that family. The percentages below apply to the 286 responses to this question.

- Costs too much 56 (19.5%)
- No health insurance 64 (22.3%)
- Health plan problem 41 (14.3%)
- Can't find a doctor who accepts health insurance 48 (16.7%)
- Can't miss work or school to go/no time 73 (25.5%)
- The hours of service are a problem 66 (23.0%)
- Not available in the area/transportation problems 29 (10.1%)
- Don't know where to go 26 (9.0%)
- Didn't like the care received 35 (12.2%)
- Other 14 (4.8%)

Received All of the Medications Needed

"*In the last twelve months, have your children been able to receive all of the medications needed?*"

Of the 627 responses, 584 parents (93.1%) said their children received all of their medications, and 39 parents (6.2%) said they did not, while 4 said they not sure.

Why All medications are Not Received

For those parents who responded to the question above that their children did not receive all of the medications needed, a follow-up question was asked listing reasons to be checked that might be a reason for this. There were 67 responses from the 39 parents that said their children had not received all of their medications.

- Costs too much 18
- No health insurance 8
- Health plan problem 15
- Can't find a doctor who accepts health insurance 5
- Can't miss work or school to go/no time 6
- The hours of service are a problem 3
- Not available in the area/transportation problems 1
- Didn't know where to go 3
- Don't like the care received 0
- Other 8

Know a Doctor or Clinic to go to for Care

"*If you do not have a doctor that you usually take your children to see, do you know about a doctor or clinic where you can go for care?*"

In an earlier question, 618 parents (95.3%) said their children have a regular doctor for their care. Of the 418 parents who responded to this question: 307 (73.4%) said yes, 80 said no (19.1%), and 31 said they were not sure (7.4%).

Know Health Care Providers that will Reduce Fee

"*If you do not have health insurance for your children, do you know about health care providers that will reduce your fee?*"

In an earlier question, 42 families said that their children did not have health coverage, and 3 others said that some of their children have coverage and some do not. However, 327 parents (49.6%) responded to this question. Of those that responded, 130 (39.8%) said they did know about providers who will reduce fees, 158 (48.3%) said they did not, and 39 (11.9%) said they were not sure.

Travel Far for Care

"*When you go for medical care for your children, do you have to travel far?*"

651 parents answered this question. Of those who responded, 141 (21.7%) said they had to travel far, 496 (76.2%) said no, 11 (1.7%) were not sure, and 3 parents provided their own response of "sometimes".

Parents Who said They had to Travel Far for Care

For the 141 parents who answered the question above that they travel far for care, they were also asked: "*How long does it usually take to get to the medical care?*" Responses were categorized into different periods of time. One response was left blank.

- Under 15 minutes 6 (4.3%)
- 15-30 minutes 47 (33.3%)
- Under 1 hour 20 (14.2%)
- One hour 37 (26.2%)
- More than 1 hour 10 (7.1%)
- More than 2 hours 20 (14.2%)

How Parents Travel to Care

"*How do you travel to medical care for your children?*"

Several options were read by the surveyor, and they were asked to check all responses that apply – so there were multiple responses by parents. There were 629 responses to this question:

- Walk 241 (38.3%)
- Subway 140 (22.3%)
- Bus 226 (35.9%)
- Cab 58 (9.2%)
- Car service 78 (12.4%)
- Other* 51 (8.1%)

*Many of the 51 "other" respondents said they traveled by car.

Travel to Care and Use of the Emergency Room

For the 141 parents who stated that they have to travel far for medical care, we looked at correlation to Emergency Room use for their children. Children in 61 of these families (43.3%) also used the Emergency Room in the last 12 months. Although small in numbers overall, the percentages of ER use were particularly high in the Bronx (56%); Brooklyn (51.5%); and Staten Island (56%).

For the 496 parents who stated that they do not have to travel far for medical care, we looked at correlation to Emergency Room use for their children. Children in 177 of these families (35.7%) used the Emergency Room in the last 12 months. Although small in numbers overall, the percentages of ER use were particularly high in the Bronx (48.7%); and Staten Island (47.6%).

Waiting Time in the Emergency Room

"*How long do you usually have to wait in the Emergency Room?*"

Two hundred and forty-three parents said their children had used the Emergency Room in the last twelve months, with 237 responses to this question. This was an open-ended question, so the responses were clustered into time periods.

- Up to 1 hour 60 (25.3%)
- 1-2 hours 86 (36.3%)
- 3-4 hours 44 (18.6%)
- 5-12 hours 30 (12.7%)
- 13 and more hours 9 (3.8%)
- Other (e.g., too long, not sure, depends) 8 (3.4%)

<u>Responses to the Open-Ended Questions</u>

At the end of the survey, each parent was asked three open-ended questions. The questions were designed to give parents more of an opportunity to tell us about their concerns and their hopes for the future. Reports on many surveys have shown that the response to initial questions is generally positive, but that when questions become more specific the character and tone of the responses can change and certainly more details of issues are shared.

In reporting these responses, the responses were clustered into various categories. They will be presented by category in each borough. This report will also identify and report some of the exact words and phrases that parents used to show the strength of what people were thinking when they answered.

The questions are listed along with the categories for clustering of responses. The category is defined below.

Immediately below each chart are selected quotes from each of the boroughs. These quotes represent the breadth of concerns and problems faced by parents who agreed to participate in this survey.

Open-Ended Question #1 (See Chart #1)
"Is there anything else that you would like to tell us about your children's health care, or health care services in your neighborhood? For example, do your children get good medical care? If not, what are the reasons?"

- Access to care refers to problems and barriers encountered when children go for medical care;
- Costs category refers to the inability to pay for care, or the high costs of care;
- Insurance coverage refers to problems with heath coverage;
- Quality of medical care refers to complaints about care or recommendations for change;
- Satisfaction refers to positive statements about health/medical care; and
- Miscellaneous is the catch-all category where a comment does not fit someplace else.

Open-Ended Question #2 (See Chart #2)
"What do you think are the most important health care problems for children in your community? For children in your family?"

- The Disease/Illnesses category means that the parent responded with a specific medical problem/condition;
- Access to care refers to the barriers or problems in getting medical care. Costs refers to the inability to pay for care;
- Neighborhood/Environmental problems refers to more general external problems in the neighborhood;
- Quality of care refers to complaints about or recommendations for change; and
- Miscellaneous is the catch-all phrase for comments that don't fit in other categories.

Open-Ended Question #3 (See Chart #3)
"If you were given the power for one day, what changes would you make in the medical care system that you feel would make it work better for your children, for children in your community? For example, bring services closer to your home? Have more of some kind of service?"

- Access to care;
- Better/more services/care from medical personnel (with complaints about specific problems);
- Costs/Coverage, Information (where types of education/information would be helpful);
- Universal coverage (where the major recommendation is to insure and provide access for everyone); and
- Miscellaneous.

CHART #1 – Children's Health Services in Neighborhoods

Category	Bronx	Brooklyn	Manhattan	Queens	Staten Island
Access to Care	15	14	18	12	17
Costs		2	2		
Information	3		3	2	3
Insurance Coverage	5	2	4	1	4
Miscellaneous	5	1			3
Quality of Medical Care	14	12	6	6	5
Satisfaction	16	15	13	15	7

Quotes:

Bronx:

"Health programs for kids that are age appropriate so they understand why their health is important."

"Not able to get appointments promptly, long waits in the waiting room, not being thorough in examining."

"Clinic located too far and walk-in clinic takes forever."

"We go downtown because I get better service and I do not know a good pediatrician around my area I can trust."

"There should be more teenage friendly clinics."

"Sometimes the doctor or nurse has problem to understand me because of the language barriers and the cultural differences."

"The only problem I have is the doctor I have been assigned from Child Health Plus says I'm not represented by him – he left the network."

"I believe self pay or private insurance get better care and service than mine's because I have Medicaid. Staff is usually not friendly or helpful and impersonal."

Brooklyn:

"Time spent with children, well-child – they only spend 15-20 minutes – should be about 45 to 1 hour for questions, consultations."

"The doctor does not explain what is going on and she does not take her time to examine the child."

"Would like to have clinics closer to home."

"There is no private doctor or clinic in my neighborhood for our children."

"Concerned about medication they receive. Don't want my kid being guinea pig."

"Not enough nurses and discriminate for being non-English speaking."

Manhattan:

"No interpreter and wait too long to see doctor."

"My doctor is never there and I have to see other pediatricians. I don't mind seeing other doctors but I rather see my doctor."

"Good health services exist in this neighborhood but more is needed for families in all financial situations."
"There are many problems in health care system that affect my community. A major issue is not having enough clinics for children and single parents. Many children sit in ER waiting to be treated for asthma attack whereas if they had a clinic opened for acute care they wait and treatment would be better."
"I have reviewed good medical care for my child. In my community we need less expensive dental care."
"I have to wait too long for appointments and I don't know any other alternative doctor. Their customer service is poor and inadequate."
"I'm applying for Medicaid for me and family. I can't pay doctor bills."
"STD's, asthma, mental health. God knows mental health is a big need."
"My kids just come to USA. I hope after this application (today) to have insurance for them as soon as possible. In order to they can have the service that they deserve."
"One of my kids rarely sick but the other child has had to go for therapy and has attention problems. I had to wait very long to get an appointment but I am satisfied with his progress."

Queens:
"We need more translators. I have friends who tell me to go to the doctor and they don't understand. I don't understand either. I have to go with my husband and he has to work."
"We are different. I used to have a cell phone number of my pediatrician back home and I could call him in the middle of the night. Here, I have to call 3 different people to get the doctor. I want to be close to my pediatrician."
"Just moved to the area. Still looking for children's clinic. Outreach events are good."
"Need to set up the student health center effectively so that working parents don't have to go to school every single time when their children have a small health problem."
"I feel the health care she is getting is not sufficient. She goes to special school and gets medical attention but it's not enough. She needs more support. The school is good but she needs more attention. My daughter is hyper and I think they medicate her."
"I believe the health care my children get is not very good, especially for children who have special needs. Disabled children or children with autism like mine. Services are so expensive and parents who have disabled children need more support. Especially for someone who does not have any insurance."

Staten Island:
"I wish I was able to find closer healthcare providers that offer adequate services."
"More translators available in hospitals and clinics."
"My child's health is well. I see other children with disabilities like autism, ADD, ADHD and others and they need a lot of help."
"What concerns me the most is that we need more help/information about asthma and obesity."

CHART #2 – Important Health Care Problems for Children

Category	Bronx	Brooklyn	Manhattan	Queens	Staten Island
Access to Care	10	13	14	5	10
Costs	3	1	1	1	5
Disease/Illnesses*	50	58	70	35	37
Insurance Coverage	3	6	7	4	2
Miscellaneous	12	11	10	8	2
Neighborhood/ Environmental Problems	8	3	6	3	2
Quality of Care		5	1	3	1

*Note: In the listing of specific diseases/illnesses; asthma was again overwhelming cited in each borough: 34 in the Bronx; 38 in Brooklyn; 60 in Manhattan; 18 in Queens; and 16 in Staten Island.

Quotes:

Bronx:

"Not being able to afford health care. The community needs more information about the health care coverage available."
"…Health insurance dictates treatment plans over doctor advice."
"Availability for dental care."
"More services and counseling for children. How to have doctors, nurses access the children better."
"Better education, not enough information on health care and health issues. Needs more awareness."

Brooklyn:

"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."
"They don't have good medical care and treatment, especially children with asthma."
"If I didn't have coverage I wouldn't be able to get medical care."
"It's hard to get the health insurance due to the parents' status."
"Children need to see doctor more. Parents don't take children often enough for preventive care – usually wait until they get sick."

Manhattan:

"Waiting for a Spanish interpreter."
"Health care system broken, needs to be fixed."
"More doctors who provide mobile units for asthma/dental."
"I have to take a day off to visit doctors and I do not receive payments those days."
"Affordable medical care. Walk-in appointments should be available. More quality doctors for medical care. Asthma should be given more attention."

“My community faces health care problems due to the costs of quality healthcare. We need funding to provide the community with more child health clinics.”
“Asthma, handicap. I worry for people who don’t have access to care.”
Asthma. I worry of the environment problems in the areas schools.”
“We do not have enough clinics for children who need care for asthma. Emergency room waiting periods are too long.”
“In my family asthma is an issue. Preventive care and workshops in the communities for parents to care for our children’s special needs.”
“Dental, asthma. We need more specialty doctors and medical doctors to prevent critical illness such as asthma, diabetes, obesity and children’s illness.
“Annual physicals. Follow-up if needed from clinics. Basic preventive care for medical and dental.”

Queens:
“More doctors for kids. There is not enough pediatrics in my area.”
“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.”
“Most children have asthma, are overweight. Maybe because there are no spaces to go out and do more exercises. No activities for children. Also lots of kids have autism, maybe because they don’t grow up in healthy environment.”
“Allergies and asthma. In my neighborhood there are no child health clinics nearby.”
“Lack of resources for family. Lack of education regarding healthcare.”
“I see lots of kids who are in need of dental problems. And very young girls who get pregnant like me.”
“Where I live, lots of kids seem to get very sick in the winter. The building seems to contribute to their asthma, which makes them very sick.”
“Better medical treatment in schools. In local clinic 2-3 hour waits. Staff is rude and if you complain they make you wait more. At clinic staff tells you if you don’t like it you can leave.”

Staten Island:
“Parents can’t afford, have to go to the free clinic.”
“Diabetes. It’s really scary how many children are getting detected with it. Then it would be obesity and asthma.”
“Everyone should get insurance whether a citizen or no, especially children.”
“The biggest challenge is that most children are not active with their health. We need activities that could help out children, like runs in the neighborhood parks, soccer, games, etc.

Chart #3 – Power to Make Changes

Category	Bronx	Brooklyn	Manhattan	Queens	Staten Island
Access to Care	26	28	21	12	14
Better/more services/ care from medical personnel	23	18	38	21	25
Children's Health	6	1	7	8	5
Costs	1	2	3		7
Information	6	5	6	2	3
Insurance Coverage		2			
Miscellaneous	10	11	5	4	3
Universal Coverage	8	15	17	12	10

Quotes:

Bronx:

"Faster service and more attention to clinicians and staff capable of attending to children's needs."

"Accept anyone regardless of insurance, race, ethnicity, culture, equal treatment for all, eliminate registration in emergency rooms til the patient is sent home, instead of delaying treatment due to registration."

"I would make health fair to inform all people of different languages about risks and discoveries."

"I would simplify the health care system in this country."

"Faster services, shorter wait time and transportation to and from clinics."

"Need interpreter to explain problem to doctor. Clinics near the house. Low price for medicines."

"Humbleness in doctors, have them communicate better with public and have doctors be more responsive to patients concerns."

Brooklyn:

"60-90 day approval process is too long. They say that insurance is for free, but the process to get it is a hassle. Can't apply."

"Patients are treated with more respect and the hours of clinics would be extended to accommodate working class people, especially immigrants who have irregular hours."

"Pediatrician offices to make it more festive for kids during the long wait (TV games, clowns, educational games/tutorials). Health education."

"First of all, it will be good to do more free health care activities or workshops at least once each month, especially in an overpopulated neighborhood, evaluate each kid that comes for a checkup and see what is the most common illnesses among those children in those neighborhoods and build more health centers in those areas in order to decrease the illness or to bring some cure to the disease."

"Build a recreation center for the children to exercise and eat healthy food."

"Have people go door to door every 6 months or so, which will remind people to go for their regular check up."
"Open HIV programs and the gang violence programs. Stop teenage pregnancy."
"Every child gets good health care regardless of status and income. Bring good doctor into the neighborhood. Get rid of fast food places and bring fresh food to the neighborhood."

Manhattan:
"I hope there are more translation services. I have to wait so long to have the translation service."
"Have health community to go to sensitivity training to understand culture and language barriers."
"I would discontinue co-payments. Medical professionals would be in schools. More clinics in our neighborhoods."
"Programs like sliding fee clinics should be able to be more available. Have child health clinic programs for everyone."
"Have more doctors providing care for everyone, for children, adults without health plans or caregiver. I will promise health care for all kids."
"I would have better customer services, a better emergency room staff that can help me and my family have better treatment."
"Working families parents would be afforded sliding scale fees."
"That everyone knows where to go when needed, that the plan that is assigned should help the client and the plan should allow the child to go to the doctor we like."
"Qualified doctors to treat children with physical disabilities and more time placed on preventive care for children and teens."
"Doctors would provide real services, nurses would pretend they really care about their patients and diagnosis would be accurate."
"That everybody would have medical insurance no matter their immigration condition."
"Universal healthcare because when I came back to NY I had problems. I could afford the care sometimes. They said I could qualify but when I travel to navigate I had issues – difficult to locate."

Queens:
"To have a doctor to be ready to see you or take your calls. A doctor who makes house calls. More accessibility and appointments in less time than 1 week or so."
"They needed interpreters in all the clinics for children and adults, especially with secondary services like receptionist, emergency room."
"Better treatment for kids. They should be looked at faster. There is no support network where children can be seen quickly and efficiently such that we don't have to miss too much work. My insurance asks for a lot of requirements in order to apply and renew. It takes too long and it's very confusing. I know some parents who have not applied because of this."
"Medical doctors seem to be so freaking busy. They don't want to spend very much time with you. I would expect them to spend as much time that you need with them because they are doctors and they should spend as much time as you need. Universal health care

a must. More health education. Preventive care. Back in Serbia we had cartoons for kids that encourage health habits and food. No more medical bills."
"Bring the services closer. Introduce more translator/interpreters in the clinic."
"I would like for more youth to have better access to health services and information."
"I would make every child will be able to get all the attention. Not to be stopped by not having papers. You don't have to have papers to get medical attention."
"Have doctors to visit schools at least a few times a year to take care of kids."
"Teach mothers how to take care of their children, sanitary conditions to avoid common childhood illness, particularly because of all germs that abound. Change the insurance system so that we do not have to recertify. They already know we are poor why do we have to do it every year."
"I would make health care CARE. Not business!"
"Recertification needs to be easier. I have missed my date and now had to reapply and there is so much I have to present in order to get health insurance."
"Changes we need: universal coverage, everyone should have medical services without the need to be a U.S. citizen or residents, they should also have more access to medications that can help, pharmaceutical companies should not charge so much for medications, that those of us who have little get the same care and access to health, in my case I have to stop medications for my son because I can't afford them."

Staten Island:
"People need to be nicer, especially nurses and receptionist, don't seem to want to help. Hospitals are short staffed and not clean, need to be clean. Some people won't go because they are dirty."
"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 specialist."
"In all schools, public and private, should be a doctor office. Children should be frequently checked by and more attention should be paid to what they eat and obesity. If every child could see a doctor, nurse, psychologist during school hours, some problems could be prevented, some sickness would be diminished."
"For one day I would make the doctors see all the uninsured, undocumented people for diagnostic and physicals."
"Get to keep the doctor I am comfortable with."

Summary of Teen Focus Groups

Twelve focus groups were conducted between April and September 2008 with young people from all five boroughs of New York City. Young people were directly involved to ensure that their voices were also heard because parents do not always know what their teenagers are thinking. The questions from the focus groups were drafted in conjunction with the survey questions and were used to elicit thoughts from young people about their knowledge and usage of the health care system. The following is written from summaries of the focus groups and contains quotes from focus group participants. The teens in the focus groups were happy to participate because it gave them a chance to speak about an important topic and one Brooklyn focus group enjoyed the discussion group focus on health issues and wanted more opportunities to do so.

Demographics of focus group

1. Staten Island – April 17, 2008
   - No demographic data provided
   - 15 young people
2. Queens – May 23, 2008 (AM)
   - At a Queens High School
   - 3 females, 6 males from 14 to 18 years old. All newly immigrated Latino students
3. Queens – May 23, 2008 (PM)
   - At a Queens High School
   - 5 females, 6 males from 14 to 17 years old. All Latino students
4. The Bronx – June 9, 2008
   - At a Bronx High School
   - 25 young people from 15-16 years old (no gender or race information available)
5. Staten Island – June 25, 2008
   - With LGBT youth
   - 4 males from 18 to 21 years old
6. Brooklyn – July 7, 2008
   - Foster care teens
   - Six 14-18 year olds, 4 females, 2 males. 5 Black, 1 Hispanic
7. Brooklyn – July 11, 2008
   - Part of a youth association
   - Eight 18 to 21 years old, 6 males, 2 females. One foreign-born individual
8. Manhattan – July 17, 2008
   - At a Manhattan High School
   - Eight 16 to 18 years old, 3 Black, 2 Egyptian, 1 Latina, 1 White, 1 Asian, all female.
9. Lower East Side – July 22, 2008
   - Part of a girls' club
   - Seven 15 to 18 years old, all female and all Latino.
10. Lower East Side – August 5, 2008
    - Recent immigrants

- Six 18 to 22 years old, 3 females and 3 males. All recent Chinese immigrants

11. Manhattan – August 26, 2008
    - Part a CBO
    - Five 17 to 20 years old, 3 females, 2 males. 2 Hispanic, 2 African America, 1 Asian.
12. The Bronx – September 11, 2008
    - Members of a settlement house
    - Ten 17 to 23 years old, 4 African American, 6 Latino, no gender division was provided.

What do you think are the most important health care problems for young people in your community? In your school?

Teens spoke on a variety of health care issues about themselves and in their schools, many of them related to sexual health and information. Specifically the teens in the focus group cited HIV, AIDS, STDs, pregnancy, and other consequences of unprotected sex. Many of them said that they lack adequate information about proper sexual health, such as where to get needed services or even the types of transmittable sexual diseases. One Manhattan focus group felt that young teens (12 or 13 years old) knew too much about sex and there were concerns about teens growing up too fast, which may be related to sexual imagery from the media. Of the twelve focus groups held, eleven had mentions of sexual health or sexually transmitted diseases.

There were also concerns about mental health with issues pertaining to body image, depression, and assimilation. One Manhattan focus group thought that having counseling services available to be an important health problem, even if it is a single adult approaching a teen. Though schools are a good place to obtain information they are also a cause of stress for many of the immigrant teens in terms of peer pressure or threats of violence. Specifically one group of immigrant Latino teens in Queens cited that they were harassed at a local train station by a group of teens from their school and it required intervention by a teacher and police presence to stop the threat of violence. One Lower Manhattan focus group cited the need to study late into the night to catch up with their studies and also to improve their English skills, which may be detrimental to their vision and rest.

The two Staten Island focus groups had deeper discussions on access to health care as well as the quality of care they received at hospitals. There were concerns about how the participants were treated in terms of the care and attention they get from the medical staff. There was more discussion on tangible issues of care such as not having enough facilities to treat patients coming from the Staten Island groups compared to the other boroughs. Some of them felt that there is a “need to treat immigrant youth with dignity and attention.”

Drugs, alcohol, and smoking were mentioned as other health issues that the teens face. In particular, participants witnessed other students smoking or drinking on school grounds or have seen evidence of smoking or drinking by students (lingering odors or fumes). Other issues which were discussed include nutrition, especially school nutrition, and general

diseases like asthma and the cold or flu. These discussions on diseases were centered in one of the Lower Manhattan focus groups but a few other boroughs mentioned obesity as a cause for concern. However it should be noted that a majority of the discussions centered on sexual health.

Only a few participants spoke about trouble communicating with others and isolation as a health problem. This is tied to students spending more time on the computer and internet and less in-person contact. Though not mentioned by the participants, isolation may contribute to depression in some people, especially if the isolation was because of a lack of self esteem. This may be attributable to the fact that some of the participants were recent immigrants, had low English language abilities, have high levels of stress trying to adapt to American culture and have difficulties communicating with parents and classmates; either because of cultural mores with talking about problems or because of language barriers. These participants felt that they faced more stress compared to their peers who are not dealing with language barriers and study pressures.

How would you define being healthy? What do you think would make a healthy community?

In terms of personal health, most teens stated that good nutrition, good hygiene, and exercise meant being healthy. One teen from Brooklyn stated that he does not get properly prepared meals from his foster parent and other teens felt that their foster parents treat them like second class citizens. They spoke about having a healthy diet consisting of balanced meals and the types of exercises they participated in like basketball, a view shared by a Lower Manhattan participant about exercise creating hormones that make a person happy, therefore reducing stress. There was also discussion on access to care from a quarter of the focus groups speaking about using 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, from a holistic point of view, and would include mental health and general happiness.

Healthy communities varied in definition, especially for those who recently immigrated. These recent immigrants had a tougher time integrating into American culture and to figure out what consisted of their "community" since it was different from their homeland. When the group described community, they used phrases such as, "*a community is when people come together, work together, and respect each other*" (Brooklyn participant).

One Brooklyn participant wanted "*an environment without illicit drugs, particularly, crack called White Girl; cocaine, called Rock; Acid, methadone called meth, Angel dust and weed*." It was noted by the facilitator that some of the participants have experimented with drugs, in particular weed. With further questioning, one participant revealed that they began experimenting at 12 years old and that youth today started experimenting with drugs when they were 9 years old. In that same focus group, participants further described a community as a place "*that looks like a garden*" – someplace pretty, fresh smelling and pleasant to live in. Most participants did not live in a healthy community but

rather in a “hood”, defined by focus group participants as places where mostly Black and Hispanic people live. For one person a community is where “*I can be myself*”.

Environmental concerns like keeping the neighborhood and homes clean, having common space for exercise or recreation was discussed and also how that contributed to the health of the community. Both focus groups in the Bronx discussed body image and weight which they agreed were not good indicators of a person’s assessment of health. In addition there was cross-talk about how proper sexual health is part of a person’s overall health and that knowledge about sexually transmitted diseases can be a part of disease prevention.

The focus groups held in Lower Manhattan had a broader discussion on health which included activities held outside of their immediate community and into their neighborhood in general. There was also discussion from one of the Lower Manhattan groups about long-term vs. short-term health with smoking as a specific example; where the negative effects are seen in a person’s health in the future.

Do you have a regular doctor or clinic that you go to for your medical care? Is it in your school?

Most of focus group participants had access to a regular doctor or clinic in their neighborhood. Only one group in the Bronx had participants who are able to access healthcare at their school. One Brooklyn focus group had participants who were in foster care and were able to access services through the foster care agency because there are medical services on-site. One Manhattan group had a greater proportion of participants who did not have a regular doctor and would instead access preventive care services through the ER and a Staten Island group seemed to have experience using ER services in a non-emergency setting.

There were discussions about the type of care they received at clinics, public hospitals and private hospitals. One Brooklyn focus group thought that facilities outside of their community provided better care and that it can take a long time to get an appointment at their regular physicians’ office, sometimes up to a month. Due to the long wait period for an appointment they would choose instead to be walk-in patients. Participants at a Lower Manhattan focus group found that the wait at private hospitals was much shorter compared to public hospitals and that an appointment with a specialist at a public hospital could take weeks or months.

Other issues brought up were the high costs of prescription medication, the gender of their health care providers, and parental presence during physicals. The Brooklyn group spent a considerable on the cost of medication said they would choose to use home remedies or order medication from other countries, particularly Canada, because prescription medication was not covered in their health insurance plan. One Brooklyn participant felt that “*you are better off doing grandma’s old register. You know, get the alcohol, rob yourself down or take a hot bath. If you have a headache, take some Tylenol.*” The Bronx

focus group had a fairly even split of the gender of their providers, however there was no further discussion about their comfort with doctors who were not of the same gender.

Is this doctor or clinic in your community, or do you have to travel to get medical attention?

Generally doctors or clinics were in the community where the participants lived. One Lower Manhattan focus group reported that their medical care is provided in the community with a little more than half using community clinics and the rest using private doctors. About a quarter of respondents had to travel to see their doctor. One Bronx focus group had participants who were able to access health services at their school. In that same focus group, many of the other Bronx participants had to travel very far by bus and/or subway to get to medical care. Focus groups in Staten Island, Brooklyn, and the Bronx reported that they had to travel far to get to their health care facilities. Staten Island especially had to travel to clinics in Manhattan to access services because the clinics in Staten Island were unavailable. In one of the Brooklyn focus groups one of the participants was willing to travel two hours to the Bronx because he was familiar with the hospital and another went to Woodhull because his insurance was accepted.

A number of participants noted that the quality of care may have to do with the type of insurance they have and where they access health services. In a Brooklyn focus group when asked about what made care poor, one respondent replied that "*it's collectively a lot of things that make it poor. But if you ask the one's that said it's excellent, ask the neighborhoods that they are in. So you get different care, I'm sorry to say, by the color of your skin, honestly*." In that same focus group another participant noted that "*unless you are paying money for upscale doctors*" you are going to have to wait. "*If you are dealing with neighborhood insurance like HIP, Neighborhood Care… you are going to wait*." Some Brooklyn participants were willing to travel long distances to receive quality care because they felt that health care varied by geographic location and that facilities in wealthier areas or in regions with fewer minority residents were seen as providing better care.

Some Brooklyn participants noted that they did not like the way they were treated in teaching hospitals – groups of staff walked into their room without permission and staff who had trouble with medical procedures such as drawing blood which made some "*feel like it was an experiment*." With further discussion a Brooklyn participant stated: "*I think the biggest problem is that they put teaching hospitals in the hood… [patients] could be sick in there and they bring in 100 other student doctors and they're teaching while they are fixing you and all that; I don't like that. Give me a real doctor. I don't want no kid doctor training on me*."

When asked about the time doctors spend during exams, overwhelmingly Bronx participants said five to ten minutes, with only one person's doctor spending half an hour with them. Some Lower Manhattan teens felt that the health clinics in low-income communities such as their own do not care about quality of services and there is high out-of-pocket payment for medications, even those with medical coverage, which is not fair.

Who encourages you to get health care/go to the doctor when you are ill? When you are healthy do you go for a check-up?

The responses were split between who encourages the focus group participants to obtain health care. Most cited themselves or their parents, specifically their mother, as the main motivators to accessing health care. There was a focus group done in Brooklyn with participants who were in the foster care system who did not get much support from foster parents and had to rely on themselves to access the required care. A few did cite some uncommon sources of encouragement, such as a daughter or the memory of a deceased parent, but most participants were conscientious in keeping up with their health regimen. A few participants from Brooklyn stated they have to encourage themselves to get routine medical care and that they would encourage their family and friends to get care as well.

How often do you, your friends, or relatives use the emergency room? What do you think are the reasons?

Almost all the focus groups reported that they save the emergency room for emergency situations, listed as gun shots, asthma attacks, broken bones, etc. One Bronx participant "*have asthma and although it is a long wait, when I cannot breathe, I go*." Most of the participants from that focus group knew the asthma triggers and tried to treat problems at home first but will access emergency services when needed. However when the facilitator asked about asthma management plans, none of the participants with asthma knew what that was, indicating that health education was missing when they access healthcare. Most participants choose not to use emergency rooms if they did not need to because of the lack of translation services as well as the long wait time associated with obtaining care. Most cited that the long wait times as the number one reason for not accessing care from ERs. One focus group from Staten Island had participants that sometimes used emergency rooms for primary care services, which they realized could take away from emergency cases.

One Brooklyn participant noted that "*If you go to the emergency room, just the paperwork alone you might be there for about 1 ½ hours. That's to deal with the triage, registration. Then you have to go back to triage for them to ask you what happened. Then you have to go sit back in the emergency room, so you might be sitting there like three or four hours you know. You get there right about now it's 5:00, you probably won't get out of there till about 10:30, 11, and that's just waiting*."

Have you gone for medical care and not been able to communicate during the medical exam? If needed, are interpreters provided to help you communicate?

Participants generally were able to communicate well with their doctors and did not have a need for translation services. This is because they spoke the same language, either English or their native language. Though there were some cases where it was difficult to communicate because "*the doctor doesn't speak good English, sometimes it is hard to understand him*" (Bronx participant). This raised the issue of having a better relationship

with doctors where doctors provided more than a cursory examination. One Bronx participant shared the story of how she had to push her doctor to have tests done on her daughter and she was ultimately proved correct about her daughter needing the tests. A few Manhattan teens wished for better communication with their providers and that they would show enthusiasm during exams.

The Lower Manhattan focus groups, which had a greater amount of immigrant participants brought up discussions on patient care. Some felt that doctors spoke too much with parents rather than with them, the patients. Also sometimes they did not understand their doctors because of the use of medical jargons. There was also the insinuation from focus group participants that medical care in China was more effective because of the use of injections to treat illnesses rather than the use of pills in the United States.

Generally translation was not needed for focus group participants because they spoke the same language as their provider and the area where translation services were needed was in the emergency rooms. Some of participants would travel with their, perhaps older, family members to help them navigate the confusing emergency room system and to help them fill out paperwork.

When you go for medical care, do you understand what is happening? Do you feel that you can ask questions and get an answer that you understand?

There was wide variability in focus group participants' understanding or communication with their primary care provider. One group in Staten Island felt rushed and not listened to at emergency rooms. Similarly, a group from Brooklyn was comfortable enough with their provider, but did not feel that the communication level was on par with expectations, whereas the other group from Brooklyn felt empowered to ask questions about their health with providers. A few of the groups tend to seek information on their own, either by gathering brochures on health topics or looking up information online. One participant from the Bronx found that "*skits by students on pregnancy, HIV, smoking – more real than reading*" was a good way to get information on important topics.

One Brooklyn participant felt that the "*[d]octors are not like the olden days. Man you got these interns coming in from college and 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*." Another Brooklyn participant felt that doctors give you medicine but "*just don't talk to you*", and would "*tell you one thing and then give you another*".

One Lower Manhattan focus group felt that the doctors give them enough information to understand what is going on but that the health care providers would speak to the parents rather than the teens (who are the patients). These participants also noted that they would have to initiate questions with the providers rather than the doctors bringing up general health concerns.

Do you think that the information you share will be kept confidential?

Most participants felt that their doctors would maintain confidentiality about their medical health. Only the Bronx focus group specifically mentioned HIPAA (Health Insurance Portability and Accountability Act) of which one section is devoted to the issue of privacy and security afforded to all patients at health care facilities, hospitals and clinics. Many participants did not like the idea that their health information would be shared unless it will be harmful to others or themselves.

Though participants maintained that it was important that patients' health matters should remain confidential, not all were secure in the fact that medical staff would not share information with parents or even with other medical personnel in passing. Some participants had instances where their personal information was told to their parents or who have overheard conversations between medical staff in public areas about a patient's health. "*I've heard doctors and nurses make comments about patients in the elevators*" (Bronx participant).

There was a division of opinion over sharing medical information with parents. A few of the participants thought that a patient's information should remain solely between the patient and doctor. A smaller minority, consisting mainly of recent immigrants, thought that since many of them was still under the care of parents then the parents should be involved with their child's health. One Brooklyn group consisting of teens in foster care would like their foster parents to accompany them for medical visits but most times the foster parents would not. One Lower Manhattan focus group understood that certain information such as their safety (suicidal thoughts, HIV status, being abused) should be communicated with their parents so that the parents can do something to protect them.

One Queens and one Bronx group spoke a bit about the lack of privacy during exams because their parents were in the room or involved in their medical process. There were some participants that felt uncomfortable with their parents being so involved in the examination process because they felt that they were adult enough to care for their health on their own.

Do you and your family have health insurance, like Medicaid or Child Health Plus? Can you use your own card?

A majority of the participants in the focus group had health insurance cards or had access to health care in a clinic. Most of those with health insurance had their own card to see the doctor by themselves. It was a mix of public and private insurance, but not all participants knew what types of coverage they had. This can be contrasted to participants who wanted independence during exams but did not know how their insurance worked. For some that have health insurance some of the participants were dissatisfied with the plan but they continued it because it was easier than trying to apply for new coverage.

If you were given the power for one day, what changes would you make in the medical care system that you feel would make it work better for you, your family, and your friends?

Recommendations for changes came in different forms. 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 by reducing wait times for and during appointments, more information about sexually transmitted illnesses, and others wanted to make changes to the health care system as a whole.

A large majority of focus group participants spoke about wanting to have universal health coverage in the United States. Some participants noted that other countries, Canada and Cuba in particular, have universal health programs in place and that the United States should follow suit. If not there should be provision for more affordable health care. Many participants come from low-income families and it would be difficult for parents to maintain health care for their family. A Brooklyn focus group was excited about the question because their opinions are seldom asked and they felt that everyone should have access to health insurance and health care.

The two Queens focus groups wanted to see more activities in communities, for it to be more welcoming and to bring the community together. Other focus groups, like one in Brooklyn focused on changing medical facilities, trying to make it more welcoming and have better items in the waiting room, like food, television and other amenities. One Staten Island participant thought that there should be "*non-profit programs that offer all sorts of resources, like medical, social help, counseling, financial*" to people accessing services.

Participants in Brooklyn wanted improved patient services with physicians, nurses and reception staff treating patients like "human beings", communicating better with patients and leaving personal problems at home, which impact patient care. To complement better care from medical staff, another group of Brooklyn participants felt that patients' attitudes and actions need to change as well by outreaching more in the community to raise awareness for health problems, have more positive attitudes when visiting the doctor and to work with medical staff to make changes in the health care system.

One Lower Manhattan group wanted to make more systematic changes in how everyone accesses health care, from youth to seniors, with better care in emergency rooms, more doctors, not just nurses and interns, with better customer service and quality of care. In a similar vein many participants wanted to have better care from doctors with better facilities for everyone, so that doctors would spend more time with patients, provide complete care and that facilities in and around participants' communities were comparable to private facilities. One Brooklyn focus group wanted to prevent abuses of elders because they felt that overall doctors will take advantage of the poor and elderly. Similarly one Manhattan focus group wanted to provide more aid to the elderly to access services.

A few of the participants had ideas in particular about doctors. One Bronx participant thought to "*cut doctor's salaries – they are late for appointments – we are told to get to the clinic at 9 and they get there at 11*" which speaks to how they think doctor's view care. Another Manhattan group wanted to hire more minority doctors from the community who would know more about the patients' environment.

One Lower Manhattan focus group wanted to have better outreach to the homeless or uninsured because of a lack of awareness in that population about what is medically available. That same focus group wanted to ensure safety in hospitals and during care. Many participants felt that the medical staff does not care enough about patient safety and perceive that medical staff have not been trained well. One participant specifically mentioned a patient's death in King's County Hospital emergency room, which mirrors some of the bad experience they have encountered in seeking medical care.

Some focus groups spoke more about desires for youth, by having clinics which opened according to students' schedules, after school or on the weekends, so that students can access services (from the Bronx) or to have school-based clinics (from Queens). The few focus groups that had predominantly immigrant participants spoke about having translation services available, though one Brooklyn participant specifically mentioned they would like health care providers with better English skills.

Only one Bronx focus group discussed raising taxes so that funds would be made available to fund changes to the health care system. One Manhattan group spoke about creating a medical home with not only providing care for the community, providing services to those who are uninsured but to have counselors available for those with long-term illnesses.

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 that people are faced with 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[12] and in the availability of health care services in low-income communities.[13] 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.

[12] *Keeping Track of New York City's Children.* 2008. Citizens' Committee for Children of New York City. Also New York City Department of Health & Mental Hygiene *Vital Statistics.*

[13] HHC Primary care study

- 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).
- 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.

APPENDIX A

Interview in _____ (borough)
Location_____
Date _____
Interviewer _____

CHILD HEALTH SURVEY

Hello. My name is _____. I work for/am a volunteer for _____. As part of a year long project to honor the 100th Anniversary of Child Health Clinics, we are interviewing parents and young people about their own, or their children's health care experiences and their opinion about what could be improved in the health care system. We will not use your name or any information that would identify you. At the end, we will write a report that will be used to work to make important changes in health care, especially for children and young people. Will you agree to be interviewed? If you will, you can choose to not answer any of the questions that I will be asking you today.

Personal Information:

1 How old are you?
__14-18
__19-25
__26-35
__36-50
__51-65
__65+

2 **Gender:**
___Female ___Male ___LBGT

3 What zip code do you live in? _____
3a How many years have you lived in that zip code?_____

4 How many people live in your household? _____
4a How many people in your household are you financially responsible for?
_____

5 What is your race? [Check all that apply]
____African American
____African
____Asian/Pacific Islander
____Caribbean/West Indian

____White
____Mixed race/ethnicity
____Other _____
____Are you Latino/Hispanic?

Health Information about Child/Children in Household

6. For each of your children 19 years or younger, please tell us their age and whether their health is excellent, good, fair, or poor.

	Age	Health Status	Place of Birth
Child #1	___	_____	_____
Child #2	___	_____	_____
Child #3	___	_____	_____
Child #4	___	_____	_____
Child #5	___	_____	_____
Other	___	_____	_____

7 Have you ever been told by a doctor or other health care professional that your child/children has any of the following conditions –please write the number of children that have the problem:
___Asthma
___Diabetes
___Hearing or vision problem
___Overweight/Obesity
___Lead Paint Poisoning Problem
___Dental problems
___Bone, joint, or muscle problems
___Attention or behavior problems
___Autism
___Physical disability
___Developing behind for his/her age
___Other What? _____

8 Have your child or children been able to get regular checkups, including shots, tests?
___All the time ___Most of the time ___Sometimes ___Never

9 When you take your child(ren) for medical care and ask questions, do you get your questions answered?
___Always ___Sometimes ___Not very often ___Never

10 If you think about the children and young people among your friends or other family members in your neighborhood, what are some of the health or medical problems that they have?
_____; _____; _____

11 Were you born in this country?
___ Yes ___No

12 If you were not born in this country, in which country were you born?
_____

13 In what language do you feel most comfortable talking about your child(ren)'s health? _____

Health Insurance

14 Does your child(ren) have health insurance?
___Yes ___No

15 How do you pay for your child's health care?
___Self-pay out of pocket
___Medicaid
___Child Health Plus
___Medicare
___Private insurance

16 If your children have health insurance, are they in a managed care plan? (HMO's such as MetroPlus or Healthfirst, Health Plus)
___Yes ___No

17 If any of your children, do not have health insurance, have you ever applied?
___Yes ___No ___Not Sure

18 Did you have a problem applying for health insurance?
___Yes ___No ___Not Sure

18a If you did, can you tell me about the problem?
_____
_____

18b Would you like help in trying to apply again?
___Yes ___No ___Not Sure

18c If you do not want to apply again, can you tell me your reason(s)._____
_____

Medical Problems

19 Do any of your children under 19 have a medical problem?
___Yes ___No ___Not Sure

20 In the last 12 months did your child(ren) get all of the medical care they needed?
___Yes ___No ___Not sure

21 In the last 12 months, did your child(ren) have to stay in a hospital bed?
___Yes ___No ___Not Sure

22 Which of your child(ren)'s medical problem(s) are you most concerned about?
_____

23 Does this medical problem often keep your children from going to school, daycare or a babysitter?
___Yes ___No ___Not Sure

24 What do you usually do when your children feel sick? (e.g. treat an asthma attack, check blood sugar) Do you take care of the problem by yourself, go to an Emergency Room, or other?
_____

Access to Medical Care

25 Did any of the following ever cause you to wait before taking your child(ren) to the doctor? (check all that apply):
Costs too much ___
No health insurance_____
Health Plan problem_____
Can't find a doctor who accepts health insurance_____
Can't miss work or school to go/no time _____
The hours of service are a problem _____
Not available in the area/transportation problems_____
Didn't know where to go_____
Don't like the care received ___
Other_____
None_____

26. Do your children have a regular doctor or clinic that they go to for medical care?
___Yes ___No ___Not Sure

27. How long does it usually take to get an appointment?
1-2 days_____
2-5 days_____
more than a week_____
more than 2 weeks_____
Please note any comments_____

28 If you do not have a doctor that you usually take your children to see, do you know about a doctor or clinic where you can go for care?
___Yes ___No ___Not Sure

29 If you do not have health insurance for your children, do you know about health care providers that will reduce your fee?
___Yes ___No ___Not Sure

30 In the last 12 months, has you child(ren) been able to receive all of the prescription medications needed? (If the answer is yes, go to question # 31).
___Yes ___No ___Not Sure

30a Why did your child(ren) not get all of the medications needed? [check all that apply]
Costs too much ___
No health insurance_____
Health Plan problem_____
Can't find a doctor who accepts health insurance_____
Can't miss work or school to go/no time _____
The hours of service are a problem _____
Not available in the area/transportation problems_____
Didn't know where to go_____
Don't like the care received ___
Other_____

31 When you go for medical care for your children, do you have to travel far?
___Yes ___No ___Not Sure

32 How long does it usually take to get to the medical care? (for example: ½ hour, 1 hour, 2 hours? _____

33 How do you travel to medical care for your children?
___Walk ___Subway ___Bus ___Cab ___Car service
(Please note any comments about this question)_____

34 In the last 12 months, did your child(ren) have to go to an Emergency Room for medical care?
___Yes ___No ___Not Sure

35 How long do you usually have to wait in the Emergency Room?
_____

35a What is the name of the hospital in which you visited the Emergency Room?
_____

36 If you speak a language other than English, are you able to find a doctor or a clinic that speaks your language?
___Yes ___No ___Not Sure

36a Is an interpreter provided to help you talk with a doctor and other health care workers?
___Yes ___No ___Not Sure

37 Have your children ever been asked to interpret for you?
___Yes ___No ___Not Sure

38 Have you gone for medical care and not been able to communicate or understand what is happening in the medical exam?
___Yes ___No ___Not Sure

39 Have you ever been given something in writing, or asked to sign something that you were not able to understand?
___Yes ___No ___Not Sure

Comments on Health Care Services

Is there anything else that you would like to tell us about your child(ren) health care, or health care services in your neighborhood? For example, do your children get good medical care? If not, what are the reasons?

_____

_____

_____

What do you think are the most important health care problems for children in your community? For children in your family?

_____

_____

_____

If you were given the power for one day, what changes would you make in the medical care system that you feel would make it work better for your children, for children in your community? For example, bring services closer to your home? Have more of some kind of service?

_____

_____

_____

APPENDIX B

Methodology: Survey Data

The 39 question survey with 3 open-ended comments was developed over a series of meetings between the Commission on the Public's Health System (CPHS), the borough coalition leaders and the members of the Policy Committee. The process took 3 months before the final survey was produced. In addition, the survey was translated from English into the following languages: Spanish, Arabic, Bengali, Chinese, Creole, French, Korean, Polish, Serbo-Croatian, Tagalog, and Urdu.

A series of field tests were conducted prior to full implementation of the survey, where borough coalition leaders surveyed some clients at their own service sites. A few changes were made based on feedback from the field tests, which resulted in changes in organization and wording of the survey.

Each borough coalition leader committed to administering at least 75 surveys during the course of the project, with the majority of surveys to be collected during Child Health Clinic events, so the population surveyed could be a representative snapshot of the borough.

Where survey data was collected:
Generally, survey data was collected in one of two venues: at Child Health Clinic events (where each borough was responsible for at least 3 events) or at specific service sites through prior permission from borough coalition leaders. Other venues were used after discussion with CPHS, such as coffee shops, Laundromats, hair braiding salons, or farmers' markets.

The celebration events were not advertised as health fairs, although some contained the word "health". One of the events was billed as a "High School Olympics." Several others were advertised as "Back to School events." Many of the parents that attended these events were not aware of the existence of the Child Health Clinic. This was particularly true in the North Bronx (Glebe Child Health Clinic) and on Staten Island (Stapleton). At the Stapleton Clinic, when asked how many parents knew they were standing in front of a clinic, only three of the approximately one hundred parents in attendance raised their hands.

Training of interviewers:
Organizations and individuals, who were part of the borough coalition and were interested in becoming interviewers, were required to go through a training process. The training involved an understanding of the project as a whole, and the role which the surveys play as part of the overall project.

The training included: which questions should be asked, which questions could be skipped depending on the person's response, and the meaning of certain terminology used. Surveyors were asked to stress the fact that the surveys were confidential and they would

not be asked for their name or any other identifying information. Surveyors were also instructed to finish the entire survey, and then offer assistance to those parents that indicated a problem, such as the child not having health insurance coverage.

How survey interviews were conducted:
At each event, designated interviewers were given surveys in English and other languages, as needed. Interviewers were instructed to approach parents at the event and ask if they are interested in being interviewed as part of a larger study on how to improve the health care system and the health care experiences of their child/children. The parents were offered incentives for their participation in the survey, typically backpacks or t-shirts for their children, or tote bags for the parents. The incentives were provided by the Health and Hospitals Corporation and CPHS.

Prior to administering the survey, the interviewers read this message to parents:

> *Hello. My name is [name of interviewer]. I work for/am a volunteer for [name or organization]. As part of a yearlong project to honor the 100th Anniversary of Child Health Clinics, we are interviewing parents and young people about their own, or their children's health care experiences and their opinion about what could be improved in the health care system. We will not use your name or any information that would identify you. At the end, we will write a report that will be used to work to make important changes in health care, especially for children and young people. Will you agree to be interviewed? If you will, you can choose to not answer any of the questions that I will be asking you today.*

Once parents consented to the statement, the survey commenced and the first question was asked. If the child or parent did not have health insurance, at the end of the survey, they were referred to a managed care company or a facilitated enroller on-site at events, or given information about facilitated enrollers in the area. If the parent wanted to receive more information about the project, they were asked to leave their contact information with the borough coalition leader, who would then send them the requested information.

At the end of the survey period, the borough coalition leaders were responsible for gathering completed surveys and delivering them to CPHS. Surveys were collected from April 2, 2008 to October 22, 2008.

Data input period:
A Microsoft Office Access database was created for the purpose of entering the data and conducting data analysis of information. Surveys were entered every other week or when there were 100 surveys, whichever came first. Surveys were entered randomly but were grouped by the boroughs they were conducted in.

During the data entry time there was a period of data cleaning where surveys were discarded or deemed void for one of four reasons: incomplete surveys (missing at least

one full page of the survey), excessive blanks (10 or more blanks during the course of the survey), or if the interviewee had no children or their children were over 19 years old. There was also a case where an older version of the survey was used which could make it difficult for accurate data analysis. In total there were 90 surveys that were voided, which accounted for 12% of the total number of surveys received.

There was a minimal amount of data correction or data matching. This was due to a lack of comparability between many of the survey respondents, which led to a lack of confidence in the data being matched. Instead the data was discarded as unusable or used as is, with the number of blank responses marked down. Data input period was from June 2, 2008 to October 22, 2008.

Data compilation period:
Data was compiled and disaggregated into the respective boroughs and aggregated again into a snapshot of New York City's children's health. Data from all the questions were presented to borough coalition leaders to elicit their input about the preparation for the survey report. Data compilation period was from June 15, 2008 to October 22, 2008.

Limitations:
The surveys that were conducted face certain methodological limitations. The survey is a snapshot of the New York City population. The results from the survey are meant to be a snapshot of children's health and health access, and not meant to be generalized to the city's population. The people surveyed were a convenience sample based on their availability and willingness to participate.

APPENDIX C

Methodology – Teen Discussion Groups

A series of twelve focus groups were conducted with youth throughout the five boroughs. These youth were contacted by borough coalition leaders to speak about their health experiences. Each borough conducted two focus groups with Manhattan having an additional two focus groups by the Lower East Side/Chinatown subcommittee. Participants were contacted through high schools, community centers, and through community based organizations. The purpose of these teen discussion groups is to collect data on the views of young people on a number of health care issues. Focus groups were used to elicit greater amounts of data from teens about their health access and to complement data gathered from surveys conducted about the health of New York City children. It was felt that parents do not always know what their teens are thinking and communication is difficult at this age.

The focus groups were held between April 17, 2008 and September 11, 2008 and lasted between 45 minutes to one-and-a-half hours. The sessions were conducted at different sites with different moderators. The skill of the facilitators varied greatly. The process varied with each group but there was usually a moderator and a note-taker with notes provided at the end of the session. Refreshments were served during the session and most focus groups did not offer incentives for participation, though all participants were offered information about accessing insurance programs in their area.

Recruitment of Participants

Each participant group was recruited because of their age (teens and early twenties) and for their potential insights into the health care system. The opinions of young people from special populations was also sought, e.g., teenagers in foster care.

Procedure

Focus groups were held either at the service site or off-site. The focus group procedure varied from each session. Generally, participants were informed about their participation in the project and to feel comfortable to speaking about their experiences with the health care system

- The facilitator began with a short introduction about the purpose of the session and explained the procedure for answering questions, which included speaking one at a time.
- Participants' were told that their identities would not be recorded
- The facilitators and volunteer staff undertook on-site note taking.

Focus Group Process

Structure

Facilitators established rules for the group at the introduction which included a speaking protocol, showing respect for differences of opinions and honoring the confidentiality of

information shared in the group. Each participant was given a chance to speak about their health care experiences and in some instances answers were aggregated for the group at large. Specific responses may be recorded for inclusion into the larger report.

Focus Group Session Protocol
The focus group sessions focused on the participants' experiences with health care.

- Health problems facing teens in schools and in their communities
- Ideas about health and a healthy community
- Access to a regular doctor or clinic
- Who encourages them to access medical care
- Use of emergency rooms
- Communication and understanding during medical exams
- Desires for changes to the health care system

Group Dynamics
Most participants in the groups had prior contact with each other as they belonged to the same class or accessed services from the same site. All of the participants were open to discussing their experience in accessing health care and were willing to elaborate upon personal experiences.

Data Analysis
Two CPHS staff members analyzed each focus group write-up independently to ensure reliability. Group themes and responses were analyzed and condensed for the report.

NYC Health and Hospitals Corporation
Child Health Clinics