

**“Mutual Responsibility”:  
A Study of Uninsured Immigrants’  
Perspectives on Health Insurance  
in New York City**

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## Executive Summary

*“Mutual Responsibility”*: A Study of Uninsured Immigrants’ Perspectives on Health Insurance in New York City was conducted during a period of unprecedented economic crisis and at a moment of increased political interest in health insurance reform. The current economic crisis has added to the ranks of the uninsured and exacerbated the pressing need for reforms in the health care and insurance systems. Indeed, research has shown that for each percentage point rise in the unemployment rate, the number of uninsured Americans rises by approximately 1.1 million. This study is intended to inform policy makers about the needs of one of the largest segments of New York’s uninsured: immigrants.<sup>1</sup>

Immigrants make up 22% of New York State’s population (for a total of 4.2 million immigrants) and 37% of New York City’s. In New York City, 57% of all children live in a family with at least one foreign-born adult. In 2007, over half (52%) of all of New York’s immigrants were naturalized citizens. The remaining two million immigrant residents of the State are non-citizens, including 1.4 million legally residing residents (lawful permanent residents or green card holders, refugees, asylees, and other statuses), and about 650,000 unauthorized (undocumented) immigrants.

Non-citizen, immigrant New Yorkers are about three times more likely than citizens to be uninsured (34% versus 11%). Despite representing 12% of the State’s population, non-citizens make up more than a quarter (29%) of the State’s uninsured under the age of 65. Further, the United Hospital Fund has estimated that, in 2005, 32% of the state’s 2.5 million uninsured persons were eligible for an existing public health insurance program, and that non-citizens constitute a large share of this group (140,000 of the estimated 800,000 eligible but uninsured New Yorkers).

Though immigrants have been identified as comprising a large segment of New York’s uninsured population, and further comprising a significant portion of those who are currently eligible for existing public health insurance programs, little primary research has focused on the real and perceived barriers to maintaining health insurance faced by this population, the factors driving their choices, or the policy designs that could increase enrollment in health insurance among eligible immigrants. This research seeks to fill this gap.

The study, conducted between July 2008 and March 2009, covered six focus groups with uninsured immigrants from the Korean, Russian and Mexican communities of New York City, and ten in-depth interviews with community-based professionals who assist immigrants with enrolling into New York State’s health insurance programs. Focus group participants were either

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<sup>1</sup> The term “immigrant” here refers to people who were born in another country, regardless of their legal status or whether they have become citizens.

eligible for public insurance (but not enrolled), or ineligible for public insurance based on their income or immigration status. The research focused on immigrants' experiences accessing health care and insurance, as well as their perceptions, beliefs, and preferences, including the fears, concerns, and values that influence their decisions to enroll themselves and their families in public and other health insurance programs.

Our research is designed to inform policy discussions about how to maximize eligible immigrants' enrollment in current health insurance programs and how to design coverage expansions that work best for immigrant populations. Drawing on immigrants' own perceptions and opinions regarding health insurance, the research indicates that acquiring comprehensive and affordable health insurance is a high priority for immigrants, and that many favor public coverage. Enrollers and outreach workers may also find that the data provides valuable insights into immigrant concerns about health coverage, which could be used to overcome widespread reluctance to enroll and to promote informed decision-making.

### *Summary of Findings*

A unique feature of this research is that we were able to compare findings from three population groups and insurance eligibility categories, and to supplement this information with rich insights from an array of immigrant health insurance enrollers and advocates. Specifically, we were able to make comparisons:

- Among three groups of participants: Mexican/Korean/Russian-speaking;
- Between immigrant participants and literature on the general population; and
- Between those eligible for public insurance and those ineligible based on income or immigration status.

While we found differences across these categories, we found that the cost of health care trumps nearly all other concerns of uninsured immigrants with regard to accessing care.

### **Population Group Comparisons:**

There were subtle differences across population groups sampled in this study.

- Mexican participants were the most likely to report experiencing discrimination when seeking health care.
- Korean participants were the most concerned that using public health insurance might affect immigration status and were the only participants to associate social stigma with public insurance.
- Russian-speaking participants were the most likely to report relying on non-practicing medical providers from their home country, though the other groups reported such practices as well.

These findings should be regarded cautiously, as cross-group differences in income and immigration status are difficult to separate from other population-specific factors.

In addition to the differences, strong similarities were noted across the different population groups:

- Lack of affordable health care and insurance options caused immigrants to delay and avoid even needed care.
- Immigrants experienced administrative and linguistic barriers to coverage and believed that the process of applying for public health insurance should be simplified.
- There was overwhelming interest in health insurance. Contrary to common public perceptions, immigrants across ethnic groups and income levels **do** desire health insurance.
  - Immigrants believed that health insurance does not have to be free, but should be affordably priced.
  - Like other Americans, immigrants were concerned about value, and wanted health insurance that enabled them to see high-quality doctors. Some believed that public insurance programs limit their choice of providers to public hospitals and clinics.

### **Comparison of Immigrants with the General Population:**

While immigrants share concerns with the general population regarding the cost of health care and insurance, they also revealed unique concerns that disparately impact their ability to access health care and insurance. Within the current health insurance environment, uninsured immigrants in New York are:

- Concerned that public health insurance will result in a public charge determination, ending their chances of maintaining lawful permanent residence in the U.S.;
- Aware that an immigrant's sponsor is financially liable for the cost of public insurance used by those they sponsor. This liability threatens access to health insurance among legal immigrants even though the liability laws are not currently being implemented by New York State;
- Often limited-English proficient (LEP) and unfamiliar with the health care and health insurance systems. LEP immigrants are commonly reliant on bilingual, community-based organizations to help them navigate the health care and insurance systems; and
- Often distrustful of the government and the information they receive regarding health insurance. In addition, immigrants may face greater difficulty documenting their income than their immigration status.

## **Eligible But Uninsured Immigrants:**

Finally, among immigrants in all three ethnic groups who were eligible for public insurance but uninsured, barriers to enrollment included:

- Lack of information about eligibility;
- Difficulties completing health insurance applications;
- Insufficient documentation of income;
- Inaccurate information about immigration status eligibility; and
- Immigrant-specific issues, including sponsorship concerns and LEP, as cited above.

### *Issues to Consider*

Our findings raise some issues to consider that are specific to immigrant populations, as well as some that overlap with concerns of immigrants and the general population alike.

1. Proactively address immigrants' concerns about potential consequences of enrolling in public health insurance, such as public charge, adjustment of status and sponsor liability. Messages should be clear and consistent, including those coming directly from government agencies.
2. Promote linguistically and culturally appropriate communication throughout insurance systems, including at enrollment and renewal of coverage.
3. Increase resources for community-based health advocates who help immigrants with inadequate knowledge of the health insurance and health care system.
4. Educate the public about coverage options, including new exemptions from Child Health Plus's six-month waiting period when transferring from private insurance.
5. Simplify and reduce the documentation necessary to enroll in public health insurance and maintain coverage.
  - a. New York State should continue to allow the use of self-attestation of income.
  - b. Eliminate documentation of income when a third-party match is available.
6. Create an affordable buy-in option for comprehensive public health insurance.
  - a. Include those left out of federal reform, e.g. most non-immigrant visa holders and undocumented immigrants.
7. Enhance consumer protections for private insurance plans with limited benefits and high cost sharing, and allow individuals to purchase full premium private health insurance regardless of immigration status.

# I. Introduction

## *Context*

*“Mutual Responsibility”*: A Study of Uninsured Immigrants’ Perspectives on Health Insurance in New York City was conducted in the midst of an unprecedented economic crisis and at a moment of increased political interest in health insurance reform.<sup>ii</sup> Research has shown that for each percentage point rise in the unemployment rate, the number of uninsured Americans rises by approximately 1.1 million.<sup>1</sup> By October 2009, New York State’s unemployment rate reached 9.0%, and New York City’s reached 9.1%.<sup>2</sup> The economic crisis has added to the ranks of the uninsured and exacerbated the pressing need for reforms in the health care and insurance systems. This study is intended to inform policy discussions about the needs of one of the largest segments of New York’s uninsured: immigrants.

Non-citizen immigrant New Yorkers are nearly three times more likely than citizens to be uninsured (34 percent versus 11 percent, respectively).<sup>3</sup> Despite representing just 12% of the State’s population, non-citizens make up more than a quarter (29%) of the State’s uninsured under the age of 65. The United Hospital Fund estimated that in 2005 that 35% of the state’s 2.3 million uninsured persons were eligible for an existing public health insurance program, and that non-citizens constituted a large share of this group – 130,000 of the estimated 800,000 New Yorkers who were eligible for public health insurance but remained uninsured.

New York State offers public insurance to individuals with a broad range of immigration statuses, and requires immigration status or citizenship documentation upon enrollment in public insurance. This range includes naturalized citizens, lawful permanent residents (green card holders), qualified immigrants (including refugees and asylees), and immigrants in transitional statuses, including those who have applied for and are waiting to adjust status (PRUCOL<sup>iii</sup>). Most immigrants besides naturalized citizens, qualified immigrants, and those who have been lawful permanent residents for more than five years are only covered through New York State expansions of Medicaid, as all other immigrants are barred from matching Federal Medicaid funds.<sup>iv</sup> This bar includes undocumented children and pregnant women, who are, however,

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<sup>ii</sup> The authors acknowledge the commitment, contributions, and insights of Danielle Holahan of the United Hospital Fund in all phases of this research project. We would also like to thank the study participants and CBO staff who recruited them and conducted interviews and focus groups, as well as those immigrant advocates and enrollers who participated in key informant interviews.

<sup>iii</sup> PRUCOL stands for Permanently Residing Under Color of Law. It is not an immigration status, but rather a term used for public benefits purposes that encompasses a broad range of immigration statuses recognized by the United States Citizenship and Immigration Services (USCIS) as individuals “living in the U.S. with the knowledge, permission, and acquiescence of USCIS and whose departure the USCIS does not contemplate enforcing”, including those with pending green card or asylum applications, persons with Temporary Protected Status, and persons granted stays of deportation.

<sup>iv</sup> As a result of federal welfare reform (Personal Responsibility and Work Opportunity Reconciliation Act of 1996), lawful permanent residents for less than five years and those who are PRUCOL are barred from accessing federally funded public insurance. A court decision in New York State in 2001 (*Aliessa v. Novello*, 96 NY2d 418) extended benefits to all legal residents and PRUCOL immigrants with State-only funding. This decision does not cover

eligible for public insurance in New York State. Hospitals and clinics throughout New York State and the country receive government reimbursement for some of the costs associated with treating low-income, uninsured immigrants, including undocumented immigrants and temporary, non-immigrant visa holders, through the Emergency Medicaid program.

Despite immigrants' broad eligibility for public health insurance in New York, they are often deterred from enrolling themselves and their children in affordable insurance in New York as a result of the complexity of the insurance enrollment process, lack of awareness of immigrants' eligibility for public health insurance, and perceptions about immigrant specific consequences of using public insurance.<sup>4</sup>

### *Background*

Immigrants<sup>v</sup> make up 22% of the population of New York State (4.2 million) and 37% of New York City.<sup>5</sup> In New York City, 57% of all children live in a family with at least one foreign-born adult.<sup>6</sup> New Yorkers are diverse in ethnicity and immigration status. In 2007, over half (52%) of all of New York's immigrants were naturalized citizens. The remaining two million immigrants were non-citizens, including 1.4 million who are legally residing (lawful permanent residents or green card holders, refugees, and asylees), and an estimated 650,000 who are unauthorized residents (undocumented immigrants).<sup>7</sup>

Immigrants face many difficulties accessing health care and health insurance. Similar to the general U.S. population, high cost is among the most significant of these difficulties. Limited English proficiency is another very commonly cited obstacle to health care.<sup>8-10</sup> There are 2.3 million limited-English proficient (LEP) individuals in New York State, and 42% of those living below the poverty line are LEP.<sup>11</sup> Nearly half of NYC residents speak a language other than English at home,<sup>12</sup> and more than one in four adults in New York City report that they do not speak English at all or do not speak it well.<sup>13;14</sup>

Immigrants also tend to work in low-wage jobs and in occupations, industries, and small firms that are less likely to offer group health coverage.<sup>3;15-17</sup> Low-income workers, regardless of citizenship status, are less likely to have an offer of coverage from an employer, and immigrants in New York earn 9%-19% less per hour than their native-born counterparts with the same educational attainment.<sup>6</sup> In addition, non-citizens are over twice as likely to work in construction jobs as citizens, and have higher rates of employment in agricultural, labor, and service industries. Uninsured rates in these industries are over 30% for all workers, regardless of immigration status, compared to 19% of workers who lack insurance across all industries.<sup>15</sup>

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unauthorized immigrants and temporary visa holders, who are only eligible for coverage in the case of an emergency.

<sup>v</sup> For the purpose of this report, the term "immigrant" refers to people who were born in another country, and were not born as U.S. citizens. We consider such foreign-born individuals to be immigrants regardless of their current legal status or whether they have yet become citizens.

Immigrants' lack of familiarity with the U.S. health care system is cited as an additional barrier to acquiring health care.<sup>4</sup> The system is confusing to much of the general public and very different from systems in other countries, so many immigrants lack adequate understanding of how health insurance works, why it should be purchased, and where to seek affordable health care. Public insurance's complex income and immigration-related eligibility requirements for low-income New Yorkers are often poorly understood, resulting in missed opportunities for enrollment by eligible immigrants in free or low-cost insurance. These cultural, linguistic, and financial barriers to health insurance and health care make immigrants less likely than U.S. born citizens to have a usual source of health care, to have visited a health professional in the past year, or to receive primary or preventive care.<sup>18</sup>

Two areas of particular concern for immigrants are public charge and sponsor liability:

### Public Charge

Most immigrants come to the United States to pursue economic opportunity, unite with family members, or escape persecution, hoping for a better life for themselves and their children. Studies consistently show that the vast majority of immigrants do not come to America in search of welfare or health care.<sup>18</sup> Immigrants are generally interested in remaining in the U.S. and avoiding circumstances that might threaten their ability to do so. To remain in the country, immigrants must negotiate with United States Citizenship and Immigration Services (USCIS), a large government bureaucracy with complex rules,<sup>19;20</sup> tremendous backlogs,<sup>21-23</sup> and significant decision-making discretion.<sup>19;20;24;25</sup> The path to becoming lawful permanent residents (LPRs or "green card holders") and citizens is complicated and long, ranging from about four years to decades.

Along this path, USCIS can deny a green card to those determined to be a public charge.<sup>4</sup> A public charge is someone found by immigration officials or the courts to be, or likely to become, primarily dependent on the government for subsistence. Being a public charge is among the many grounds for being "inadmissible" or not allowed to enter (or remain in) the United States. There is evidence that immigrants fear that enrollment in public health coverage programs will classify them as public charge and preclude them from obtaining LPR status, acquiring a visa to travel to the U.S., or remaining here.<sup>4</sup> However, the federal government has clarified that the use of non-cash benefits such as Medicaid, does not render an individual public charge, unless used for long-term care.<sup>26</sup>

### Sponsor Liability

Beyond the personal and immediate concerns regarding health insurance and the adjustment of one's immigration status, immigrants may also have concerns related to the sponsorship of other family members who wish to visit or live permanently in the United States. Migration to the United States is largely family-based<sup>21</sup>, with citizens and lawful permanent residents being

allowed to sponsor spouses, children, siblings, and parents. In order to sponsor a relative, an individual must sign a federal affidavit of support (form I-864), which attests to his or her responsibility for repayment of any means tested public benefits that the sponsored immigrant uses, including Medicaid and the state Children's Health Insurance Program. However, the final federal regulations requiring States to enforce sponsor liability have not yet been issued. Many New Yorkers have signed affidavits of support to sponsor their family members for lawful permanent residency.

The vast majority of states have refrained from suing sponsors for repayment of medical assistance benefits, and no such attempt has ever been made in New York. Advocates in New York have received reassurance through personal communications with Department of Health officials that New York will not pursue reimbursement from sponsors until and unless a final federal ruling is made. Nonetheless, this risk to the sponsor's financial well-being poses potential cause for reluctance on the part of sponsored immigrants to enroll in coverage.<sup>27</sup>

### *Health Insurance Reform*

New York has taken several steps in recent years to expand public health insurance coverage and simplify enrollment and renewal. These steps affect low-income citizens and immigrants alike, and continue to place New York ahead of the nation in terms of State expansions on Federal Medicaid. Specifically, in 2008 New York implemented an income eligibility expansion for children in Child Health Plus 400 percent of the Federal Poverty Level (FPL). In addition, since 2007 New York has enacted a series of streamlining reforms to ease enrollment and retention of eligible children and adults in public coverage. These include:

- Reduced documentation requirements for Medicaid and Family Health Plus (FHP) at renewal;
- Presumptive eligibility for children into Medicaid;
- Elimination of drug and alcohol screening and finger imaging;
- Establishment of a single eligibility level for single adults and childless couples, replacing the county-specific levels;
- Elimination of the Medicaid and FHP asset test requirement;
- A shift to gross income test for Medicaid.
- Elimination of the Medicaid and FHP face-to-face interview requirement; and
- Elimination of age-based eligibility distinctions in CHIP and Medicaid.<sup>vi</sup>

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<sup>vi</sup> The effective dates of these reforms are as follows: reduced documentation requirements for Medicaid and FHP at renewal (January 2008); presumptive eligibility for children into Medicaid (February 2008); elimination of vestiges of welfare, including drug and alcohol screening (April 2008) and finger imaging (July 2009); establishment of a single eligibility level for single adults and childless couples (April 2008); elimination of the Medicaid and FHP asset test requirement (January 2010); elimination of the Medicaid and FHP face-to-face interview requirement (April 2010); and elimination of age-based eligibility distinctions (CHIP and Medicaid) and a shift to gross income test for Medicaid (April 2010, contingent upon federal approval).

New York is also developing a centralized statewide Enrollment Center to process renewals for certain children and adults who are eligible for its public health insurance programs.

State reforms are taking place within the context of a national legislative health care debate that aims to increase access to insurance for millions of uninsured and underinsured Americans. Within the national debate, coverage for immigrants has generated significant controversy. Reflecting widespread American sentiments, members of Congress are eager to demonstrate that new benefits, such as more generous access to Medicaid and subsidies toward the purchase of affordable health insurance, will not be available to particular groups of immigrants. As of this writing, the bar on immigrants receiving public insurance in their first five years as lawful permanent residents remains in both the House and Senate health care reform bills.<sup>vii</sup> Legislation in the Senate includes a provision to prevent undocumented immigrants from purchasing insurance, even at full cost through a program called the Exchange, though legal immigrants are not restricted from subsidies or full premium insurance in either the House or Senate's version of the Exchange. Federal limitations on public coverage for certain immigrant groups mean that New York State will be faced with covering the care for low-income uninsured persons. As mentioned above, New York State already covers many types of immigrants who are not entitled to public insurance under existing Federal Medicaid structures.

### *Contributions of this Research*

Though immigrants have been identified as a large segment of the uninsured population of New York, as well as a significant portion of those who are eligible for but not enrolled in existing public health insurance programs, little primary research has focused on the real and perceived barriers to health insurance faced by this population. This research seeks to fill this gap.

Drawing on immigrants' own perceptions and opinions regarding health insurance, our research was designed to inform policy discussions about how to optimize immigrant enrollment in current health insurance programs and how to design coverage expansions that are appropriate for immigrant populations. Enrollers and outreach workers may also gain valuable understanding of immigrant concerns about health coverage that they may use to promote informed decisions and overcome widespread reluctance to enroll.

It is our hope that in the context of health insurance reform at the state and national levels, policy makers will use the findings as they refine health insurance models and messages. The immigrant-focused research described in this report offers evidence from a sample of New Yorkers impacted by and intended to benefit from such health reforms. We urge policy makers to consider the findings in order to maximize the impact of recent and future reforms to the health insurance system.

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<sup>vii</sup> Legislation refers to the House Health Reform Bill – HR 3962 – passed on November 7, 2009, and Senate Health Reform Bill – HR 3590 – introduced on November 18, 2009.

## II. Study Design and Methods

The data presented here come from a study of uninsured immigrants, along with the individuals at community-based organizations who help them navigate the health care system and enroll in insurance. The study focused on three immigrant populations in New York City: Korean, Russian-speaking, and Mexican. These populations were selected because of their large size, and their relative diversity with respect to one another in terms of immigration status and socioeconomic characteristics. Participants were drawn from linguistically isolated communities in three different boroughs of the City. Focus groups were conducted with Koreans primarily living in Queens, Russian speakers living in Brooklyn; and Latinos living on Staten Island. In addition, staff of community-based organizations (CBOs) serving these and other immigrant communities participated in in-depth one-on-one interviews with the researchers. Study design and data collection took place between July 2008 and March 2009.

### *Focus Groups*

The New York Immigration Coalition (NYIC) and three immigrant-serving CBOs organized six focus groups with uninsured immigrants from these three distinct communities. Participants were recruited by Korean Community Services, Shorefront YM-YWHA of Brighton Beach, and El Centro del Inmigrante using purposive sampling that sought immigrants who were Korean-, Russian-, or Spanish-speaking, and over eighteen years of age and uninsured.

Respondents were further screened into a specific focus group based on the following criteria: 1) eligible for public insurance based on their immigration status and income; 2) ineligible because they were over-income for public insurance; or 3) ineligible because they did not have the appropriate immigration status (i.e., either undocumented or residing on a valid non-immigrant visa). In determining income eligibility for public health insurance at the time of study recruitment, the income limits for Family Health Plus (FHP) were used. FHP is a New York State sponsored Medicaid expansion program for parents with a household income up to 150% of the federal poverty level (FPL), and childless adults up to 100% (FPL). The 2008 guidelines for FHP income eligibility can be found in Appendix A.

These three focus group categories were selected based on an interest in both increasing enrollment of those eligible for existing public health insurance programs and developing new programs for those who are ineligible due to their income or immigration status. Participants who were eligible for existing health insurance programs were offered application assistance by the community organizations following the screening survey and focus group discussions, so as to facilitate connection to affordable health insurance.

Fifty-three individuals from the immigrant communities served by three CBOs were screened for eligibility to participate in a focus group; all participants completed a survey that determined

their eligibility and gathered background information on their health status, and health care and insurance use.

This study includes data from these surveys and from 48 individuals<sup>viii</sup> who ultimately participated in the focus group discussion. As it turned out that all Spanish speakers were from Mexico, this report will herein refer to this population group as Mexican. Similarly, Russian is used as an abbreviation for Russian speakers who emigrated from many parts of the former Soviet Union, including Russia, Ukraine, Turkmenistan, Uzbekistan, and Kyrgyzstan. The breakdown of participants by population group was 22 Korean, 14 Russian, and 12 Mexican.

The focus groups and interviews were conducted during December 2008 and January 2009.<sup>ix</sup> Focus groups included approximately eight individuals; because of recruitment challenges, one focus group had just 2 participants.<sup>x</sup> The largest group had 14. The focus groups were approximately two hours long and followed a 17-question guide that focused on participants' experiences and concerns as immigrants seeking health care and health insurance, explored barriers to enrollment in public health insurance and solicited suggestions for increasing access to public insurance. Trained bilingual moderators from each CBO conducted the focus groups in the native language of the participants. A bilingual note taker co-facilitated the groups, which were audio-recorded and transcribed into English for analysis by CBO staff. The study protocol was approved by the Institutional Review Board at The New York Academy of Medicine. All focus group participants received a cash incentive in recognition of their time and effort, and refreshments were provided during the sessions.

Distribution of participants among the six different focus groups is shown in Table 1:

**Table 1:** Number of Focus Group Participants by Insurance Eligibility Category

<b>Eligibility Category</b>	<b>Korean (n=22)</b>	<b>Russian (n=14)</b>	<b>Mexican (n=12)</b>	<b>Total (n=48)</b>
Eligible but Uninsured	14	7	2	23
Ineligible: Over-income	8	7	0	15
Ineligible: Due to Immigration Status	0	0	10	10

<sup>viii</sup> Data on the five individuals who were screened for this study but did not ultimately participate in a focus group is included because screening was conducted anonymously, and it is not possible to separate out who ultimately participated and who did not. Furthermore, the data in the screening form was obtained with full consent of the participant, and offers meaningful evidence on immigrant eligibility for health insurance, health status, and health care and insurance use.

<sup>ix</sup> The focus group interview guide was jointly developed by the New York Immigration Coalition, the United Hospital Fund, and the New York Academy of Medicine. It was also circulated for outside review by national experts in the field of immigrants' access to health care, and pilot tested among a group of largely uninsured young adults from Latin America who are members of the New York State Youth Leadership Council.

<sup>x</sup> While only two participants are suboptimal for a focus group, the protocol was consistent with the other groups and the findings were consistent. Therefore this group is included throughout the report with the focus group findings.

### *Enroller Interviews*

In addition to the six focus groups with uninsured immigrants, ten staff members whose job responsibilities involve helping immigrant clients to navigate and access the health care and insurance systems were interviewed using a semi-structured interview guide. Interviewees worked at a community-based organization, a non-profit health plan, or a non-profit insurance enrollment facility in Brooklyn, Queens, or Staten Island. The sample included 1) staff from the focus group CBOs, allowing us to examine consistency in perceptions between clients and staff; and 2) people who provide enrollment assistance to immigrants in other communities, to check if concerns from the three communities were similar to or different from those of other immigrant groups.

Interviews with staff were conducted at each participant's office. Respondents worked with Korean (n=2), Russian (n=2), and Latino (n=1) communities. Five worked with other immigrant communities including Haitian, Arab, Balkan, and South Asian communities, as well as non-immigrant populations. Interviews took up to two hours to complete and followed a 20-question guide that focused on the individuals' general work, their specific work with immigrants and health insurance, and their opinions about improving immigrant enrollment in health insurance. The interviews were conducted in English, audio-recorded, and transcribed.

Coding and analysis of qualitative data was conducted using a qualitative software package (NVivo) that facilitates management and analysis of data. In order to protect the confidentiality of the participants, pseudonyms have been used throughout the report of findings.

### III. Findings

A unique feature of this research is that we are able to compare findings from three population groups and insurance eligibility categories, and supplement this information with rich insights from an array of immigrant health insurance enrollers and advocates. In doing so, we found similarities and differences:

- Among the three population groups;
- Between immigrant participants and literature on the general population<sup>xi</sup>
- Between those eligible for public insurance and those ineligible based on income or immigration status.

It should also be noted that while findings are largely reported according to these three sets of comparisons, some themes repeat throughout. Before reporting on these analyses, we offer some background information on the demographics of the study participants and their patterns of health care and insurance use.

#### *Demographic Background of Focus Group Participants*

Most of the respondents to the pre-focus group screening survey and participants in the focus groups were limited-English proficient and all were foreign-born. As shown in Table 2, over half (52%) were under forty years of age, and most were married or living with a partner. Less than half had children under age 18 living in their home, although there were notable differences by population group, with all Mexicans and just over one-quarter Russians having children at home. Most focus group participants had lived in this country for less than ten years (60%).

The sample indicates a disparity in education levels between the Mexican participants and the other two groups. While 60% of Mexican participants had a middle school education or less, 53% of Russian and 64% of Korean participants were college graduates. The disparity likely reflects – in part – the decision to draw a portion of the Russian and Korean samples from those who are over-income for public health insurance, without drawing a similar Mexican sample.<sup>xii</sup> It also reflects prevalent educational attainment among the three groups. Among the three

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<sup>xi</sup> Findings from our immigrant specific research were compared with reports on health insurance and health care use by the general population in the health policy literature, including *One-Two Punch: Unemployment and the Uninsured* by Families USA (October 2009), *Findings From a New York Statewide Poll on Health Reform, 2009* by Community Service Society (September 2009), and *The Unheard Third 2009 Executive Summary: Job Loss, Economic Insecurity, and a Decline in Job Quality* by the Community Service Society (October 2009). Primary data on the general population was not collected in this study.

<sup>xii</sup> This decision not to draw a sample from each of the three categories of eligibility (or ineligibility) for public health insurance was based on limited resources, not on the relative number of potential participants for each category by population group. For example, given sufficient resources, there would have been equal opportunity to draw a sample of Russian and Korean participants who are ineligible for public insurance based on their immigration status, as there would have been to draw a sample of Latino participants who are over the income limit for public insurance.

groups, Korean participants were almost twice as likely as the Russian or Mexican participants to be earning an income through a job with a steady paycheck (20%, 11%, and 9%, respectively), while all three groups had significant numbers receiving hourly or daily wages. Russian participants reported the highest reliance on other means of income, including support from friends or a spouse, and unemployment benefits (58%).

**Table 2: Demographic Characteristics of Study Participants**

<b>Characteristics</b>	<b>Korean (n=22)</b>	<b>Russian (n=19)</b>	<b>Mexican (n=12)</b>	<b>All Participants (n=53)</b>
<b>Gender</b>				
Female	50%	86%	92%	71%
Male	50%	14%	8%	29%
<b>Age</b>				
20-30	18%	11%	33%	19%
31-40	23%	33%	50%	33%
41-50	18%	22%	17%	19%
51-60	23%	6%	0%	12%
60 +	18%	28%	0%	17%
<b>Lives With</b>				
Spouse/Partner	68%	35%	83%	61%
Children Under 18	32%	26%	100%	45%
<b>Education</b>				
8th Grade or Less	0%	0%	60%	12%
Some High School	5%	0%	40%	10%
High School Diploma/GED	14%	16%	0%	12%
Some College	18%	32%	0%	20%
College Graduate	64%	53%	0%	47%
<b>Source of Income</b>				
Steady Paycheck	20%	11%	9%	14%
Paid by Day/Hour	55%	32%	91%	54%
Other	25%	58%	0%	32%
<b>Years in the U.S.</b>				
<5	27%	53%	18%	35%
6-10	18%	32%	27%	25%
11-15	36%	11%	36%	27%
16-20	9%	5%	18%	10%
21+	9%	0%	0%	4%
<b>English Proficiency</b>				
Well	32%	16%	0%	19%
Not Well/Not at All	68%	84%	100%	81%

\*Percentages reported are based on valid responses. Missing data is excluded from the analysis.

### *Participants' Health Care and Health Insurance Use*

Though all the participants screened for the study were uninsured, they reported considerable experience with health insurance and health care in New York. Forty-nine percent had been insured at some point in time in the United States (Table 3).

**Table 3: Health Insurance Experience**

Characteristics	Korean (n=22)	Russian (n=19)	Mexican (n=12)	All Participants (n=53)
Participant Ever Had Insurance	23%	79%	50%	49%
Participant with Insured Household Members	23%	21%	92%	38%

Among those who reported having insurance in the past, 22% reported having private insurance through an employer or a spouse, and 78% reported having had public insurance (Table 4). Twenty-three percent of those who reported having had public insurance in the past had Emergency Medicaid, a type of hospital reimbursement that only covers treatment for an emergency medical condition. Seventeen percent reported having had Emergency Medicaid coverage for the delivering of a child. Thirty-eight percent reported having some form of Medicaid Managed Care, or full-coverage Medicaid. As could be anticipated, Mexican participants, the majority of whom were ineligible for public insurance based on their immigration status, only reported experience with Emergency Medicaid and pregnancy-related Emergency Medicaid. Korean and Russian participants were the only participant groups to report experience with private insurance. Among the 38% (n=20) who reported having an insured household member at the time of the screening interview, 95% (n=19) reported that the household member had some form of public insurance, including 45% (n=9) who reported Child Health Plus.

**Table 4: Type of Health Insurance among Those Insured in the Past**

Characteristics*	Participants Who Reported Prior Insurance Use (N=26)
<b>Private</b>	22%
<b>Public</b>	
Pregnancy-Related Emergency Medicaid	17%
Emergency Medicaid	23%
Full-Coverage Medicaid	38%

\*Percents are not broken down by population group because of the small sample size of each.

Despite being uninsured, nearly half of those surveyed reported a regular source of care (Table 5), which may have been an artifact of our sampling strategy. A program to extend free or low cost health care services to uninsured residents of Staten Island may explain why all of the Mexicans surveyed (n=12) reported having a regular source of health care.<sup>xiii</sup>

**Table 5: Health Care Use and Health Status**

Characteristics	Korean (n=22)	Russian (n=19)	Mexican (n=12)	Total (n=53)
<b>Health Care Use</b>				
Any Regular Source of Health Care	36%	32%	100%	49%
Community Clinic**	33%	0%	75%	44%
Private MD**	44%	100%	0%	37%
Hospital Clinic**	22%	0%	25%	19%
<b>Use of Health Care</b>				
ER Use in Past 12 Months	23%	32%	27%	27%
Overnight Hospital Stay in Past 12 Months	23%	16%	46%	25%
<b>Health Status</b>				
Very Good/Good	36%	53%	25%	40%
Fair	36%	32%	75%	43%
Poor	27%	16%	0%	17%

\*Percentages reported are based on valid responses.

Missing data is excluded from the analysis.

\*\* Percentages represent the proportion of those reporting a regular source of care.

Over a quarter of all screened participants had been to the emergency room in the past 12 months, and a quarter had remained overnight in a hospital. When participants were asked to

<sup>xiii</sup> Because Staten Island does not have a public hospital, New York City's Health and Hospital's Corporation (HHC) worked with local private doctors to create the Staten Island Health Access (SIHA) program for those who were uninsured and ineligible for public insurance. Those eligible for SIHA met the income guidelines for public insurance, but not the immigration status requirements. By signing up for SIHA, residents were able to select from a list of affordable primary care doctors and specialists on Staten Island, and spare themselves a lengthy and costly trip to public hospitals in other boroughs of New York City. SIHA was originally designed to address the health care needs of Staten Island residents until HHC established a new Community Health Center in the Richmond neighborhood. SIHA ceased new enrollment in June 2008. Though the program had ended by the time of our focus groups, several participants reported past enrollment in this program.

assess their own health status, 60% reported being in fair or poor health, suggesting that this was an atypically unhealthy population.

### *Population Group Comparisons*

The focus groups revealed subtle differences in access to health care and insurance among the three population groups. These findings should be regarded cautiously as cross population differences in income and immigration status are difficult to separate from other factors, such as length of time in the U.S., education, and gender. That said, Mexican participants, nearly all of whom were undocumented women, notably reported the highest level of perceived discrimination among the three groups. They explicitly articulated poor treatment by staff in hospitals and clinics, including long waits and feelings of being ignored due to language and cultural barriers. They also reported being challenged when accessing health care because of their immigration status.

Silvia, a Mexican woman living on Staten Island, characterized the treatment she received from ER staff at a local hospital while she was in labor as “racist.” She said that the nurses tried to intimidate her by asking where she was from, and if she had “papers”. There is often the perception that hospitals may interact with or report to USCIS, though in reality this does not happen. Speaking about receiving health care in general, she explained:

*Sometimes they don't want to help us in the emergency room because we're immigrants and we don't have health insurance. If you show up without any kind of card, the receptionist does not treat you properly... it worries me if I am not able to pay that they could probably get immigration on us.*

Among the three groups, Korean participants were the most concerned about possible consequences of using public health insurance, such as public charge and sponsor liability. As the bulk of this report addresses this topic, examples will appear further along. They were also the only participants who reported social stigma as a barrier to enrolling in public insurance, whether they were eligible for public insurance or over income.

Russian participants appeared to be the most reliant on advice from non-practicing medical professionals from their home country. Both Korean and Russian participants also reported seeking health care in their home countries on return visits, and regarded the medical systems in their countries of origin as models for universal health coverage in the United States. An excerpt from the Russian focus group for those eligible for public insurance but uninsured demonstrates this practice.

- Anna: I don't have health insurance. I can't go to the hospital because I am afraid of getting a large medical bill. When my child had health problems, I called a doctor in Russia and got medication [sent] from there.*
- Evgenia: Once, after a visit to my gynecologist, I got a phone call from the doctor's office, and was told that my test results had been abnormal and I needed to do another complicated and expensive test. I was very upset. Coincidentally, I was renovating my apartment at the time, and the painter who was working in my apartment used to be a gynecologist in Russia. I showed him the results of my test, and he told me that it was normal for my age, and gave me some advice that helped.*
- Tara: When I had problems with my teeth, I went to Russia because it's much cheaper there.*

Despite subtle differences, uninsured immigrants in this study shared many perspectives on health care and health insurance. Overwhelmingly, participants who lacked health insurance avoided seeking health care, nearly always because they could not afford it. June, a young Korean immigrant diagnosed with thyroid cancer in 2004, described how she refrained from using medical care for some time:

*I just started to lose weight rapidly... I thought it was due to my irregular diet, and relied on my own reasoning to explain such dramatic weight loss. I didn't seek a doctor's opinion. Others kept urging me to go to the hospital but since I didn't have health insurance at the time, I just kept avoiding and postponing. Later, my friend took the initiative of making an appointment at a nearby clinic, despite my resistance. The test results came out, and I was told that I had a thyroid problem. They told me that they had found cancer cells, and they had started to spread in three little clusters. It was quite a traumatic experience, from the diagnosis, and prognosis, to the thought of medical bills that would follow.*

Financial concerns represent an important barrier to care. For example, in a focus group discussion with Korean individuals who were over-income for public insurance, the following conversation about seeking care occurred:

- Moderator: Where do you go when you're sick?*
- Jihun: I go to the pharmacy.*
- Ruby: I can't be sick in this country. I had oral surgery more than a year ago. I'm still paying for it.*
- Moderator: What about when the condition is very severe and needs immediate medical attention?*

*Jinny: I had appendicitis after I graduated from school. I didn't have coverage, and of course I didn't really think twice before I picked up the phone to call an ambulance, doubled over in pain. After the surgery, I started to receive the bills. I can still relive the initial shock. Thankfully, I was able to get generous financial assistance. But the thought of having to do this every time I get sick... I don't want to go through the experience again.*

Focus group discussions with participants revealed that communicating with health providers and insurers when limited-English proficient compounds the difficulties of seeking expensive health care. Despite laws and regulations regarding language access enacted from 1964 to 2006<sup>xiv</sup>, limited-English proficient patients continue to face difficulties receiving interpretation and translation services when seeking care in hospital clinics, and therefore prefer private practices set up by doctors who speak their language. For example, Kim, a participant in the focus group for Koreans who were eligible for public insurance but not insured, explained the following:

*The choice of hospitals is very limited for people like us. Without health insurance, the only places that I can go are one of those city hospitals. If I could, I would rather go to a private clinic where I can communicate without difficulty.*

More examples of how language proficiency affects access to health care will appear in the next sections. To continue on the topic of cost and health care, interviews with health insurance enrollers reveal that clients often seek help only when they're sick and need medical attention. They often have major concerns about the cost of health care and health insurance. Jane, a Korean facilitated enroller commented:

*They first get sick, then they get [medical] bills, then they start freaking out. That's why they think they need health insurance... Even though someone sick comes to apply for health insurance, it takes two or three months. So why don't they go to the doctor's office? Because they're afraid they'll have to pay. If they don't have cash right now, they don't want to go to the doctor. So sometimes they're in pain until they get Medicaid.*

Many enrollers and health advocates described their clients' desperate desire for health insurance, yet its inaccessibility. Salim, a South Asian health advocate, explained:

*They know [insurance], they want it. And that's the amazing thing. It always comes down to how much it costs. Really, I've met so many people. They all*

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<sup>xiv</sup> These include Title VI of the Civil Rights Act of 1964 and New York State's Codes, Rules and Regulations, Title 10 (Health) sections 405.7 and 751.9 effective September 13, 2006.

*want health insurance. If it was only affordable – they’re like, ‘I don’t mind paying for it, but that’s not how much I’m willing to pay.’... If they can get something like Medicaid, they’re very happy. But up to this point, I’ve never convinced anyone to take private insurance.*

### ***Comparison of Immigrants with the General Population***

Similar to findings in the literature on general population,<sup>28-30</sup> our study shows that cost is a major concern among immigrants when making choices about whether or not to seek health care and insurance. The focus groups and interviews with health advocates are filled with worries about bills and finances related to health care use. Participants recalled struggles to pay their medical bills. The immigrants who participated in this study were overwhelmingly interested in having health insurance, and understood its importance to accessing health care and doing so affordably.

Like many among the general population,<sup>31</sup> participants’ experiences with private insurance were not positive. In a Korean focus group composed of individuals who were eligible for public insurance but uninsured, two people had experiences paying for private insurance and being disappointed with the coverage. Chang-su complained about paying 90% of his dental bills and a significant portion of his doctor’s visits for allergies, despite having insurance. Upon cancelling the insurance, he began seeking health care at a local Chinese language community clinic. He speaks in broken English to the providers but finds the services more affordable. When asked about the quality, he says:

*Quality, I can’t really tell, to be honest. I’m primarily motivated by the price differences. It’s come down to “how much.” I can afford it, so I go.*

May, another participant in the focus group, summarized the problem with private insurance as follows:

*Premiums are way too high; I simply can’t afford it. And, even if you can afford it, you end up feeling cheated. Prior to enrollment, they talk as if the plan would cover everything—this and that... no problem. But when you actually try to use the plan, they cover very little to nothing. You’re essentially just paying the premiums. When you’re well and don’t need the coverage, the ludicrously high premium that you pay is a waste. When you get sick, well, that’s a waste, too; you pay for both the premium and most of your medical expenses. This type of problem is so common. It doesn’t matter which plan you choose, because most plans function this way.*

Yet immigrant-specific concerns compound general concerns of the cost and quality of health insurance. This section will explain these concerns through the words of those affected and the advocates who try to help them navigate the health insurance system in New York.

### Public Charge

Despite the official federal guidance from USCIS indicating that use of public health insurance will not result in a public charge determination, contradictory information is spread by private immigration lawyers who are ill-informed or are overly cautious in seeking to minimize the risk that their clients will be denied a green card. Many participants in the focus groups expressed concerns around desired adjustments of immigration status.

Most of the Koreans participating in the focus group for those eligible for public insurance but not insured were in the process of becoming lawful permanent residents. The moderator asked the participants if they thought that using health care or insurance would affect the process of adjusting their immigration status, and several people responded affirmatively:

- Eun:* I heard this from my cousin whose lawyer had warned him.
- Jae:* I used to have Medicaid, but terminated it when someone told me that I shouldn't use such public benefits. It made sense, later when I go in for an interview, such record wouldn't work in my favor. I even have diabetes, and need more than \$150 just to pay for my medications. When I had Medicaid, I only had to pay \$5. Now, \$150, month after month...
- Moderator:* Many people seem to share such notion.... the fear of discovery, and potential rejection.
- Jae:* Rejection, isn't that almost guaranteed if the interviewer finds out that you had used Medicaid or Family Health Plus? If not rejection, then probably a lengthened process.
- Sun:* You just want to avoid complications or problems. If there's a risk, then people think it's better to completely eliminate the potential source of the problem.

Interviews with health advocates in the Russian community described the difficulty of convincing their clients that it is safe to apply for public health insurance.

- Clara:* Their immigration lawyers told them to cancel their health insurance before going to the interview in Federal Plaza, the interview for the green card. Even though I provide a copy of how it works, they prefer to cancel it.

- Sima: They know they can [get insurance] after they get their documents. They don't want to argue with the immigration department.*
- Clara: Getting their papers is more important than health [insurance].*

Despite the difficulty, advocates in the Russian community were apparently successful in their efforts to convince at least some community members that it is safe to use public health insurance; no one in either of the two Russian focus groups believed that using public health benefits would result in a public charge determination.

The concern over public charge not only affects whether people are willing to apply for public insurance, it also affects the choice of insurance among those that opt for it. Jane, a Korean facilitated enroller, explained that parents would rather enroll their children in Child Health Plus B,<sup>xv</sup> which requires them to pay a monthly fee, than for them to have free insurance through Medicaid (Child Health Plus A), because they feel that their children have less risk of being found to be public charge if the family pays something for their health insurance. She explained this in disbelief:

*It's interesting, but what's the difference when the child is enrolled in Child Health Plus or Medicaid? It's the same health insurance, but they are worried about when the child is enrolled in Medicaid...about "what if there's a problem when they're applying for a green card?" But Child Health Plus, they never, never worry. They want to apply for Child Health Plus rather than Medicaid... and pay the co-pay or whatever the money for Child Health Plus.*

### Sponsors' Financial Liability

Participants were very knowledgeable about the responsibility of the immigrants' sponsor, and the commitments of sponsors who sign the immigrant's affidavit of support. A participant in the focus group for Korean speakers who were over-income for public insurance explained the process as follows:

- Sun: The form states that you will be fully responsible for the person you're sponsoring. That is the condition, and you sign your name acknowledging it. If you or the person you're sponsoring use federal money to pay for the medical bill, and they somehow put*

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<sup>xv</sup> Child Health Plus B (CHP B) is a State expansion program offering subsidized public insurance to children under 19 years of age in families earning up to 400% of the federal poverty level (FPL). Families pay low monthly fees if their earnings are between 160% and 400% of the FPL, and can buy in at the full, group-rated monthly premium if their earnings are higher. Children who are undocumented and meet the income guidelines are also eligible for CHP B, making New York a state that offers near universal coverage for residents under 19 years of age.

*the two [pieces of] information together and decide to charge you... what can you say?*

*Moderator: What would you say?*

*Sun: I don't think I can say anything. That would just be horrible.*

Russians who were eligible for public insurance but uninsured expressed similar concerns. When asked if a sponsor should worry about repaying the medical expenses of those they sponsor, everyone believed that the sponsor might be responsible for paying medical bills. In subsequent interviews, two Russian facilitated enrollers explained the situation as follows.

*Sima: They are always scared. The persons who signed the affidavit of support are always scared that the person who came here is not eligible for insurance, especially old people, parents. Or the children always call me and ask about the situation.*

*Interviewer: The situation is when the kids are afraid to enroll their parents because they may have to pay?*

*Clara: Yes, because they are the ones that signed the affidavit of support. And parents [who immigrate] come to my organization for consultation, asking if they can get health insurance because they are worried about their [children having to pay].*

Charles, a health advocate for an organization serving the Haitian community explained:

*Usually the person who is providing support is the one that feels uncomfortable with all the questions [regarding support for immigrants and health insurance].*

Yasmine, a Medicaid Managed Care enroller, told how sponsors' fear about repaying the government the cost of immigrants' health care deters the family from getting needed health care services.

*I know a guy who is Spanish, and his wife is Yemeni. Her mother had an emergency case. They were scared to take her to the hospital. He is a well educated guy, but he was nervous. I told him to trust me and to get Emergency Medicaid. He didn't trust me and so he went online to make sure it was true. She got [Emergency Medicaid] and was in the hospital for four days. It was kidney failure, so it was really serious... He was just so scared because he sponsored her.*

## Trusting the Government

Focus group participants indicated a generalized mistrust of the government, particularly its potential use of personal information and documentation shared on public insurance application forms. While hospitals, Medicaid offices, and health insurance plans do not share information with USCIS or other government agencies except to verify information, as needed, to determine eligibility for public coverage, concern persists. Participants were not able to identify a specific consequence of sharing their personal information. Instead, they expressed fear that something could happen either to their livelihood or their ability to remain in this country. Jane, a Korean facilitated enroller, believed that her clients would prefer employer-based or private coverage over public coverage, citing mistrust of how the government handles their personal information as the primary cause.

Several health advocates expressed their own uncertainty when trying to reassure clients about the safety of using public health insurance with regard to immigration-related consequences. Their concerns reflect larger issues surrounding the relationship between immigrants and the government. Yasmine, an enroller with a Medicaid Managed Care health plan and a former case worker within the Arab community, recalled the stress of the post-9/11 period when immigrants, particularly Arabs and South Asians, were forced to undergo the federal government's Special Registration program, and thousands were deported. When asked about whether she thought the government keeps information confidential, the insurance enroller responded:

*It's not that I'm afraid. I know, I do my job, and I know I provide them with the right information. I had training about this. But in the end, I don't know, maybe they will [report confidential information from health insurance applications to immigration]. The FBI? I don't have control.*

Salim, a South Asian health advocate, expressed a similar sentiment:

*They ask me, 'are you SURE? Can you guarantee that it won't happen?' And I'm like, 'well, I'm not an immigration lawyer.' So they don't believe you... I personally don't feel very confident [telling them it's safe to use public benefits]. I mean, I let them know that technically it's not going to happen, but... I just wonder. Even today, I was like, 'yeah, they're not supposed to do it, but then they end up doing things that they aren't supposed to do...' So I usually say there's no hundred percent guarantee for anything. But we have never heard about anyone being arrested or denied for [using health insurance].*

The fear of being reported to immigration or deported is shared by legal and undocumented immigrants alike, but is heightened for the undocumented population. Kathleen, a facilitated enroller who works on Staten Island, explained, "If you're here illegally, you are always afraid

*that someone is going to be turning you in and you will be shipped back. There needs to be trust, and there is an inherent distrust with the government.”* Issues around trust are expressed generally, and not specific to the health care encounter.

Liz, a participant in the focus group with Koreans who are over-income for public insurance, expressed her belief that health should come before immigration status concerns:

*A long time ago, I read an article in the paper that certain individuals, who were afraid that their undocumented status would be exposed did not go to the hospital, and some actually died as a result. They should have just gone to the hospital. If they get kicked out of this country, fine—so be it. Even if that is the consequence, life takes precedence.*

### Language, Culture, and Navigating the Health Care System

Many immigrants lack the linguistic skills, cultural knowledge, and general experience to help them navigate the health care system on their own. As demonstrated in the findings about public charge and sponsor liability, misinformation affects where immigrants seek health care and how they pay for it. The lack of English proficiency and unfamiliarity with the health care and health insurance system lead many immigrants to seek information and assistance from community-based organizations that serve immigrants in their language.

Yasmine, an enroller for a Medicaid Managed Care health insurance plan, recalled:

*We had a family from Yemen, they are here legally but they didn't speak the language, and they didn't know anything [about public health insurance eligibility]. They were here for seven months and she was pregnant—for seven months! Imagine, they are qualified!*

Rose, a health advocate with a Korean community-based organization had the following to say about why clients come to her:

*They need help. It's as simple as that. They don't have the confidence in their linguistic ability and—it sounds like a cliché at this point—but navigating the health care system in the U.S., even if you are proficient and fluent in English, is such a damn hard thing to do, excuse my language.*

Her colleague Jane describes herself as part accountant, part immigration counselor, and part enrollment specialist because of the complex problem-solving that she employs when helping her clients. She explains:

*There are a lot of job requirements for me besides the normal part... like problem-solving on everything related to the health insurance program, like choosing doctors, how do I use the insurance...even if I already explained it to them, how do I use this card, what is the effective date, what is the expiration date, which doctor accepts this health plan, and letters from HRA [Human Resources Administration, which administers public benefits in New York City], letters from the health plan, they just come, bringing me the letters and ask 'what is this?'*

By educating immigrant communities about the health care and insurance in their own language, community-based advocates are able to address general concerns that immigrants share with the general population.

## Comparisons Based on Eligibility for Public Insurance

### Eligible but Uninsured

In addition to the immigrant-specific concerns such as public charge, sponsor liability, and language barriers detailed above, immigrants who were eligible for public insurance but uninsured faced administrative challenges to enrolling in public health insurance. In order to apply for public health insurance, applicants must provide documentation of their identity, income, place of residence, and immigration status. There are many other particularities to documentation that make fulfillment of such requirements difficult.<sup>xvi</sup> However, for the purposes of this paper, we focus only on documenting income and immigration status.

#### *Income:*

A major challenge for many applicants, but particularly for immigrants, is providing documentation of income. New York State's Medicaid program accepts pay stubs, tax returns, and letters from an employer, but many immigrants who lack work authorization and are working "off the books" have problems providing any of the above. The state also, in theory, allows for the self-attestation of income with a form called the "declaration of income," as a last resort in limited cases. However, nearly all of the enrollers and health advocates interviewed have the perception that applications submitted with a declaration of income are routinely denied by the Medicaid program. This policy results in citizen children being unable to enroll in affordable health coverage if one of their parents works without being authorized. Nationally, more than four million citizen children live in this type of household.

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<sup>xvi</sup> For example, when documenting proof of residence, one facilitated enroller pointed out that HRA (Human Resources Administration—the New York City agency that administers the public health insurance programs) does not accept utility bills without the zip code printed on it. Con Edison electrical bills only print the zip code on the payment slip, and not the part retained by the resident.

Yasmine, the Medicaid Managed Care enroller, explained:

*We're talking about immigrants. What do they do? Work for a store owner, restaurant, construction, in the streets selling flowers. They don't have an 'employer.' We have this problem when we have to report their income. We don't want to use the declaration of income because the state doesn't like it. [They want] pay stubs, tax returns.*

Jane, a facilitated enroller serving the Korean community, described the difficulty of explaining the income documentation to self-employed business owners.

*I don't say, 'please bring the pay stub.' I cannot say it, because they don't know what the pay stub is. There are a lot of Korean businesses; they already established the business, the corporation. They get the pay or wage from the corporation, and never get the pay stubs, because the corporation is so small, they never issue pay stubs.*

Jane explained that she received formal notice to avoid self-declaration of income from the agency the State contracts with to supervise insurance enrollment. Yet even those with employers may have trouble getting a letter:

*When the clients come to see me, I ask for the letter from the employers. Some clients, but not that many, say 'my employer doesn't want to write me a letter.' Then I just ask them again, saying, 'it's much better for you to provide a letter from your employer instead of self-declaration of income.' At first, they hesitate, but they try and they get the letter<sup>xvii</sup>.*

Enrollers at a Russian community-based organization described the same problem, and some efforts to encourage immigrants to bring letters from their employer. In contrast, Gaela, a health advocate with a community-based organization serving people from the Balkans, reported that her clients are not having a problem when applying for insurance using a self-declaration of income. She explains:

*They are babysitters, janitors, or in building maintenance. I don't have someone who works off the books and makes a lot of money.*

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<sup>xvii</sup> It is not always possible for individuals working off the books to receive letters from their employers. First, many day laborers frequently change employers, and second, many immigrants would not be allowed to continue working if they approached their employer seeking a written declaration that the employer is violating labor laws by paying an individual who is not authorized to work.

Contrasting reports by different enrollers about the acceptability of self-attestation as proof of income for public insurance indicates that there is an inconsistent application of state policy.

*Immigration Status:*

While participants were acutely aware that undocumented immigrants are not eligible for public insurance, they are not always aware of the categories of immigrants that are eligible. As described in the background, New York State extends public health insurance eligibility to a broad range of immigrants, including lawfully residing adults and almost all children. However, participants tended to assume they are not eligible. For example, Rosa, a Mexican lawful permanent resident in her forties who has lived in this country for over fifteen years, plainly admitted:

*This is the first time that I've heard that immigrants could get health insurance, but before I didn't know you could apply.*

Enrollers and health advocates interviewed admit that a large share of their work involves explaining immigrant eligibility to their clients. Public insurance rules regarding income eligibility and immigration status change regularly, and advocates must educate their community members about these changes. An example includes a recent change to immigration status eligibility for Child Health Plus.

Participants noted the dismay of parents upon learning that though once covered, children holding non-immigrant visas have recently been barred from Child Health Plus in New York City. Non-immigrant visa holders include students, workers, tourists, and religious workers, and there are penalties for re-entry into the United States or adjustment of status if the terms of these visas are violated, for example by overstaying their designated time limits. Though the policy to prohibit non-immigrant visa holders from Child Health Plus is not new, it seems that its enforcement has become noticeably stricter in the past two years. Simultaneously, stricter enforcement of immigration laws in the U.S. has led more immigrants to choose to retain some form of a legal non-immigrant visa status, if possible, rather than become an undocumented immigrant. Participants noted the irony that children of immigrants who are here lawfully on non-immigrant visas are not eligible for state children's health insurance, whereas undocumented children are. This example demonstrates the complexity of understanding eligibility for public insurance based on immigration status.

**Ineligible: Over-Income**

Among those with incomes too high for public health insurance, there is an acute awareness of the income eligibility restrictions. For example, in the focus group for uninsured Russian individuals who are over the income limit for public insurance, Boris explained his insurance situation with expert precision:

*I don't have insurance because my gross family income [per month] is \$1,230; in order to be eligible [for subsidized public insurance] it has to be no more than \$1,167. I have never had health insurance.*

Gaela, a health advocate from a CBO serving people from the Balkans described the desire her clients have for affordable health insurance:

*I have clients repeatedly coming to me, wondering if they can qualify now. They'll ask me, 'I have no savings, can I now?' People are very close, but for various reasons can't qualify. And now [due to the economic crisis], they're calling a lot: 'I won't have any savings in a month—can I qualify now.'*

Immigrant participants whose income is too high to qualify for New York State's subsidized public insurance expressed a sense of injustice, because they contribute taxes without receiving important government benefits like health insurance. Many lack access to employer-sponsored health insurance, but prohibitive costs make it impossible to purchase private insurance. Jihyun, a Korean medical student in New York City, had strong feelings about the contradictions in government policy:

*I am still angry. I look at my parents, who work hard and long hours. They strive hard to make a decent living so that my sister and I can move up the social ladder without restrictions. They don't have coverage. If you can afford to pay four to five hundred dollars for your health coverage, who wouldn't? I asked my dad what his blood pressure was recently... He's stage two hypertensive. He tries to limit his salt intake... He's not taking medication because he can't afford it... It's sad how I see the overmedication of patients at the hospital while my dad and mom who've worked so hard all of their lives can't even afford basic health care.*

Concern over the cost of health insurance does not just apply to individuals with low incomes. Several enrollers and health advocates noted that middle-class people would rather have their children use the government-subsidized Child Health Plus program than private health insurance, because of the high cost of private coverage. Though Child Health Plus is available to all children in New York regardless of family income, health advocates criticize a state policy that requires children to go without health insurance for six months when they switch from private insurance to Child Health Plus. The State's policy is intended to prevent "crowd out"—people choosing public coverage when they have a private coverage option. This policy affects citizens

as well as immigrant children, and enrollers cite it as a deterrent to parents enrolling their children in affordable public insurance programs.<sup>xviii</sup>

The recent economic crisis and job loss have expanded the number of uninsured individuals. Middle-class individuals who have always had health insurance are suddenly finding themselves without any health coverage and forced to consider the often insurmountably high cost of health insurance on the individual private market. By collecting unemployment benefits in New York State (maximum benefit of \$400/week), some adults are over the income limit for Medicaid. This study's Russian participants were the most experienced with employer-based coverage, and several recently unemployed individuals participated in the focus group for those over income for public insurance.

One dramatic story was of a recently unemployed Russian couple expecting their first child. The expectant mother called on Sima, a community-based facilitated enroller, panic stricken over how she would be able to afford having a child with no insurance. Pointing to the income eligibility chart for the state's Prenatal Care Assistance Program (PCAP), Sima explained:

*Together they get \$3,100 [in unemployment]. See the limit? Pregnant women—\$2,900 for the person who is pregnant and the child. They don't see it. You know what she told me, 'I am going to the Medicaid office.' [I told her], 'Please don't scream, think about the child'. [I spent] maybe 30 minutes over the phone to calm her down. She said, "Trust me, I am going to the Medicaid office, laying on the floor, and not moving until they give me insurance."*

Yasmine, an enroller with a Medicaid Managed Care health plan, explained the current economic situation and its impact on her clients as follows:

*Today is a different story, because many people lost their jobs. Part of my job is to receive phone calls, we are part of a call center and people call us to find out information on how to apply and the requirements. You hear it every single day, more than 10 times a day, "I lost my job". They are collecting unemployment. If they're single and make \$900 or less, they will be qualified [for subsidized public health insurance]. If more than \$900 a month, not... We refer them to Healthy New York [The monthly Healthy New York premium is] \$240 per person. It's still not affordable.*

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<sup>xviii</sup> On June 11, 2008 the Obama Administration agreed to allow New York State to add several exceptions to the six-month waiting period for families who drop employer coverage to enroll their children in Child Health Plus. Two of particular interest are: children under age five and children in families for which the cost of the child's private coverage exceeds 5 percent of a family's income.

Nancy, a Latina facilitated enroller on Staten Island, expressed her sympathy with members in her community who have lost their jobs:

*They are devastated; they don't know what to do either. It's so bad. I feel bad for them too. This person worked all their life, and here she is getting unemployment and this person cannot be eligible for health insurance. How could she afford to pay insurance, \$500 [per month]—you can't!*

### Ineligible: Due to Immigration Status

Not surprisingly, people without lawful immigration status face the greatest challenges to seeking health care and health insurance. Undocumented immigrants tend to avoid medical care due to concerns about cost, but also because they fear potential immigration consequences. There was a general assumption among immigrants who participated in the focus groups that without a Social Security number, a person could not receive public health insurance. Though this is not always the case,<sup>xix</sup> the impression persists. Further, participants generally and correctly understood that the undocumented cannot receive Medicaid or other public health insurance. Among participants in the focus group for undocumented immigrants, there was the correct understanding that undocumented immigrants could receive Emergency Medicaid and the Prenatal Care Assistance Program, and that undocumented children could enroll in Child Health Plus.

As stated earlier, the focus group with undocumented immigrants revealed concerns about the quality of care, discrimination, and cost. Silvette, a Mexican woman living on Staten Island, described the delivery of her child at a local hospital as follows:

*I remember telling the nurses that I was in pain, ready to go into labor, and they wouldn't pay attention to me. I was treated badly by the nurses. Finally, my husband, through his boss, found someone that worked at the hospital. So when that person called, all the nurses started to be nice to me. [But] I felt discriminated [against].*

Salim, a South Asian health advocate, explained the situation facing his undocumented and uninsured clients as follows:

*They think [health insurance] is going to cost too much. They don't have money and if they're undocumented and they're working here, it's not fun. They're*

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<sup>xix</sup> For those with the appropriate immigration status but no social security number, a letter attesting that they have tried to apply for a social security card and are not eligible for one at this point may be submitted instead of the social security number. Social security numbers are also not required for Emergency Medicaid, PCAP, and Child Health Plus B.

*working, and they're supporting families back home... And if you're earning only sixteen hundred dollars a month, you're working full time, less than minimum wage—and your medicine is going to cost a lot... because you find out how much it costs... and then you just stop it, you're like, 'I'm not able to afford it.'*

## *Immigrant Priorities for Health Care Reform*

### *Affordability*

Immigrants who participated in this study are overwhelmingly interested in health insurance, and their primary concern about enrollment is cost. Participants in the focus groups overwhelmingly expressed a willingness and desire to pay a fair share and obtain health insurance. They believe that people should pay an amount to obtain coverage based on their income, and that everyone should be able to pay for a plan that they can afford.<sup>xx</sup> For many people, affordable health care means government subsidized public health insurance. The participants in the Korean and Russian focus groups were very enthusiastic about government health insurance. They did not believe that it had to be free, but did feel that public coverage had to be priced at a level that people can afford to pay.

Jae, a participant in the focus group for Koreans who were eligible for public insurance but not insured, shared this view:

*If an individual can pay for a certain percentage of his or her medical expenses, with the government funding the rest, the system would be sustainable. Everyone pays his or her due. Mutual responsibility. In Korea, all the medical expenses are paid for those who are considered to be of low income. If you make more, then you pay accordingly. It's both reasonable and practical to share the cost. Here, if you don't make the cut, you're left with nothing. How is that fair? You can't stop working just to maintain your health coverage. The government should adjust the bar, instead of setting a limit and cutting people off when they rise above the poverty line. That's not very encouraging for those who are striving to make a better living for themselves and their families.*

Among Russian speakers in both the eligible but uninsured and the over-income focus groups, all were in favor of affordable, but not necessarily free, government health insurance. Boris elaborated on the idea:

*“Health insurance has to cover the basics, and everyone can buy extra coverage.”*

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<sup>xx</sup> Participants were not asked to define “affordable” health insurance.

Two enrollers with a Russian community-based organization described wanting to see a public health insurance program like Child Health Plus for adults. They believe that their clients have been waiting for a product that would allow people who are over-income for free insurance to buy into a form of comprehensive public insurance, at an affordable rate. Sima explained:

*\$1, \$2, \$20 [of income above the eligibility limit] and they are not eligible. It's impossible! If the person wanted to pay some money, not much, but \$30, \$50, even \$100 – it will be helpful. It's not for free, there's money.*

Significantly, other enrollers, including those serving the Spanish, Haitian, Balkan, Arab, and South Asian communities agreed on this point.

### Mandates

Participants were not opposed to mandates for health insurance, as long as the insurance is affordable and of sufficient quality. Some participants in the focus groups confused mandates with a guaranteed right to health insurance, which they enthusiastically embraced. Most believed that making health insurance mandatory was redundant, since it was something that everyone wanted, if they could only afford it.

One enroller, Yasmine, pointed out that her clients are very law-abiding, and would be more inclined to buy insurance if it was mandated than if not. She explained:

*Through my experience, when they come here, they really follow the rules. If this is from the government, they would do it. I know that sometimes people don't like to send their daughters to school but they do because it's the law. They have to do it, they have no choice.*

### Quality

Some participants believed that private- and employer-based insurance were better quality and preferable to government insurance. Yasmine, a Medicaid Managed Care health plan enroller, believed that her clients would prefer private insurance because it is perceived as better quality, but then stated frankly, “but we have to be realistic, they cannot afford it.”

There was consensus that the priority is for everyone to have access to basic, comprehensive health care that is affordable.

### Streamlined Enrollment

Finally, beyond the affordability of health insurance, participants in this study pleaded for simplification of the process of applying for public health insurance. Russian participants, some

of whom had formerly been enrolled in public insurance, offered suggestions to improve the current system:

- Anfisa: An application has to be simple and [the eligibility determination] prompt.*
- Vera: The application process should take no longer than 1 hour and an applicant should get an insurance card in 3 days.*
- Darya: Not 3 months.*
- Eva: We have been waiting 5 months already.*
- Tara: Detailed and easily accessible information about health insurance has to be provided.*

Jane, the Korean facilitated enroller, described public insurance enrollment policies that add unnecessary bureaucratic layers to an already difficult application process. For example, even though Social Security Numbers (SSNs) are not technically required to apply for public health insurance, an applicant without an SSN must submit a letter from the Social Security Administration stating that it will not issue an SSN before the individual's application for public health insurance will be processed by the State. This requires a visit to a government office to request something for which the applicant is ineligible and will assuredly be denied, then submitting proof of that denial along with the application for the public insurance for which they are still eligible. She summed up the situation as follows:

*This is no longer facilitated enrollment, because facilitated enrollment is supposed to make it easier for the clients to get the documents. Right now, it's much harder. This is no longer 'facilitated'.*

Inadequately supervised insurance enrollers can also be a problem. Some enrollers ask undocumented immigrants to prove that they are undocumented in order to apply for a limited range of programs, including Emergency Medicaid, Child Health Plus, and PCAP. However, as Jane incredulously explained: “*There is no proof of being undocumented. [They say] 'You are undocumented, so submit the undocumented documents.' It's insulting.*”

### Enrollment Assistance

Enrollers interviewed in this study were adamant about the benefit and necessity of enrollment assistance in order to simplify the process and make it as efficient as possible. While it may seem self-interested, Kathleen, an enroller on Staten Island, explained:

*The advantage of face-to-face [enrollment assistance] is that there is so much to go over that the enrollers can say “do you have anything of –” and give specific examples to prevent problems like not being aware of resources that will be*

*counted against [insurance applicants]. I think the face-to-face [assistance] really helps in not as many people being rejected because they didn't include the correct documentation or they didn't answer the question properly. So I think it helps people get insurance, and I think that's what the whole facilitated enroller program was probably designed to do.*

Though New York State plans to eliminate the face-to-face interview requirement in 2010, according to some enrollers and advocates interviewed in the study, CBO facilitated enrollment in public health insurance offers a chance to provide more comprehensive social services to low-income and vulnerable clients. Going beyond the limited services of a Medicaid office, enrollers at Russian CBO have the opportunity to address other needs, and to offer their services in a friendly, and culturally and linguistically appropriate manner.

*Clara: When they come here, we can identify very difficult cases like domestic violence. They really need it because we serve the same population. We have mutual clients: Single Stop, DV [domestic violence], health enrollment, social services, seniors, teen departments. Comprehensive services.*

*Sima: We work together as a team.*

*Clara: We have a relationship with clients and their family and their history... Especially during this time when we need to help people. They are so in need of social services, counseling.*

Focus group participants were quick to acknowledge that they rely on community-based organizations as resources for information about health care and health insurance; however, this may in part represent a recruitment bias since most study participants were clients of such organizations.

## IV. Issues to Consider

The findings of this study indicate that immigrants are eager to enroll in health insurance that is affordable and provides access to good doctors, and are willing to pay their fair share for health insurance. The study also illustrates how the enrollment assistance provided by community-based organizations can positively impact immigrants' willingness and ability to enroll in insurance coverage. Our findings raise some issues to consider that are specific to immigrant populations, as well as some that overlap with concerns of the general population.

### **1. Proactively address immigrants' concerns about the potential consequences of enrolling in public health insurance.**

*This research reveals that immigrants hold misperceptions about the consequences of using public health insurance, particularly with regard to public charge and sponsor liability. These two issues raise major concerns for immigrants because they relate to the pursuit of lawful permanent resident status and the financial well-being of their sponsors. Income and immigration status requirements are also not well understood. Public education for immigrants, lawyers, health enrollers and advocates about eligibility requirements and the safety of using public health insurance benefits could improve enrollment of immigrants in existing coverage options. To be most effective, USCIS and New York State should participate in public service announcements, and issue information about immigrants' eligibility for health insurance that is clear and consistent.*

### **2. Promote linguistically and culturally appropriate communication throughout insurance systems, including at enrollment and renewal of coverage.**

*Participants indicated that language barriers persist despite federal, state, and local laws requiring the provision of language assistance service to limited-English proficient individuals seeking public benefits such as Medicaid. The state should develop a system that would translate public notices and benefits materials, staff information and complaint lines in multiple languages, identify promising practices, develop interpreter standards and credentialing, support interpreter training, and make funding for interpretation services available through the Medicaid program.*

### **3. Increase resources for community-based health advocates who help immigrants navigate the health insurance and health care system.**

*This research speaks to the invaluable position of health advocates within immigrant communities. They help bridge the information gap between newcomers and the complex system of health care and insurance. By serving as interpreters not only linguistically but also culturally, they facilitate the transition of immigrants to their new homes, providing*

*them with accurate information that can make them and their families more healthy and productive. Ongoing funding for community-based health advocates and facilitated enrollers is critical to ensure the continuation and expansion of services to meet the demand of ongoing migration to New York.*

**4. Educate the public about coverage options, including the exemptions from Child Health Plus' six-month waiting period when transferring from private insurance.**

*As the economic crisis and recession continues, and possible federal health reforms are implemented, more people are in need of information on how to enroll in and maintain affordable health coverage. Options may include continuing employer-based coverage through COBRA, purchasing private insurance through the individual market or a new "Connector" or "Exchange" entity, should it be established, enrolling in a form of public insurance, or utilizing hospital-based financial assistance when seeking health care. One affordable option is for families to switch their children from private coverage to public coverage. Recognizing the concern many parents have with the requirement to leave their child uninsured for six months before switching, the State requested and received an exemption of this waiting period from the Centers for Medicare and Medicaid and Services. Children under age 5 and those in families that pay more than 5% of their income for their child's health insurance may now enroll in public insurance without delay when switching from private insurance. Training of facilitated enrollers and community-based health advocates can help alleviate concerns regarding the waiting period and allow eligible families to switch more readily. Ongoing training of Medicaid program workers on income and immigration status eligibility is also important for maximizing public insurance enrollment during this time of record unemployment.*

**5. Simplify and reduce the documentation necessary to enroll in public health insurance and maintain coverage.**

*Though the state has enacted several measures to simplify public insurance enrollment, there continue to be challenges to providing documentation for the enrollment and renewal of public insurance, especially for immigrants. A particular challenge is the documentation of income requirement for those working in the cash economy. We recommend that in these instances, New York State continue to accept self-attestation of income, and issue clear guidance to facilitated enrollers that self-attestation is acceptable. Furthermore, we urge the state to eliminate documentation of income when a third-party match is available.*

**6. Create an affordable buy-in option for individuals and families for public health insurance.**

*Participants who do not meet income eligibility requirements for public insurance expressed an eagerness to pay a premium for this coverage, as long as it is affordable. They often*

*recommended a program like Child Health Plus for adults. For future insurance reform options, we recommend that the state allow adults to buy into coverage at an affordable rate. Options for purchasing subsidized public health insurance through private managed care companies are particularly important for New Yorkers who will be left out of federal health reform, i.e., undocumented immigrants and most non-immigrant visa holders.*

**7. Enhance consumer protections for private insurance plans with limited benefits and high cost sharing, and allow individuals to purchase full premium private health insurance regardless of immigration status.**

*While participants want health insurance and value such products, they have also had experience with unsatisfactory private health plans with limited coverage or high deductibles and copays. There should be more clarity and transparency when marketing plans with limited benefits and high cost sharing so that consumers are fully aware of the products purchased. Furthermore, restrictions on the purchase of full premium private insurance based on immigration status should be rejected to allow maximum opportunity to decrease the number of uninsured in New York State.*

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## Appendix A

2008* Family Health Plus/Resource Levels - Monthly										
Parents Living with Children Under 21 in their Household; 19-20 year olds living with parents								Adults Without Children Under 21 in Household, and 19-20 Year Old Living Alone		
Family Size	1	2	3	4	5	6	Each Add'l Person	Family Size	1	2
FHP** Limit	\$1300	\$1750	\$2200	\$2650	\$3100	\$3550	\$450	FHP Limit	\$867	\$1167
150% FPL								100% FPL		
Resource Level	\$13050	\$19200	\$19800	\$19950	\$20100	\$20400	\$2550	Resource Level	\$13050	\$19200

\*Recruitment for this study took place in 2008 following the 2008 Federal Poverty Level (FPL) for income eligibility for Medicaid. Therefore, we chose to show the 2008 guidelines here. Income guidelines change annually depending upon the FPL, and increased slightly in 2009.

\*\* FHP stands for Family Health Plus. Income eligibility for FHP is at 150% of the Federal Poverty Level. This level was chosen to allow for inclusion of those with the maximum allowable income for public coverage to participate in the study.