INSURING THE CHILDREN OF NEW YORK CITY'S LOW-INCOME FAMILIES

FOCUS GROUP FINDINGS ON BARRIERS TO ENROLLMENT IN MEDICAID AND CHILD HEALTH PLUS

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EXECUTIVE SUMMARY

Nearly 20 percent of children in New York City, or approximately 370,000 individuals under age 18, are uninsured—a proportion exceeding that for the nation and for New York State.[1] Uninsured children are more likely than those with health insurance to go without preventive care and immunizations, often lack primary care providers, and sometimes do not receive acute medical care when they need it.[2] Families of uninsured children are also at risk for incurring substantial medical bills should these children become ill.

The nation is poised to begin a massive expansion of insurance coverage for children in low-income households using newly available federal funds. New York State will use $256 million in annual Title XXI funds to further expand eligibility and benefits for Medicaid and Child Health Plus (CHP)—the state's insurance program for low-income children who do not meet Medicaid's eligibility requirements. These program expansions will ultimately reach families with incomes up to 250 percent of the federal poverty line ($41,059 per year for a family of four).

For these expansions to succeed, overcoming enrollment barriers and implementing effective outreach strategies will be crucial. The vast majority of uninsured children in New York—nearly three of four—are eligible for but are not enrolled in either Medicaid or CHP. The problem of lack of insurance among the city's children could be largely eliminated if all of those eligible were enrolled in these programs.

To gauge awareness of Medicaid and CHP, understand why so many eligible families are not participating in these programs, and inform efforts to increase participation, the Global Strategy Group, Inc., supported by The Commonwealth Fund, conducted seven focus groups with parents in August and September 1998 of children in families that are eligible for or participating in one of the programs. To gain multiple perspectives on why eligible children remain uninsured, Global Strategy supplemented these focus groups with two additional groups: one comprising Medicaid and CHP eligibility workers and one comprising community-based organization workers. Each of the focus groups comprised approximately 10 individuals and lasted about two hours. Global Strategy also conducted interviews with executives of six health plans that participate in Medicaid and CHP.

The focus groups revealed that low-income parents struggle to meet the health care needs of their children. Parents with household incomes below 250 percent of poverty often cannot afford the costs of private health insurance or of medical care for their children. As a

[1] Tabulations by New York State Department of Health of *Current Population Survey*, U.S. Bureau of the Census, March 1994–March 1997.

[2] Cathy Schoen and Catherine DesRoches, *New York City's Children: Uninsured and at Risk*, The Commonwealth Fund, May 1998.

result, these parents sometimes do not get their children the preventive and primary care they need and delay seeking medical care when they are seriously ill. They sometimes take their children to emergency rooms for routine care, yet these facilities can often be as expensive as private physicians' offices.

Obtaining health insurance for their children is a high priority for low-income parents. They want to participate in Medicaid and CHP if they qualify and are eager to enroll their children given the opportunity. They are often unaware of the eligibility criteria for Medicaid and CHP, however, and encounter substantial barriers to participation.

Many choose not to attempt enrolling their children because they incorrectly assume that employment disqualifies them. Enrollees and potential enrollees lack understanding of how factors such as income, family size, assets, and child care expenses interact to make some families eligible and others ineligible, and they suspect that rules are applied arbitrarily. Parents also suspect that program administrators attempt to disqualify families whenever possible.

Familiarity with other public assistance programs often has a great deal to do with parents' awareness and knowledge about the Medicaid and CHP programs. Those who are not seeking welfare or other public assistance are especially unlikely to be aware that children's health insurance is available. Welfare reform efforts exacerbate this problem by potentially isolating more eligible families from information about Medicaid and CHP and also contribute to confusion about insurance eligibility.

Medicaid is relatively well-known among low-income parents. In contrast, CHP was virtually unheard of in the parents' focus groups. Eligibility workers confirmed that families are rarely referred to CHP.

Parents whose children are on Medicaid view the program as useful, cost-free, and comprehensive. CHP is also viewed very favorably by parents whose children are enrolled in it; they say the enrollment process is relatively easy and the program offers good access to quality health care. CHP participants are therefore potential ambassadors for the program: upon hearing reviews of CHP by parents whose children are enrolled, other parents take a keen interest in joining the program.

On the other hand, the Medicaid enrollment process is perceived as time-consuming, burdensome, and requiring a great deal of persistence and patience. Gathering the necessary documentation is a lengthy process in and of itself. Once the required materials have been submitted, the interview process often requires a full day. Many low-income workers are

nonsalaried, and the daylong application process and face-to-face interview for Medicaid eligibility is a financial hardship.

Parents say that enrollment is also demeaning, and their interactions with eligibility workers are often confrontational and uninformative. Applicants frequently perceive questions as unnecessarily prying into their personal lives, and view workers as uninformed, unconcerned, rude, and actively discouraging enrollment. Some parents have experienced hostility firsthand, while others have been jaded by the experiences of other parents. They also believe that eligibility workers play favorites and that factors such as physical appearance make a difference in whether someone is certified as eligible.

In addition to these issues, the systems designed to facilitate enrollment in Medicaid and CHP do not always work. Many parents of uninsured children report that their attempts to seek coverage have been limited to calling information hotlines, yet these hotlines are often automated and have no option to speak to a live individual, keep callers on hold for long periods, and provide misleading information.

Immigrant families often face additional difficulties such as language and cultural barriers. Enrollment workers report that they are sometimes unable to communicate with immigrant parents and are sometimes forced to complete paperwork for those who are illiterate.

To reduce the number of uninsured children in New York City, intensive efforts are needed to reach the parents of those who are eligible for Medicaid and CHP and to assist them in enrolling in these programs. Parents list schools, workplaces, local community centers, doctors' offices, and public benefits agencies as the best places to receive information. Direct mail is also an effective tool for reaching households.

While educational materials can help clarify eligibility rules and inform parents about the enrollment process, parents and eligibility workers indicate that information campaigns by themselves are not sufficient to boost enrollment of eligible children. Parents require one-on-one assistance to gather documentation, complete enrollment forms, file applications, and ensure timely and accurate processing of their applications.

Structural improvements are also needed to facilitate the enrollment of eligible children in Medicaid and CHP. Strategies could include eliminating Medicaid's requirement of a face-to-face interview, deputizing community-based organizations to conduct face-to-face interviews and assist families with the application process, shortening application forms, reducing documentation requirements, providing educational materials in multiple languages, staffing telephone hotlines with live operators, and extending office hours to evening and

weekends. Government agencies that administer Medicaid and CHP must also become more responsive to low-income families and foster a culture that treats applicants with dignity.

New York, and the nation, have an unprecedented opportunity to provide health insurance coverage and access to health care for virtually all low-income children. New York's longstanding commitment to the health of its low-income residents continues through expansion of the Medicaid and CHP programs. Effective outreach and enrollment efforts must be made a priority to fulfill the vision of health insurance for more of New York's children.

INSURING THE CHILDREN OF NEW YORK CITY'S LOW-INCOME FAMILIES: FOCUS GROUP FINDINGS ON BARRIERS TO ENROLLMENT IN MEDICAID AND CHILD HEALTH PLUS

INTRODUCTION

Nearly 20 percent of children in New York City, or approximately 370,000 individuals under age 18, are uninsured—a proportion exceeding that for the nation and for New York State.[3] Uninsured children are more likely than those with health insurance to go without preventive care and immunizations, often lack primary care providers, and sometimes do not receive acute medical care when they need it.[4] Families of uninsured children are also at risk for incurring substantial medical bills should these children become ill.

The nation is poised to begin a massive expansion of insurance coverage for children in low-income households using newly available federal funds. New York State will use $256 million in annual Title XXI funds to further expand eligibility and benefits for Medicaid and Child Health Plus (CHP)—the state's insurance program for low-income children who do not meet Medicaid's eligibility requirements. Beginning January 1, 1999, subsidized insurance under CHP will be available to families with gross incomes up to 230 percent of the federal poverty line, or $37,901 annually for a family of four. Effective July 1, 2000, eligibility for subsidized CHP coverage will be extended to families with gross incomes up to 250 percent of the federal poverty level, or $41,059 per year for a family of four. Similarly, eligibility for Medicaid coverage will ultimately be expanded so that children from 1 to 19 years of age will be eligible if their families' net household incomes are below 133 percent of the federal poverty line, or $22,020 for a family of four.

For these expansions to succeed, overcoming enrollment barriers and implementing effective outreach strategies will be crucial. The vast majority of uninsured children in New York are already eligible for public coverage. Nearly three of four uninsured children in New York City are currently eligible for but not enrolled in either Medicaid or CHP. Approximately 130,000 children are eligible for Medicaid but are not enrolled, and another 147,000 children are eligible for CHP but are not enrolled.[5] Lack of insurance among the city's children could be largely eliminated if all of those eligible were enrolled in these programs.

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[3] Tabulations by New York State Department of Health of *Current Population Survey*, U.S. Bureau of the Census, March 1994–March 1997.

[4] Cathy Schoen and Catherine DesRoches, *New York City's Children: Uninsured and at Risk*, The Commonwealth Fund, May 1998.

[5] U.S. Bureau of the Census, March 1994–March 1997.

To gauge perceptions of these programs and understand the barriers to participation, The Commonwealth Fund supported Peter Feld, Ph.D., of the Global Strategy Group, Inc., to conduct focus groups in August and September 1998 with low-income parents and eligibility workers and interviews with health plan administrators. The focus groups examined the enrollment processes for these programs and identified administrative, cultural, and other factors that may prevent eligible families from participating. This research project was designed to inform efforts to increase participation of eligible but uninsured families with children in Medicaid and CHP.

Key Research Questions

The questions the researchers sought to answer through the focus groups included:

- What are the experiences of New York City's low-income families in obtaining health insurance and health care for their children?
- What are the current levels of awareness and attitudes toward Medicaid and CHP?
- Why are children who are eligible for Medicaid and CHP not enrolled?
- Among parents with children enrolled in these programs, what has facilitated their participation?
- What are the points of satisfaction with and criticisms of the enrollment processes for Medicaid and CHP among those who are enrolled and those who are not enrolled, as well as among the professionals who assist these families?
- What strategies would increase awareness of Medicaid and CHP, improve outreach, facilitate the enrollment of more children, and maintain continuous enrollment?

Methodology

To satisfy these research goals, qualitative research methodology was implemented. Qualitative research is an inductive means of understanding the attitudes, perceptions, and experiences of individuals or a group. It also allows for the observation of people from their own frame of reference. Qualitative research is not intended to yield statistically reliable findings.

Nine focus groups were conducted from August 12, 1998, to September 16, 1998. Seven of these group discussions were conducted with parents in low-income households—that is, in households with incomes below 250 percent of the federal poverty level, or $41,059 per year for a family of four. At this income level, children are already eligible or will be eligible for coverage under Medicaid or CHP. Participants were recruited from samples of low-income families throughout the five boroughs of New York City, and through informal contacts with city agencies, private organizations, and community-based medical providers.

Focus Group	Description
1.	White, non-enrolled, without health insurance
2.	White, CHP/Medicaid enrolled
3.	African American, non-enrolled, without health insurance
4.	African American, CHP/Medicaid enrolled
5.	Spanish-speaking, non-enrolled, without health insurance
6.	Spanish-speaking, CHP/Medicaid enrolled
7.	Chinese-speaking, non-enrolled, without health insurance
8.	Human Resources Administration eligibility workers
9.	Community-based organization eligibility workers

The parent group discussions were structured to reflect the diverse population of New York City. Additionally, efforts were made to keep similar populations together—ethnicity and language, for example, were taken into consideration to facilitate discussion. The parent groups were also organized by coverage status (i.e., enrolled or non-enrolled). Specifically, the family group discussions included:

- Parents with children enrolled in either Medicaid or CHP. Participants were chosen from white, African American, and Spanish-speaking families.

- Parents who lack insurance but whose incomes and family size would make their children eligible for either Medicaid or CHP. Participants were chosen from white, African American, Spanish-speaking, and Chinese-speaking families.

Two additional focus groups were conducted with Medicaid and CHP eligibility workers. One group consisted of Medicaid eligibility workers who are employees of the New York City Human Resources Administration (HRA). The other comprised eligibility workers who are employees of community-based organizations (CBOs).

All nine focus groups were conducted in New York City by Global Strategy Group, Inc.,[6] a private research firm, in collaboration with staff from The Commonwealth Fund.

[6] An independent moderator from the Chinese community in New York City conducted the Chinese focus group.

Each focus group comprised approximately 10 individuals and discussions lasted about two hours.

In addition to the nine focus groups, Global Strategy conducted six in-depth interviews with administrators of health plans that participate in Medicaid and CHP. These interviews supplemented the focus group research findings.

FOCUS GROUP AND INTERVIEW FINDINGS

HEALTH CARE EXPERIENCES OF LOW-INCOME FAMILIES IN NEW YORK CITY

Low-income families in New York City often find obtaining health care coverage a challenge. The costs of medical care and insurance are often unaffordable for these families, and many work for employers who do not provide sufficient insurance benefits. Often, they must choose between paying for health insurance or other bills such as rent and food. Even with employer assistance, low-income families who have insurance find paying a monthly deductible difficult.

> *"Insurance, for my husband, just for him, from his job alone would be like $200 or something a month. For a family of four, it was, like, almost $400. We can't afford that." [white, non-enrolled]*

> *"The coverage that I got from the city was practically free, but working in the private industry is different, because you have to pay for everything. And the coverage is very expensive.... I ended up not really getting it because I couldn't afford to pay." [African American, non-enrolled]*

> *"To buy insurance costs over $4,000 a year. Each quarter we'll be charged over $1,000, but we have other expenses—putting food on the table. So the money I earn, after buying insurance—we'll have only a little left. So we do not really want to buy it. But if we do not buy it, we become worried. If we buy it, we will have no money left." [Chinese, non-enrolled]*

> *"In the job, they offered something to my husband. But they said, since we're a big family, the cost comes up to $400 a month. We just can't afford that." [Spanish-speaking, non-enrolled]*

> *"If the income is small, for example, $40,000, $50,000, the company mostly has medical insurance to be covered by the boss. It is those who are stuck in the middle that the boss does not cover." [Chinese, non-enrolled]*

Employment-based coverage is often unstable or discontinuous for low-income families. Changes in jobs or reduced work hours can result in a loss of coverage despite past premium payments. As a result, low-wage families find that they cannot depend on having coverage when they need it.

"My job does not cover me or my children, because it is part-time." [Spanish-speaking, non-enrolled]

"I work in catering now and you just get paid per party or per event you work at, so there is no insurance, because I guess we are all freelance." [white, non-enrolled]

"It's temporary, no guarantee to be insured permanently, because if you do not have enough work credit you will be cancelled. Our factory has a union, we have union insurance." [Chinese, non-enrolled]

"Formerly I had a job, and I was covered. Now I only work part-time, so I prefer to pay for each visit to the doctor." [Spanish-speaking, non-enrolled]

Eligibility workers believe that many low-income families who could benefit from Medicaid and CHP are not enrolled. Eligibility workers note that families often wait until a medical crisis occurs before applying for benefits. In addition, immigrant families, regardless of their legal status, are often afraid to apply for the health insurance to which they are entitled.

"Plenty of eligible families are missing benefits." [CBO caseworker]

"We don't have membership as big as it should be because so many people lose Medicaid for various reasons. But maybe those rules and regulations need to be looked at. Maybe people don't come back and apply because they're intimidated." [plan administrator]

"Many will wait until it's a crisis before trying to get Medicaid." [CBO caseworker]

"Working people miss out most." [HRA eligibility worker]

Uninsured children are at high risk for going without needed primary and preventive care. Uninsured, low-income parents struggle to obtain health care and pay their medical bills when their children become sick. They stretch their resources as far as possible, yet they often delay seeking care, try home remedies, and hope their children will get well so that medical bills can be avoided.

"Better not to get sick— my child is so young—if something happened to him, I fear I would have no way to get special care for him." [Chinese, non-enrolled]

"I struggle, but I take my son to the doctor." [white, non-enrolled]

"I take my kids to the doctor when they are almost dying." [Spanish-speaking, non-enrolled]

"Very often I went to see the doctor only when we have a problem. Then they said, 'You need to make an appointment.' By the time I make an appointment and wait for over a month later, I'm well again. I have to pay other doctor. It's very expensive." [Chinese, non-enrolled]

"I just buy some medicine without going to the doctor." [Chinese, non-enrolled]

"Mostly we would go to see our own doctor and we pay out-of-pocket." [Chinese, non-enrolled]

"I think most of the people just hold their pain." [Spanish-speaking, enrolled]

Parents without medical coverage often rely on clinics and emergency rooms. Some visit private physicians on an as-needed basis, while others visit free public and community clinics or use home care agencies. Parents also use emergency rooms for routine and preventive care, yet this health care can be as costly as private physician care and waiting times are often lengthy.

"Basically there is no choice under the circumstance that you have no insurance. It is pretty scary to live without insurance." [Chinese, non-enrolled]

"I used to go to emergency and it got to the point where my days were going by. So one day I say, 'Look, I am just going to have to get into a health plan.'" [white, enrolled]

"Right now I am looking for some insurance for my son. You know, because without that you are subjected to health clinics." [African American, non-enrolled]

"The fire department will get me to the hospital and I'll get cared for in about 45 minutes. If I go walk into an emergency room, I'll be there all night." [African American, non-enrolled]

EXPERIENCES WITH MEDICAID

Awareness of Medicaid

Medicaid is generally well known among low-income parents who have had any contact with other public assistance programs. Many Medicaid beneficiaries indicate that they were introduced to the program through contact with a public assistance office or through word-of-

mouth. Families who do not seek public assistance such as welfare are often unaware of their eligibility for Medicaid.

"When I was on public assistance it was much easier to get Medicaid." [white, enrolled]

"As soon as I applied for public assistance, I had Medicaid." [white, enrolled]

"I generally go by PA standards." [HRA eligibility worker]

"I didn't have an income, so they wouldn't have given me or my children Medicaid. She would have said, again, 'You have to go get welfare.'" [African American, enrolled]

Families in need will not be identified if public assistance is used as the key measure of eligibility for Medicaid and/or CHP. If families are not Medicaid beneficiaries, CHP cannot be passed on through that program, and parents do not want to feel pressured to take public assistance if all they need is Medicaid. Medicaid and CHP recipients are often working parents who do not want or do not need public assistance.

"If you just go to the Medicaid office they will deal with you accordingly that day.... My suggestion to you would be go straight to the Medicaid. Don't get on any welfare program." [African American, enrolled]

"As a matter of fact, the person, well she told me the first time, 'We have Aid for Dependent Children. You have to get on welfare.' And I said, 'I am not getting on welfare.'" [African American, enrolled]

Understanding Who Gets Medicaid

Many parents are confused and have misperceptions about their children's eligibility for Medicaid. They often believe that the program is a source of health coverage for children up to 18 years of age whose families are very needy. (Program expansions are geared to reach families with incomes up to 250 percent of the federal poverty level.) Among focus group participants who were not enrolled in Medicaid, "very needy" meant the unemployed or destitute, or illegal immigrants. Some low-income parents of uninsured children expressed resentment toward groups whom they felt unfairly qualified for benefits.

"To get any type of service in New York City, you have to have a certain aura about you—poor and needy." [African American, enrolled]

"We pay our taxes. We can have foreigners come in here and they can get more than we can being American blacks. And I can't understand that. I can come in here, their children will get more than our children?" [African American, enrolled]

"If you are, like, blond, blue eyes in New York, you may get Medicaid." [African American, enrolled]

"Why is it that those illegal aliens can get it and we cannot?" [Chinese, non-enrolled]

"You become eligible when you are almost in the street." [Spanish-speaking, enrolled]

"The best chance of getting this is being homeless." [African American, non-enrolled]

"I think Medicaid is for very low income. You take one to the government hospital, you do not have to pay for seeing a doctor." [Chinese, non-enrolled]

"But Medicaid won't give me nothing now because I just finished working. And I earned too much last year." [African American, non-enrolled]

Getting information about Medicaid generally requires a face-to-face visit, tenacity, and time. Many potential beneficiaries' questions could be answered by CBO caseworkers if they were given documentation to supplement their understanding of the program. Limited by a lack of sufficient information, CBO employees sometimes escort potential enrollees to a Medicaid office to get answers about the program. CBO caseworkers, however, do believe that they have some understanding of the eligibility rules. CBO focus group participants said they believed that Medicaid:

- Is a government-sponsored health program covering all low-income children under the age of 21, depending on the size of the family.

- Provides for working families as well as unemployed families.

HRA eligibility workers expressed greater confidence in their knowledge of Medicaid than did CBO caseworkers. HRA workers defined Medicaid as a state-sponsored program that reaches out to low-income families. They said that medical coverage is generally provided to these families free of charge, and that pregnant women automatically qualify for the program, although some might have to contribute to a "surplus program." HRA workers,

however, are concerned that information about changes in the system, such as a shift toward managed care, is not being passed along to them.

"There are too many confusing situations. Even supervisors are not always sure what to do in a tricky situation." [HRA eligibility worker]

Neither families, eligibility workers, nor CBO caseworkers believe that the Medicaid hotline is a reliable source of information about the program. Many non-enrolled parents reported that their attempts to seek coverage were limited to calling the eligibility hotline—which kept them on hold for long periods and was not particularly helpful. Some parents who have called the hotline for eligibility information found that the information conveyed was different from one call to the next.

"No, don't use the hotline. The hotline is better when you have a problem." [white, enrolled]

"If they really need information, come in." [HRA eligibility worker]

"I keep calling there and nobody answers the phone." [white, enrolled]

"The hotline says $18,000, but it doesn't apply to everyone. Everyone has different criteria for being accepted to Medicaid. It's not like there is a general standard." [African American, non-enrolled]

Perceptions of Medicaid

Parents of uninsured children want to participate in Medicaid. The program is viewed as useful, cost-free, and comprehensive by enrolled families—it enables them to obtain routine care as well as dental services that they could not otherwise afford. Most believe that the benefits of the program outweigh its shortcomings.

"Medicaid covers dental and so forth and so forth." [white, enrolled]

"Right, and they will give it to you for awhile until you get on your feet. That's what I heard." [white, enrolled]

Opinions differ on how widely accepted Medicaid is among providers. Some parents have encountered physicians who do not take Medicaid patients. While many HRA workers believe that doctors widely accept it, others believe that Medicaid is not as widely accepted as they are led to believe.

"Most of the doctors do not accept Medicaid patients." [Spanish-speaking, enrolled]

"The Medicaid and CHP, these two things, it is for you to go to the government hospitals. Sometimes private doctors would not accept it. It is not covered." [Chinese, non-enrolled]

"That's why people on Medicaid use emergency rooms or clinics—because the doctors don't take Medicaid." [white, non-enrolled]

"There is so much bureaucracy and so much paperwork and garbage involved. A lot of doctors don't even want to deal with it." [African American, non-enrolled]

"With Medicaid, very few doctors accept it and if you have a bigger problem it's very hard to find a good doctor. That was always a problem. Like, I was always left with the Medicaid, but I didn't use it. I was always going to private doctors paying out-of-pocket." [white, enrolled]

"You can go to a number of hospitals or private doctors." [HRA eligibility worker]

"Medicaid can go anywhere." [HRA eligibility worker]

"You can go to a number of good hospitals or private doctors." [HRA eligibility worker]

"Some private doctors don't accept Medicaid because they are only getting $6 or $7 per visit." [HRA eligibility worker]

Some Medicaid beneficiaries believe that they have been stigmatized and receive poorer quality care than parents with private insurance. They believe that certain doctors demonstrate bias against Medicaid recipients.

"I feel that I am being…I don't know…I just feel that doctors make you feel little." [white, enrolled]

"I feel that if somebody has private coverage they get, like, 'Oh, Mrs. Smith, come on in.…' And it's just, 'Mrs. X, you have to wait in the corner over there. But Mrs. Smith, you *can come in.'" [white, enrolled]*

"I had a pediatrician and she accepted Medicaid as well as private insurance and she mistreated everybody with the Medicaid. Like, she looked at you like you were a

piece of garbage. And I just couldn't take that. I left her. Even though I paid for a different doctor, I felt better." [white, enrolled]

"It's more like not quality, the doctors, the way they treat you. If you don't have what they want you to have, they treat you like a nothing. And to me, that's discrimination." [African American, non-enrolled]

"If you have your own personal doctor…he is going to take care of you. A doctor that's exhausted because he has seen 25 kids before you got there…they are not going to give the best, you know, the quality care that you would actually expect." [African American, non-enrolled]

Enrollees and eligibility workers largely blame the Medicaid system for tension between parents and doctors. Parents believe that they (not their children directly) are punished because doctors are underpaid or not paid on time by Medicaid administrators.

"A reputable doctor doesn't want to pick up dealing with Medicaid patients, because they are not paying on a timely basis." [African American, non-enrolled]

"A doctor told me, 'I will only see you for 10 minutes, since I only get paid 10 dollars [by Medicaid].'" [Spanish-speaking, enrolled]

"I feel also that doctors are underpaid and that's why we don't have high-quality doctors." [white, enrolled]

"For one, they're bad pay masters. The city Medicaid is really bad. They pay late or sometimes doctors don't get paid and years go by." [African American, non-enrolled]

Barriers to Medicaid Enrollment

Many parents misunderstand income qualifications for Medicaid eligibility and often mistakenly assume that employment disqualifies them. Others do not apply based on the experiences of coworkers and friends who have applied and been denied. Parents also often lack understanding of how income, household size, and assets interact to make some families eligible and others ineligible, and they suspect that rules are applied arbitrarily. In the focus groups, parents reported that disqualification is often unexplained.

"I had asked about my daughter's case several times, but to no avail. I don't know why—I cannot understand." [Chinese, non-enrolled]

"They ask you what is the reason you were turned down the first time, like you had the answer to that. 'Oh, I see you applied before. What's the reason?' 'Hell if I know.'" [African American, non-enrolled]

Eligibility criteria are perceived to be outdated, unrealistic, and out-of-sync with the costs of living in New York City. Families, eligibility workers, and plan administrators agree that to qualify, household incomes must be very low and that families could not survive based on the eligible income standards.

"Who can live off of $250 for rent in New York City?" [plan administrator]

"You need to have a very low income in order to get Medicaid." [Chinese, non-enrolled]

"The money they are talking about is money you can't live on. They took me off because of what, I don't know. The money I am making can't feed people and pay for health care." [African American, non-enrolled]

"It should be a little bit different, because I still consider poor to be up until maybe $30,000 or $40,000. You're still struggling; that's not enough money." [African American, non-enrolled]

Medicaid's assets tests are also considered to be prohibitive to parents who have any assets, such as a car or very limited savings.

"You can't own anything—you can't have money in the bank." [African American, enrolled]

"If you have an account with $2,000, you don't qualify for Medicaid." [Spanish-speaking, non-enrolled]

"'Your income is not low enough, you cannot apply.' I did not even bother to consider it because my savings account is not below $3,000. So when they check the account this is the problem. But then the yearly income cannot be over $10,000—husband and wife get two jobs—how can it be so little?" [Chinese, non-enrolled]

Applying for Medicaid—Documentation Requirements

Gathering the proper documentation for eligibility determination is in itself a lengthy and time-consuming process. Applicants are aware that they must provide birth certificates,

Social Security cards, utility statements, pay stubs, housing contracts, proof of citizenship, divorce/marriage certificates (when applicable), and proof of ability to manage finances.

"Applying for Medicaid is very difficult, especially considering that getting the required documents does not depend solely on you." [Spanish-speaking, non-enrolled]

"They wanted for me to establish that she was my daughter, so I had to go to Social Security, get a letter stating that she was born, and apply for her to get a card." [white, enrolled]

"They have to be notarized." [white, enrolled]

"'Oh, well, I don't know if the paperwork was lost. Let's do this all over again—you bring your life back again.' A fair hearing takes three to six months. It's supposed to take 90 days. By that time, you are just so frustrated you don't want to be bothered.... After you do all of that you still didn't get no results. You do the whole process over again. And I have done that three times." [African American, non-enrolled]

"There are so many documents it turns people off. The reason it turns people off is it's a little bit confusing and intimidating." [plan administrator]

The Interview Process

Focus group participants reported that the interview process is time-consuming and inefficient. Once the necessary documentation has been gathered, the interview process often requires a full day of waiting. Many low-income workers are nonsalaried, and the daylong application process is therefore a hardship. Eligibility workers often send away applicants because their documentation is incomplete.

"They use this system to tire you out and make sure you won't come back. I think they do it on purpose." [Spanish-speaking, non-enrolled]

"You go down to that 34th Street office for Medicaid and you get in that line and you go back, and you go back, and you go back, and you go back until they give it to you. That's what you do. You just got to keep going and keep going. But you know, if you want coverage you can't get discouraged." [African American, enrolled]

"To apply they ask a lot of questions, so we have to go back and forth many times." [Chinese, non-enrolled]

"To try to get Medicaid you would never get a job, because there is too much time running back downtown." [African American, non-enrolled]

"They bug you so much—I think they do it on purpose so you just give up." [Spanish-speaking, non-enrolled]

"They make you miss days of work to get the documents required, and after all that, they tell you: 'You have two dollars more than we allow, you don't qualify.'" [Spanish-speaking, non-enrolled]

Eligibility workers find that much of their time with applicants is spent sorting documentation. Workers indicate that they are under a great deal of pressure to complete a number of appointments, and informing applicants of missing documentation is time-consuming.

"We try to explain but we don't have the time to spend." [HRA eligibility worker]

"People don't expect to wait. It's a government agency—what do they expect?" [HRA eligibility worker]

"First take your Prozac, because it's forever." [HRA eligibility worker]

"I hate sending people away because it's unclear what they need to bring." [HRA eligibility worker]

"We have a form that goes with them when they are given an application. It's explained to them." [HRA eligibility worker]

Tension Between Parents and Medicaid Eligibility Workers

The tension between parents and Medicaid eligibility workers is often reason enough not to apply for Medicaid. Parents, CBO caseworkers, and plan administrators view HRA eligibility workers as uninformed, unconcerned, and rude—and trying to keep people from enrolling. The application process is considered degrading and requires a great deal of persistence and resilience to complete. If not for the belief that Medicaid benefits are important for their children, many parents indicate they would not have accepted such treatment.

"I've worked in the system long enough to know about applying for Medicaid and public assistance. The staff you're dealing with needs a lot of customer service training. They are not user-friendly at all and that deters people." [plan administrator]

"They need to do something about the whole Medicaid enrollment application process. It's almost demeaning to people." [plan administrator]

"I go to these places and see lines and lines of people and you literally see people in tears because they've waited so long—and then they had to deal with someone so nasty. Eligibility workers need sensitivity training to make the process a lot easier." [plan administrator]

"I didn't even want to go for it. I sent my husband." [white, enrolled]

"First of all, they should handle every person personally, not like another number. And besides, they themselves should be more educated." [white, enrolled]

"That's why people go crazy there. That's why people want to kill people.... It's like a zoo." [white, enrolled]

"I think if they communicated with us…as human beings, I think it would run a lot smoother. There are people that want to smash the glass. They had some fights. That's what holds up everything. If he is in front of me and he explodes, then that holds up the whole rest of the line for a good hour, hour and a half. If they just communicate with him and maybe talk to him instead of just shutting him out…, I feel that would help." [white, enrolled]

"You have to swallow your pride and say, 'Oh, my god, I never thought I would be in this place.' But here I am, you know." [white, enrolled]

"The eligibility workers wanted me to beg from them personally." [white, enrolled]

"You just swallow your pride, because it's a real low-respect type of place if you don't." [white, enrolled]

"Even when you have to re-certify, they treat you like garbage. You feel so down that you have to go there." [white, enrolled]

Parents believe that eligibility workers ask questions that unnecessarily pry into their personal lives.

"They want to know from the day you were born." [white, enrolled]

"You shouldn't have to show management, because if you were able to manage your money then you wouldn't need Medicaid." [African American, enrolled]

"They want to know why you need the help and where you live and how you eat." [white, enrolled]

"They pry into your business." [white, enrolled]

"Ultimately, you have the Social Security number. Once you put that in, you know everything about me. So, why they asking me these questions?" [African American, non-enrolled]

"To apply, you almost need to bring the story of your life." [Spanish-speaking, enrolled]

Parents believe that eligibility workers play favorites, and that factors such as appearance make a difference in whether someone is ruled eligible. Eligibility decisions are often viewed as arbitrary and unfair.

"If the clerk does not like your face, you are fried." [Spanish-speaking, non-enrolled]

"You have to dress shabby and look poor. The way you look…it's really important to that person behind that desk. You look like you got more than what they got and you ain't getting any." [African American, enrolled]

"You got to look mean. You got to either look mean or look demanding. You are not going to get it: You are too intelligent. You are too intellectual. They will say to you, 'Please, spare me—you are making $14,000. You will make some more next year.'" [African American, enrolled]

HRA eligibility workers concur that problems exist and are well aware that turning families away and prying into personal lives makes them very unpopular. They, too, perceive the enrollment process as long and demeaning and express empathy for applicant families. In addition, they recognize that some of their coworkers carry a bias against families who apply.

"Parents think that I have a personal vendetta against them—that I'm trying to stop them from getting Medicaid." [HRA eligibility worker]

"Some eligibility workers care, some don't." [HRA eligibility worker]

"Some workers may be arbitrary in accepting documents." [HRA eligibility worker]

"The rules are different in different offices." [HRA eligibility worker]

"Photocopying and fingerprinting keeps a lot of people away." [HRA eligibility worker]

HRA staff are not necessarily in favor of the enrollment process but must carry it out to the best of their ability. Many of them feel overworked and overwhelmed and are looking for support. Workload, paperwork, and outdated information systems are cited as major problems.

"We don't have the time." [HRA eligibility worker]

"We book 50 clients per day." [HRA eligibility worker]

"A paperless system was promised but we'll never see it. We're still waiting for computers." [HRA eligibility worker]

"We have the oldest computers in the world. We have five computers for ten workers." [HRA eligibility worker]

"We have nowhere to vent our frustrations or talk about new procedures." [HRA eligibility worker]

"Most changes have to come from the top. In reality, our input doesn't matter." [HRA eligibility worker]

"It's a numbers game that nobody can win." [HRA eligibility worker]

Language

Interviews are difficult to complete when different languages are spoken and can be a deterrent to enrollment. Accommodations have been made for Spanish-speaking families, though communication difficulties still persist. Non-English and non-Spanish speaking families are less likely to be aware of Medicaid. Even when they are aware of the program, they find getting basic information difficult, often because no one can interpret for them. Hiring an interpreter is a costly option.

"We are not fluent in English, so we did not go to apply. If we are fluent in English, truly it would be very nice. Don't say that the program is no good, right, we are

ignorant, unable to speak the language. Of course it is good." [Chinese, non-enrolled]

"Yes, yes, the most important thing [is being able to communicate]. Truly it will be great if you can get it. If everybody could get it, it would be nice, but we do not speak English, we cannot communicate. Even if you speak English, we want to say something but cannot express ourselves—cannot understand what is being said. But I am not sure if there is any Chinese assistant there. Some places do have, sometimes they don't." [Chinese, non-enrolled]

"This is very true: the most important thing for our Chinese people, our English is no good.... If my English is good I want to apply for it, so when I go out to work I will have peace of mind. First you don't know anything, and everybody's working to make a living. You can't just go and ask someone constantly to be your interpreter—this is too hard." [Chinese, non-enrolled]

"They treat you like you are stupid.... 'You speak Spanish—you don't speak English.'" [Spanish-speaking, enrolled]

"A lot of people do not speak English. For them it is really difficult; they really give them a hard time." [Spanish-speaking, enrolled]

"I think they make people who do not speak English feel lower than the floor." [Spanish-speaking, enrolled]

EXPERIENCES WITH CHILD HEALTH PLUS

Awareness of Child Health Plus

Awareness of Child Health Plus (CHP) is significantly lower than awareness of Medicaid. Many parents of potentially eligible children have never heard of it. Those who are currently enrolled in the CHP program indicate that they learned of it from health plan representatives at a health fair, or from friends who had recently lost their Medicaid eligibility.

"They said they got my name through public assistance from when I was on Medicaid." [white, enrolled]

"I don't know how it is called in Chinese. I only know—only heard this phrase, 'Child Health Plus.'" [Chinese, non-enrolled]

"I want to see the information in Chinese. Sometimes there's a health forum—the Chinatown Health Clinic would have this thing. Sometimes I would go over there and hear them talk about this thing." [Chinese, non-enrolled]

Information about CHP has been slow in coming to HRA enrollment workers. They feel unable to alert the public about CHP because their clients are the ones informing them about the program. Enrollment staff have few information resources available to them; supervisory staff are not well-educated about CHP, and documentation is difficult to obtain. As a result, eligibility workers have a fragmented understanding of CHP and what it provides. Also, they find managing both CHP and Medicaid difficult. Based on the information that they have managed to acquire, HRA eligibility workers believe that CHP has been designed to cover children 19 years of age and younger who are ineligible for Medicaid. The service area of CHP is presumed to cover Brooklyn, Queens, and the Bronx, but workers are unclear whether Manhattan is covered as well.

"You have to be ineligible for Medicaid." [HRA eligibility worker]

"It takes care of ineligible children." [HRA eligibility worker]

"It's only in Brooklyn and Queens." [HRA eligibility worker]

Understanding and Perceptions of Child Health Plus

Parents of uninsured children who have heard of CHP believe it has a very good reputation. Low-income families believe that they can use the program to cover their children through age 18 and that the benefits are accepted city- or borough-wide. They also think that CHP covers many of the same services offered by Medicaid. Dental coverage has thus far not been part of the program; however, a number of enrollees have been led to believe that this will soon change.

"We read about Child Health Plus earlier: it's for those who do not meet the criteria of Medicaid." [Chinese, non-enrolled]

"I've heard [CHP] is really good." [Spanish-speaking, non-enrolled]

"Un seguro, seguro." [Spanish-speaking, non-enrolled]
(Note: The translation of this play on words is, loosely, "The insurance that gives you security," or, "The insurance that makes you feel assured." Many Spanish-speaking parents made this comment.)

"If you are able to get enrolled, you get a lot of benefits." [Spanish-speaking, non-enrolled]

"With CHP, one does not feel limited." [Spanish-speaking, non-enrolled]

"Starting in 1999, Child Health Plus is planning to include dental." [white, enrolled]

Parents whose children are enrolled in CHP report favorable experiences with the program and believe it has advantages over Medicaid, including clear qualification criteria. They report that CHP is easy to use and provides affordable access to quality health care. The doctors available through CHP are highly rated. Lack of coverage for dental care is the only issue taken with the program.

"Everything that should be changed about Medicaid—CHP has it." [Spanish-speaking, enrolled]

"To me, CHP is the best thing the government has come up with." [Spanish-speaking, enrolled]

"I'm very happy with CHP. I like it more than Medicaid, and even though I don't get covered, my children do." [Spanish-speaking, enrolled]

"I would recommend it.... My kids get whatever coverage they need.... I am really thankful that they have Child Health Plus, because that was the only type of coverage that I was able to get. And they didn't give me a whole bunch of problems or anything like that." [African American, enrolled]

CHP participants are potential ambassadors for the program. They implore other parents looking for child coverage to consider CHP. Upon hearing reviews of CHP by parents whose children are enrolled, parents of uninsured children take a keen interest in participating. Many parents requested informational materials about CHP (which was provided at the focus groups) and felt convinced that their children would qualify for enrollment.

"If it could benefit me and my children—forget me—it sounds good. And if it gives my children what they need, I am going for it." [African American, non-enrolled]

"I think Child Health Plus sounds just beautiful. Sounds like an insurance." [African American, non-enrolled]

CBO caseworkers also have favorable impressions of CHP. The program does not carry the same stigma as Medicaid, because CHP is a newer program and not often associated with the government. Community enrollment workers find the program particularly helpful in getting immigrant families to pursue coverage for their children.

"CHP is a lot more user-friendly…and a more lenient program." [plan administrator]

"It's good. It covers undocumented children." [CBO caseworker]

"Immigrants overstate their tax filings so that their family members can be brought in to the country. With CHP they can still get medical care and end up just having to pay a premium." [CBO caseworker]

Applying for Child Health Plus—Documentation and Income Requirements

Much of the same documentation is required to apply for CHP as it is for Medicaid. Pay stubs, birth certificates, and a driver's license are among the necessary documents. However, CHP's enrollment process is perceived to be less harrowing than Medicaid's. Provided all documentation is in order, eligibility for CHP is determined comparatively faster, and applications can be handled by mail.

"They ask for what is really necessary." [Spanish-speaking, non-enrolled]

"Well, [the CHP staff] were very helpful when I applied." [white, enrolled]

"It's easy because they are looking out for you." [Spanish-speaking, non-enrolled]

"The people at CHP are really kind. If they don't know something, they find it out for you." [Spanish-speaking, enrolled]

"They call you and encourage you to apply. They sent me the applications…. At first I thought, this really can't be true." [Spanish-speaking, enrolled]

"Actually, I think within a month I heard from them…. So, finally what they did is over the phone they gave me an ID number, and they said if you need to go to the doctor you just let them have this ID number." [white, enrolled]

"Very polite and very nice. They would return my calls. I sent them the information that I had provided previous to the application through the fax. And they were very nice." [white, enrolled]

"They give you an opportunity no matter how much you make." [Spanish-speaking, non-enrolled]

"Child Health Plus form is also in English, but there are few questions, like date, Social Security number, and this and that. Even I, myself, can fill it out." [Chinese, non-enrolled]

"It was very easy for me. It was at a health fair in the community. And I approached the table with Child Health Plus.… She came to my job, as a matter of fact. She picked up copies of my pay stubs and my driver's license. She attached that to my application and a little after I heard from them, and I was accepted." [white, enrolled]

The cost-sharing arrangements for CHP are affordable for low-income families. Parents might not get free care, but they can still obtain access with a small copayment. CHP makes child coverage affordable based on income level.

"I think it's really good. I am poor so I was definitely able to get it." [African American, enrolled]

"I do have a copayment of two dollars, which is not much." [African American, enrolled]

"Actually, if you are within a certain income they will pay for [your copayment]." [African American, enrolled]

"And the more money you make, you know, it has to come out-of-pocket. But it's still basically inexpensive." [African American, enrolled]

"I hope they can raise the CHP income level higher. The income level should not be set so low. And they should relax their criteria for those who have slightly high income, relax the income level a bit." [Chinese, non-enrolled]

Families are more confident that with CHP their incomes will not be a deterrent to receiving care. They also believe that they do not have the same pressure to humble themselves when asking for assistance. Overall, CHP is viewed as a sizable improvement over Medicaid, and parents would like to enroll their children in the program.

RECOMMENDATIONS

Increasing participation in Medicaid and CHP is largely dependent on building awareness and removing barriers to enrollment. Program benefits and copayments are not of major concern to enrollees or potential enrollees.

Building Awareness of Medicaid and Child Health Plus

- **Make greater use of referral structures.** HRA employees and CBO workers should better educate families seeking guidance about CHP. Systems should be put in place that refer those ineligible for Medicaid to CHP.

- **Efforts should be made to reach low-income parents through their employers.** Access to Medicaid is facilitated by the process of applying for public assistance. The system misses many working families through this narrow approach, however; alternative means should be implemented to reach them.

- **Support information dissemination within communities and at locations frequented by parents and children.** Any location that offers services to families or children should be targeted—doctors' offices, hospitals, clinics, schools, and libraries. Community-based organizations such as churches and daycare centers are also valuable resources. In addition, subways, grocery stores, and laundromats are valuable advertising sites.

- **Outreach and communications campaigns should be expanded.** Families seek information on health insurance programs from health fairs and advertisements (television, radio, and print). Radio can be especially effective for hard-to-reach populations. Parents do not object to receiving information by mail.

- **Provide documentation and incorporate communications campaigns in more languages, including Chinese, French, Russian, and Arabic.**

Removing Barriers to Enrollment in Medicaid and Child Health Plus

- **Provide communications training for eligibility workers.** Families must be comfortable with and trust the people who apply the rules and make eligibility determinations.

- **Improve support systems for eligibility workers.** Supervisory staff must be capable of answering questions when workers cannot. Documentation should also be readily

available to workers. Access to more information and the ability to spend time with government administrators of both Medicaid and CHP would help New York City HRA eligibility workers become a more active resource in increasing enrollment.

- **Increase the number of staff determining eligibility.** Mechanisms for expediting eligibility decisions should be developed.

- **Make improving computer systems a priority.** This improvement would eliminate the replication of documents and enable workers to provide more accurate and timely service to their clients.

- **Improve staffing and the accuracy of information available from telephone hotlines.**

- **Increase the number of staff members who are multilingual and make application forms available in multiple languages.**

- **Evaluate the feasibility of a single application form for Medicaid and CHP, and eliminate duplication of documentation requirements.**

- **Send eligibility workers into neighborhoods and delegate face-to-face interviews to CBOs.** Avoid the need for parents to visit Medicaid and welfare offices when possible. Consideration should be given to eliminating Medicaid's requirement for a face-to-face interview.

- **Offer extended business hours for enrollment.**

- **Build better relationships with physicians.** Medicaid and CHP programs should be parent-, child-, and physician-friendly to bring optimal services to families.