Childless Adults: Barriers to Enrollment in Public Health Insurance

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Executive Summary

As the nation expands the availability of health insurance to more Americans, it is essential to consider the large number of individuals who are already eligible for public health insurance but do not have it. In New York State 36 percent of uninsured adults — or a total of 820,000 people — are currently eligible for one of New York's public coverage programs (Medicaid or Family Health Plus) but unenrolled.[1] New York State has committed itself to finding and enrolling all uninsured New Yorkers who are currently eligible for coverage, and there have been numerous studies of this population. However, these studies have looked either at the population as a whole or at families and children specifically. While there are good reasons to focus on children and families, little is known about childless adults who are eligible for public health insurance but not enrolled in it. This is a qualitative study, conducted in New York City, designed to understand what the barriers are for this population in particular and to identify strategies and policy changes to address these barriers. The findings will be particularly useful now that eligibility for public programs has been expanded and incentives to increase participation have been created through the health care reform act recently signed into law.

Of the adults who were eligible for public health insurance and not insured in New York State in 2005, 70% of them had no children. This report focuses on these adults: childless adults, noncustodial parents or parents of children who are over the age of 18.[2] These adults also do not have illnesses or disabilities that qualify them for Supplemental Security Income or Social Security Disabilities Insurance. New York State is one of only seven states (the others are Arizona, Delaware, the District of Columbia, Illinois, Massachusetts, and Vermont) that offer any public health insurance to childless adults, and its coverage is more generous than that in many states;[3] however, the range of income eligibility is still narrow. In 2009, the income level for eligibility for single, childless adults was set at approximately 80% of the federal poverty level (FPL) for Medicaid and 100% for Family Health Plus. Under' the recently enacted health care reform act, eligibility for Medicaid will be expanded to 133% of FPL.

A United Hospital Fund analysis of 2005 data on New Yorkers who are eligible for public health insurance but not insured found that 57% have excellent or very good health, compared to only 39% of those enrolled in public health insurance. Those who are not insured are more likely to be younger (53% are 19-34, compared to 41% of those enrolled in public insurance) and are more likely to be at or below the poverty level (88%, compared to 68% of those enrolled).[4] An analysis of 2007 data showed that 57% of eligible but uninsured childless adults are men.[5] These

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[1] Holahan D, A Cook, and E Lawton. February 2010. *Health Insurance Coverage in New York, 2006-2008: A Snapshot.* New York: United Hospital Fund.
[2] Holahan D, A Cook, and L Powell. 2008. *New York's Eligible but Uninsured.* New York: United Hospital Fund. Note: The laws of the state are such that noncustodial parents may be required to pay child support but are not allowed to deduct their child support payments from their income for the purposes of qualifying for public benefits.
[3] Rosenbaum S. October 19, 2009. Medicaid and National Health Care Reform. *New England Journal of Medicine* 361 (21): 2009-2012.
[4] Holahan D, A Cook, and L Powell. 2008. *New York's Eligible but Uninsured.* New York: United Hospital Fund.
[5] Urban Institute analysis for the United Hospital Fund of 2008 *Annual Social and Economic Supplement* to the *Current Population Survey* (2009). Note that this estimate was based on a small sample size.

statistics suggest that younger and healthier adults and more men than women are not successfully enrolling in public health insurance, which may be explained by the "young invincibles" theory that these individuals do not recognize the importance of health care. However, the statistics do not provide a complete explanation of why this population has a low participation rate in these programs.

This study, carried out in New York City between June 2008 and November 2009, involved 23 interviews with "key informants" and 8 focus groups with the target population. "Key informants" were individuals with direct contact with the target population, either as case workers, facilitated enrollers, supervisors of case workers or facilitated enrollers, or policy analysts at organizations that serve the target population. In addition, the researcher consulted with an advisory board composed of experts in policy, advocacy, and service organizations who focus on understanding and improving the enrollment process for public health insurance programs, described in Appendix E.

The research found that childless adults in New York City do face many of the same barriers that have been found to inhibit enrollment for the eligible population in general; however, there are several additional barriers specific to childless adults. Most notably, this population is less aware that public health insurance even exists for childless adults, especially those with any income at all. Those that are aware of public health insurance assume that they will not be eligible. There are several reasons for this assumption. On the one hand, the income levels at which an adult without dependent children may qualify are extremely low: In 2009 the eligibility level was $706 per month for Medicaid (approximately 80% of FPL) and $903 per month for Family Health Plus (100% of FPL). Although adults may earn some income and still be eligible, it is not surprising that many assume that a job of any kind will disqualify them. In addition, the emphasis in the promotion of public health insurance has been on children and families. Many childless adults, particularly men, do not recognize that these programs are designed to include them.

In addition, many of the eligible individuals have fluctuating incomes. They may work intermittently, seasonally, or a different number of hours each week (based on employment opportunities, skill level, or health status). This makes it difficult to both determine eligibility and document an eligible income. Technically, an applicant must submit proof of income for the month prior to application. This suggests that a person whose income fluctuates may not be eligible during a month when his or her income happens to be higher than usual. In addition, the system that checks eligibility for each applicant and does periodic checks of continued eligibility uses income data that is three to six months old. There is no policy in place to base eligibility on an average income. The focus group participants expressed fear that they could be accused of fraud if they were enrolled in public health insurance and then earned too much at a certain point. Their fear of the accusation of fraud or of an attempt to recover costs seemed disproportionate to the likelihood of this happening. For many people who participated in the focus group who had fluctuating incomes, the decision not to apply for public health insurance could be seen as a rational one, since enrollment might result in an accusation of fraud and could also require a shift

of health care providers who treat the uninsured to the choice of providers in a health plan. An individual who may go in and out of eligibility would experience discontinuity of care.

Furthermore, this population has benefited less from the major shift toward community-based enrollment than have children and families, although those who have benefited from community-based, facilitated enrollment have had very positive experiences. The community-based enrollment program seems to reach families and children more than childless adults, although it is not clear whether this is a result of the design of the program or the behavior of the population. The low income range that qualifies childless adults for public health insurance is likely to make them eligible for other public benefits too, especially food stamps, which makes contact with government benefits offices more likely. Both key informants and focus group participants stressed the strong negative feelings that consumers have toward these government benefits offices, in spite of recent efforts to improve the services at these offices. While the facilitated enrollment process has brought public health insurance enrollment outside of these settings to neighborhoods, health care providers, and community-based organizations, the target population of this study seemed more likely to need to use the government enrollment sites or to have had extensive contact with them, which in itself was a deterrent. In addition, many had seen facilitated enrollers on the streets (in small tents, on vans, or at tables) and had shunned them or assumed they offered health insurance only to children and families.

There was no conclusive evidence about whether this population has less interest in health insurance in general or in public health insurance in particular. Key informants were more likely to say that their clients did not value health insurance. However, several key informants stressed that older clients, clients with health conditions, and immigrants considered public health insurance to be “golden,” and most focus group participants stated that health insurance was very important to them. Key informants and focus group participants alike discussed perceptions that Medicaid was not the highest quality health care, but no one thought that concerns about quality were a deterrent to enrolling.

As mentioned, this population does face barriers that many in the general population eligible for public health insurance face including the difficulty of the enrollment process; the difficulty of gathering the required documentation; challenges of the recertification process; stigma; competing priorities; fear of negative impact on immigration status; and reluctance to join “the system.”

The findings of this research suggest a number of policy and practice changes that could help address the low enrollment of childless adults in particular. These include:

Practice Recommendations:

- Increase publicity on the value and importance of health insurance.
- Increase publicity about the availability of public health insurance for childless adults with low incomes.

- Put into effect the 12-month continuous eligibility recently approved by the federal government for New York State.
- Increase facilitated enrollment and target childless adults with placement of facilitated enrollers and outreach efforts in places where such adults go, such as job training centers, Workforce One, and programs for formerly incarcerated. Add training on reaching and assisting these individuals.
- Train enrollment workers about how to identify and reach potentially eligible childless adults. Clarify rules on income variation, sponsor deeming, recoveries, sanctions, fraud.

Policy Recommendations:

- Advocate for the elimination of reporting requirements for changes in eligibility during year of continuous eligibility.
- Create a buy-in option for Family Health Plus similar to the Child Health Plus full premium buy-in option for those with incomes above the subsidized eligibility level.
- Consider mechanisms for using an annual average of income for eligibility.
- Consider changing the name of Family Health Plus to convey that it is designed for adults with or without children.
- Make better use of available electronic documentation to minimize burden on applicants of providing documentation.

Acknowledgments

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The author would also like to thank the key informants who agreed to be interviewed as well as the individuals at the community-based organizations that set up the focus groups and each of the focus group participants.

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Introduction

As the nation expands the availability of health insurance to more Americans, it is essential to consider the large number of individuals who are currently eligible for public health insurance but do not have it. A recent paper in *Health Affairs* estimated that 25% of the uninsured nationally are eligible for Medicaid or the Children's Health Insurance Program (CHIP).[6] In New York State, where eligibility for public health insurance is relatively generous for adults, 36 percent of uninsured adults — or a total of 820,000 people — are currently eligible for one of New York's public coverage programs (Medicaid or Family Health Plus).[7] New York State has committed itself to finding and enrolling all uninsured New Yorkers who are currently eligible for coverage and there have been numerous studies of this population.[8] However, these studies have looked at the population as a whole or, most often, at families and children specifically. While there are good reasons to focus on children and families, less is known about childless adults who are eligible for public health insurance but not enrolled. This report describes a qualitative study designed to understand what barriers this population faces and to identify strategies and policy changes to address them. The findings will be particularly useful now that eligibility for public programs has been expanded and incentives to increase participation have been created through the health care reform act recently signed into law.

Methodology

This study was designed to examine the population of adults who are eligible for but not enrolled in public health insurance to determine if this population has different reasons for not enrolling from others that have been studied. It was designed to be exploratory but not to provide definitive answers. The research was all qualitative, with key informant interviews and focus groups as the primary tools supplemented by consultation with public insurance enrollment and eligibility policy experts. The key informants were identified using a "snowball technique" whereby advocacy experts provided names of case workers and enrollment specialists who serve this population and then the researcher asked each key informant to recommend others. The researcher also asked key informants to organize and recruit individuals for the focus groups who were noncustodial parents or childless adults who were either currently eligible for and not enrolled in public health insurance or recently had a period in their lives in which they were eligible and not enrolled. The researcher promised the focus group participants anonymity. The appendices provide complete lists of key informants interviewed with their affiliations,

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[6] Dubay L, J Holahan, and A Cook. 2007. The Uninsured and the Affordability of Health Insurance Coverage. *Health Affairs* 26(1): w22-w30.
[7] Holahan D, A Cook, and E Lawton. February 2010. *Health Insurance Coverage in New York, 2006-2008: A Snapshot.* New York: United Hospital Fund.
[8] See, for example: Center for Children and Families 2007; Boozang, Braslow, and Fiori 2006; New York State Health Foundation 2009 (all listed in references).

organizations that held focus groups with make-up of focus group, interview guides, focus group guides, and the individuals consulted.

Because this research was being conducted concurrently with a qualitative study about eligible but uninsured immigrants,[9] the research design did not plan focus groups in other languages. Immigrants were not excluded; however, they were not specifically sought out. *"Mutual Responsibility": A Study of Immigrant Enrollment in Health Insurance in New York City* serves as a complement to this report, citing barriers to health insurance enrollment that are specific to immigrants.

The perceptions described in key informant interviews were sometimes consistent with those described in focus groups, and at other times were quite different. To some extent, this is attributable to the fact that the interview subjects generally had the perspective and experience of many clients, whereas the individuals in focus groups each were primarily describing their own experiences. Furthermore, the interview subjects were trained to know the enrollment rules, requirements, and procedures.

Limitations of Study

The population is difficult to find. Because they do not have dependent children, they do not have regular connections to social services and public institutions that are related to children. The fact that a large portion of this population is not enrolled in health insurance suggests that they may also be disconnected from other services. In order to learn more about their experiences and perceptions of health insurance, this study attempted to reach them through the community-based organizations that serve them; however, this technique does not provide information about adults who are in no way connected to a community-based organization. One key informant suggested that there is a high rate of mental illness in this population; however, another key informant pointed out that individuals with mental illness are more likely to be enrolled in health insurance because their health care providers will make sure they have health insurance in order to ensure their own reimbursement. Finally, individuals participating in focus groups are said to be subject to "group think," a process by which individuals agree to something said by a particularly charismatic member or stated in an appealing way.

[9] Freij M, J Rejeske, A Gurvitch, A Ferrandino, and L Weiss. February 2010. "*Mutual Responsibility": A Study of Immigrant Enrollment in Health Insurance in New York City.* New York: New York Immigration Coalition.

Background

Of the adults who were eligible for public health insurance and not insured in New York State in 2005, 70% had no children. This report focuses on these adults: childless adults, noncustodial parents, or parents of children who are over the age of 18.[10] These adults also did not have illnesses or disabilities that qualify them for Supplemental Security Income or Social Security Disabilities Insurance. New York State is one of only seven states (the others are Arizona, Delaware, the District of Columbia, Illinois, Massachusetts, and Vermont) that offer any public health insurance to childless adults and the coverage is more generous than many.[11] Nevertheless, the range of eligibility is narrow: In 2009, the income level for eligibility for single, childless adults was $706 per month for Medicaid and $903 per month for Family Health Plus (approximately 80% and 100% FPL, respectively). Under the recently enacted health care reform act, eligibility for Medicaid will be expanded to 133% of FPL.

Generally, childless adults who are eligible for public health insurance earn less income than eligible adults who are parents. According to many of the study's key informants, they are more likely to be transient, be in crisis, have other priorities, or simply be disconnected from stabilizing forces such as family, schools, and other institutions. A national study shows that able-bodied, prime-age (25-49) adults without dependents who are low-income (defined as earning less than twice the federal poverty level) are twice as likely as other prime-age adults to have dropped out of high school. Fifty-nine percent of this childless adult population are men and one quarter of those men are non-custodial fathers who have the additional pressure of having to pay child support, which is not taken into consideration for eligibility determination for public health insurance.[12]

A United Hospital Fund analysis of 2005 data on New Yorkers who are eligible for public health insurance and not insured found that 57% of eligible but uninsured adults have excellent or very good health, compared to only 39% of those enrolled in public health insurance. Those who are not insured are more likely to be young (53% are 19-34, compared to 41% of those enrolled in public insurance). An analysis of 2007 data showed that 57% of the eligible but uninsured childless adults are men.[13] These statistics suggest that younger and healthier adults and more men than women are not successfully enrolling in health insurance; however, the statistics do not provide a complete explanation of why this population has a low participation rate in public health insurance.

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[10] Holahan D, A Cook, and L Powell. 2008. *New York's Eligible but Uninsured*. New York: United Hospital Fund. Note: The laws of the state are such that noncustodial parents may be required to pay child support but are not allowed to deduct their child support payments from their income for the purposes of qualifying for public benefits..

[11] Rosenbaum S. October 19, 2009. Medicaid and National Health Care Reform. *New England Journal of Medicine* 361(21): 2009-2012.

[12] Bell SH and J Gallagher. February 1, 2001. Prime-Age Adults without Children or Disabilities: The 'Least Deserving of the Poor' — or Are They? Number B-26 in *New Federalism: National Survey of America's Families.* Washington, D.C.: Urban Institute.

[13] Urban Institute analysis for the United Hospital Fund of 2008 *Annual Social and Economic Supplement* to the *Current Population Survey* (2009). Note that this estimate was based on a small sample size.

Adults Eligible for Public Health Insurance: Enrolled vs. Uninsured, New York State, 2005

	Eligible Adults Enrolled in Public Health Insurance	Eligible but Uninsured Adults
Totals	1,520,000	650,000
% who report being in excellent or very good health	39%	57%
% who are aged between 19 and 34	41%	53%
% who are at or below the poverty level	68%	88%
% who are working	36%	48%
% childless	52%	70%

Source: D. Holahan, A. Cook, L. Powell, “New York’s Eligible but Uninsured,” United Hospital Fund, 2008.

Findings

Narrow Range of Eligibility

As mentioned above, New York State is one of only seven states that offer any public health insurance to childless adults, and its coverage is more generous than that seen in many of the others.[14] Nevertheless, the range of eligibility is slim.

Childless Adult Eligibility for Medicaid and Family Health Plus, New York State, 2009

	Medicaid	Family Health Plus
Annual Income	$8,472	$10,836
Monthly Income	$ 706	$ 903
As a Percentage of FPL	78%	100%
Number of Hours/Week at Minimum Wage	22.4	28.7

Source: http://www.health.state.ny.us/health_care/medicaid/ and http://www.health.state.ny.us/nysdoh/fhplus/who_can_join.htm, both accessed on 2/4/10.

Unaware of Eligibility. The reason cited most commonly by key informants to explain why many eligible individuals are not enrolled is that they do not know they are eligible. The key informants stated that low-wage workers, young people who have aged out of their parents' Medicaid cases. Medicaid eligibility or never had Medicaid, and the recently unemployed do not have a clear idea of Medicaid eligibility and often have no conception of Family Health Plus (FHP). Most do not think to ask about it. One key informant said, "They think you have to have children or **no** income to be eligible." Another stated, "they don't just think they are not eligible; they **know** they are not eligible." A third added, "FHP is not marketed to childless adults. Even the name connotes family, children." Key informants generally agreed that people who have been living in poverty for a long time tend to be more aware of their eligibility for benefits. Those who have been "out of the system," that is, not receiving any kind of public assistance, are less aware of the benefit and are more likely to associate Medicaid with Public Assistance, Food Stamps, and going to large government offices to apply. These associations in themselves can be deterrents, as described below in "The System."

Because the focus group participants were recruited through community-based organizations where they had contact with case workers or facilitated enrollers, it is not surprising that they were aware that they could qualify for public health insurance even with an income; however, their perception of the eligibility criteria was that almost any income was too high to qualify. "Ninety-nine point ninety-nine percent I'm going to be denied," said one participant. Another pointed out that, "If you get unemployment, you make too much even with child support," alluding to the policy that child support is not deducted from gross income. Another participant described the whole process this way: "The majority of the time that I even tried participating in

[14] Rosenbaum S. October 19, 2009. Medicaid and National Health Care Reform. *New England Journal of Medicine* 361(21): 2009-2012.

anything what ends up happening is, I spend x amount of time attempting it and then I find out that either I don't qualify or, for some reason, they feel that I'm not a good candidate for it. So after a while you just get jaded and you don't want to deal with it unless it's an emergency."

Unstable Eligibility. People whose income is in the eligibility range for Medicaid or Family Health Plus — particularly the lower-income ranges for those without dependent children — are also likely to have incomes that fluctuate week to week or month to month. As one focus group participant put it, "What tends to happen is things fluctuate. I may get employed and then in the timeframe my first six months of coverage between the time I am enrolled and the time I might lose that job my income is going to change. So what I reported to you when I first applied isn't going to be the same thing I report to you for my recertification." Since a full-time worker earning minimum wage would be ineligible at about $1,000 per month, people with eligible income levels are much more likely to work part-time.

A fluctuating income or expectations of a rise in income can discourage an eligible applicant in two ways. First, when income does rise, the beneficiary is required to report this and will then often lose the benefit.[15] Individuals in focus groups expressed a lot of concern about this requirement and worried about being accused of fraud. As one focus group participant put it, "and when they slip up and get caught out there then they got to pay it back." Second, it is very difficult to provide documentation of a fluctuating income. When applying, individuals are required to submit proof of the last month's income. The income is verified by the NYC Human Resources Administration's Resource File Integration (RFI) system, which has income data from a variety of sources as well as social security benefits data and unemployment insurance data; however, the income data can be three to five months old. If there is a discrepancy between what is provided on the application and what is shown in the RFI, the applicant's information is checked; in some cases, the applicant is asked to provide further verification (letter from employer, pay stub, etc.). So the fear of denial or allegations of fraud is understandable.

As the quotations from focus groups above indicate, the process of applying is burdensome, and individuals are less motivated to start if they feel they are likely to be denied. This is a rational decision not only because of the time spent applying but also because of the disruption this can cause for anyone who is receiving any kind of health care services. While enrolling in a public health insurance program may represent a cost savings and access to better doctors or services, it often represents a need to change doctor or providers as well. If the applicants are not confident that they will remain eligible for a reasonable period of time, they may feel that it would be better for continuity of care to remain uninsured. The difficulty of applying, the difficulty of proving an unstable income, and the possibility that income will rise and change eligibility act together as serious deterrents for eligible low-income, childless adults.

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[15] Note that even with the implementation of 12-month continuous eligibility for adults, individuals will still be required to report changes in income and other eligibility criteria.

Target Population Characteristics. In general, childless adults who are eligible for public health insurance have lower income than eligible adults who are parents. They are also more likely to be transient, in crisis, beset by other priorities, or simply disconnected from stabilizing forces such as family, schools, and other institutions. They are cut off from the institutions and services that a parent is more likely to be connected to through their children, such as schools and pediatricians. It is generally harder for such individuals to maintain an address, an income status, relationships with case workers, and contact with a regular health provider. As with all eligible populations, a large number lose their coverage at renewal, and an address change or the lack of a reliable, confidential location to receive mail is often a reason. This was affirmed in both key informant interviews and focus groups. One key informant stated, "For people who don't have stable, permanent housing, public benefits are difficult to get and difficult to keep." And another stated, "Because of [concerns about] confidentiality, people don't want mail sent anywhere."

This population is also likely to be eligible for additional benefits, including public assistance, for which they must apply at Human Resources Administration offices. Interviews and focus groups also confirmed that eligible individuals do not always fully understand if their coverage is active and why or why not. Individuals may carry a benefits card long after coverage is terminated or they may assume they were denied coverage when in fact they just did not receive a card because of a mailing glitch. In every focus group, participants asked the focus group leader questions about their coverage that often revealed a lack of comprehension of their own status.

Attitudes toward Health Insurance

There was a variety of opinions about how much this population values health insurance in general or public health insurance in particular, and why. Key informants were more likely to say that their clients did not value health insurance than were the focus group participants themselves. Some key informants said that their younger clients did not recognize the need for regular health care. Others said that their clients did not value it because they had successfully gotten care in an emergency department (ED) of a hospital or a clinic. Others stated that women valued health insurance much more than men because of reproductive health needs and child care responsibilities. Another perspective was that any client with health needs was very likely to understand the value of health insurance, but those in good health were not likely to value it. Also, the statistics cited earlier indicate that younger and healthier adults are less likely to enroll in health insurance.

In discussing how this population handles health challenges without health insurance, most key informants mentioned emergency rooms, clinics, and informal networks of care. Immigrants sometimes go back to their home countries or get treated by individuals who had credentials in their home countries. Key informants and focus group participants agreed that many simply go without care. A young man who had been uninsured stated, "I've been going without the medication. Just trying to eat healthy, exercise, and do other things. But I'm not taking my

medication that they recommended due to the fact that I can't really afford it." Additional strategies included alternative medicine, traditional healing techniques, vitamins, preventive medicine, purchasing prescription medication on Craigslist, "I've become a witch doctor. I go to the health food store to get medicine, drink herbs."

The majority of focus group participants were aware of the importance of health insurance and many had experienced the high cost of medical care without insurance. Participants were articulate about the importance of preventive care for maintaining health. However, when the questions got more specific about how high a priority it was, some participants admitted that it was not always a top priority. "My thing was just — I don't get sick that often. But if I really get sick I just go to the emergency room." And another stated, "I think it's only a super high priority when you — you don't really think about it unless you get sick. It's like right now that's the last thing on the list. The first is getting a paycheck, getting a new place to live. You don't really think about health insurance." Not surprisingly, several people in a focus group at a homeless shelter put it as second priority after housing.

<u>Attitudes toward Medicaid.</u> While key informants and focus group participants mentioned dissatisfaction with Medicaid, only one key informant expressed that a concern about quality was a deterrent to enrollment: "Because of stigma and poor treatment in clinics and Medicaid offices — second rate delivery system — people opt out and use the ED" But most key informants agreed with the sentiment expressed by one: "Once they've had it, they do value it." Another stated that her clients "realize the value of health insurance, especially those trying to get their lives together. They don't want bills."

Focus group participants were a little more specific about their concerns with the quality of care in Medicaid. One stated, "It seems like they don't really respect Medicaid too much and they just trying to give you the basic care they try to get you in and out as quick as possible." Another stated, "The pool of doctors that you have as your caregivers are either doctors who have lawsuits against them… some sort of malpractice, something going on. They're having insurance problems. They're not very good physicians." Even with these complaints, participants tended to agree that Medicaid was a far better choice than having no health insurance. As one participant put it, "Medicaid is pretty much the only horse running. You really don't feel like you have a choice."

<u>Managed Care.</u> There seemed to be as many complaints about the restrictions of managed care as there were expressions of satisfaction that beneficiaries could enroll in private plans and see private doctors. A key informant stated that her clients "hate managed care: referrals, travel reimbursements (request a week in advance), more paperwork, confusing, two different cards, less freedom." A few key informants and focus group participants mentioned that they had trouble finding doctors in their neighborhoods that were accepting new patients. Several participants complained about having to get referrals and being limited to certain doctors. Another young adult complained about not being able to see the pediatrician that he had seen all his life. A third participant had a bad experience when he needed a specialist: "I was on Medicaid and it helped me get a physical and stuff. But I had a problem. I had Bell's palsy and

needed to see a specialist and Medicaid didn't cover it in my plan. That was really a problem because I needed to rehab my face and it just took it that much longer to get that fixed. It helps but it doesn't always help. It depends on what you need it for." Echoing a common complaint about managed care, another participant stated, "You don't actually have a health professional as far as someone who is giving treatment to your client, you have a number-cruncher deciding whether or not you're going to get treated. You have a bean-counter deciding whether or not you're going to get surgery on your kidneys."

Understanding Medicaid and Medicaid Managed Care requirements is important. For example, demonstrating the confusion over what is Medicaid, one participant said, "Yeah, I don't want that [Medicaid]. I got MetroPlus. I don't want public assistance. I don't want help from the government because it's trouble in the end." Such confusion can be a major problem for beneficiaries when they get their recertification notices and they don't recognize that they are on Medicaid and therefore don't realize that to continue the coverage they have, they need to recertify. Key informants described the experience of completing applications for a consumer and finding that they already had an active Medicaid case.

Several participants expressed a great deal of satisfaction with getting Medicaid through a health plan. When asked by the focus group leader, "The card doesn't say Medicaid anymore. Does that make you feel better?" participants generally agreed that it did. One participant sang the praises of his plan that enabled him to see doctors on Central Park West. In one focus group, participants engaged in a lively argument over whether it was better to have "straight Medicaid" or one of the plans.

Stigma. Another area where key informants and focus group participants tended to differ in opinion was over whether there was a stigma to getting public health insurance. The key informants, with the exception of the one quoted in the section above, generally said that people who had been "in the system" for a long time did not experience a stigma but people who were newly eligible did. However, many of the focus group participants expressed some sense of a stigma regardless of how long they had been in the system.

One participant said, "I never thought of myself like having to be in that position. I just never thought." Another put it this way, "Now it's almost embarrassing. I need Food Stamps and Medicaid. You know. It's a weird feeling because you don't imagine yourself in that office." And a third said, "I think also the income limits kind of puts a tone in your mind about where only certain people are utilizing that. When you're working and paying your bills you feel like a productive citizen. You kind of want to keep that going. You don't want to go backwards and sign up with something that's associated with welfare this and that."

One participant suggested that the stigma was closely tied to the Medicaid office itself, "It's very humbling to go there … and have them be condescending. They make a mockery out of your situation, there's nothing to feel good about."

Another participant made clear that he viewed Medicaid as a government service he deserved: “I have my benefit card in my wallet. I’m off it but I kept it. When I was working my taxes paid for those benefits. If I need to get on PA, I’m an American citizen. I helped somebody else get theirs; I’m getting mine.”

The System

As is evident from some of the quotations above, participants view Medicaid as closely linked to other public benefits. Many of them have been eligible for Medicaid as part of a package of benefits. While negative experiences in Medicaid do not seem to be a major deterrent, associations between Medicaid and “the system” could be a much more significant deterrent for certain populations. Several key informants described their clients’ bad experiences with any part of what they view as “the system,” which can include food stamps, public assistance, Medicaid, Medicaid offices, and even facilitated enrollers, who are by definition non-governmental.

These bad experiences include long waits, disrespectful treatment, a laborious application process that sometimes involves errors, long waits for benefits, and denial of coverage. The key informants explained that whether the denial is justified or not, the client is left with a feeling of failure, after working hard to put the application together and revealing personal information and nonetheless being denied the service. Regardless of whose fault it may actually be, the clients are under the impression that “the system” makes frequent errors.

For some, “the system” also includes shelters, prison, child welfare, and other government offices and services. Key informants expressed that bad experiences can be a major deterrent, even if the bad experience was with a different part of the “system.” As one key informant explained, “Minority men are disconnected, period, from services and from benefits…very resistant to being part of anything that is government organization system. Their involvement with systems is usually punitive, so they try to stay away. It is a challenge to engage these men, period.” Another stated, “They have all had bad experiences at the Medicaid offices. They do all the right things if they change their address, but it never works. They complain about how they are treated. Nasty attitude. Many mistakes are made. One person was told she had to have a lease. That is not accurate. Another woman was separated from her husband. She was told she needed a separation agreement. That is also not accurate. She wasn’t even divorced.”

The focus group participants were very articulate about the atmosphere and treatment at government offices. There have been efforts in recent years to improve these offices; however, the participants did not seem to be aware of them. One focus group participant described the poor treatment and the difficulty of securing benefits this way: “Because it’s like being in court, being in jail, and they’re giving you nothing. If you make something they’re going to tax you. So it’s not really helping you to lend you something so that when you get something they take it away.” Another participant described the workers at Medicaid offices this way: “Eighty-five

percent of them take a course in nasty 101-102. It makes you want to say I'm not dealing with this because I'm going to react a certain way." A third said, "It was the most dehumanizing thing ever. Not for the fact you're asking for something your country's supposed to provide you. But it's just how the people treat you there."

These experiences are certainly not unique to the childless adult population, though they may be slightly more likely to experience such frustration with the system since they have, on average, lower incomes, and tend to be less connected to other sources of support.. However, the facilitated enroller program, designed partly to address these deterrents, may not be reaching the childless adult population as successfully as it reaches parents and children. The key informants and focus group participants who had enrolled with facilitated enrollers celebrated the success of that system: "Facilitated Enrollers are hugely important," and "With an FE, you get an advocate," and "now that we can enroll on site, it's super-easy. We have many fewer people not interested in signing up. It's easier to convince them." A focus group participant said, "getting [the application done] was a breeze compared to the Food Stamp office." When asked what could be done to increase enrollment, another participant said:

> *More community-based places like this that offer those services. The government offices have a bad stigma, a bad reputation. Getting the word out about these places. When I did it here it was like 15, 20 minutes and that was it. It was very easy. I walked away very happy. Going to those other offices, you hear bad stories, negative things about it. You don't want sit there waiting for a number on a screen.*

Increasing facilitated enrollment was a common suggestion for reducing the number of eligible but unenrolled adults.

However, since childless adults tend to be lower income than parents who are eligible, they are likely to be eligible for additional benefits that they cannot apply for with facilitated enrollers, so they may be more likely to use the government offices for their health insurance applications. The NYS Department of Health has no specific policy directing facilitated enrollers to target parents, families and children, and has made public its willingness to base facilitated enrollers or outreach efforts at organizations that serve childless adults. Nevertheless, several key informants believed that the State Department of Health was less willing to base the facilitated enrollers at such organizations. One key informant went so far as to say that her group "had to make the argument to the state that it was worth putting an FE in the Workforce One center and job training sites. They tend to want to prioritize children and families, but we pointed out that single adults not only need insurance but also can become parents at any time." Other key informants expressed an impression that facilitated enrollers might target parents and families since they are more likely to be eligible and more likely to follow through with the application process, including the gathering of documents.

The focus group participants in this study were all recruited through community-based organizations, some of which had facilitated enrollment on-site, so they could not provide an objective view of whether the FE system was more directed toward children and families. However, many focus group participants indicated that they shunned the facilitated enrollers they see on the streets. Some said that when they see a business operating out of a van or tent, they immediately distrust it. “Don’t you have an office?” was the question that goes through one participant’s mind. Another said, “Me personally, my mom told me don’t take information from people in the street, so I just don’t go.” A third complained about the sense he got that the outreach people he sees on the streets “have to meet quotas.” On the other hand, some participants had more positive experiences with street enrollment: “I talked to him and he called me and a few weeks later he came by my house and talked to me and then I really thought I was going to get denied but he talked to me he and said just try. A few weeks later it came.” It is difficult to know if this sense of distrust is greater among the childless adult population and if so, why that might be. It is worth considering whether facilitated enrollers may unintentionally or intentionally focus their efforts on parents and families, and may thereby do less than they could to dispel the distrust.

Recommendations from Key Informants and Focus Group Participants

When asked what could be done to increase enrollment among eligible, childless adults, key informants and focus group participants recommended more education and public service messaging about the importance of preventive health care and health insurance. Some even recommended the scare tactics used in some of the city's recent public health campaigns, such as the current anti-tobacco ads. They envisioned an ad showing a crowded emergency room with text that says, "You don't want to end up here." People recommended more education in school, so that young people grow up valuing preventive health and health insurance and retain that value in adulthood.

Many people recommended increasing the number of facilitated enrollers and making Medicaid offices more pleasant and efficient. Key informants talked about targeting childless adults more with facilitated enrollment services.

Another common recommendation was to make it easier to apply by reducing the documentation requirements or creating ways to make it easier to obtain documents.

Several people also thought it would be helpful to provide better ways to remind people when their coverage was up for renewal. Nearly every focus group participant not only had an e-mail address but stated that they checked their e-mail regularly and had not changed their e-mail address since they got it. Others felt that a text message reminder would also help. Some key informants recommended notifying a case worker or case manager for beneficiaries who have one. One participant in a focus group suggested that with every food receipt, the beneficiary's renewal date for food stamps (now called SNAP) be printed, and with every health care provider visit, the beneficiary's renewal date for Medicaid be printed on a receipt or notice given after the visit. Some suggested that fewer people should be required to recertify, pointing out that certain populations (for example, the seriously and persistently mentally ill) are very unlikely to lose eligibility.

Focus group participants and key informants alike would like to see higher income limits or more flexibility with income. All participants agreed that it would be beneficial to have a buy-in option for Family Health Plus, similar to the one that exists for Child Health Plus, to enable people to continue their coverage as their incomes rise above eligibility for subsidized coverage.

Policy/Program Responses to Research

While expanded eligibility and increased federal financing to support the expansion are important components of the recently enacted federal health care reform, the research described here suggests that other strategies are needed to improve enrollment among eligible childless adults. This population may still experience the barriers described above, including lack of awareness of eligibility, fluctuating eligibility, and difficulties enrolling and recertifying.

Practice Recommendations:

- Increase publicity on the value and importance of health insurance.
- Increase publicity about the availability of public health insurance for childless adults with low incomes.
- Put into effect the 12-month continuous eligibility recently approved by the federal government for New York State.
- Increase facilitated enrollment and target childless adults with placement of facilitated enrollers and outreach efforts in places where such adults go, such as job training centers, Workforce One, and programs for the formerly incarcerated. Add training on reaching and assisting these individuals.
- Train enrollment workers about how to identify and reach potentially eligible childless adults; clarify rules on income variation, sponsor deeming, recoveries, sanctions, and fraud.

Policy Recommendations:

- Advocate for the elimination of reporting requirements for changes in eligibility during year of continuous eligibility.
- Create a buy-in option for Family Health Plus similar to Child Health Plus full premium buy-in option for those with incomes above the subsidized eligibility level.
- Consider mechanisms for using an annual average of income for eligibility.
- Consider changing the name of Family Health Plus to convey that it is designed for adults with or without children.
- Make better use of available, electronic documentation to minimize the burden on applicants of providing documentation.

Appendix A: Key Informant Interviews

Most of the 23 key informant interviews were conducted between March 2009 and June 2009; two that were conducted earlier as part of preliminary investigation for the project. As per the original research design, the researcher identified a short list of key informants to interview and continued to add to and revise that list, based on results of early interviews, recommendations of key informants, and consultation with an advisory group (Simplification Workgroup, see Appendix E). Two health plan facilitated enrollers were interviewed in order to provide the plan perspective on enrollment and renewal. A representative from NYC Health and Hospitals Corporation was interviewed for the HHC perspective on the issue in general and for reactions to specific comments made in other interviews.

Organization	Name	Title	Populations Served
AmeriChoice	Joan C. Denker and Constance Martin	Senior Director, Sales and Marketing, Downstate Region and Director, Business Planning and Development	Medicaid and Family Health Plus eligible
Brooklyn AIDS Task Force	Farah Tanis and Donna Lawrence	Director of Supportive Care and Senior Case Manager	Low-income HIV+
Callen Lorde	Nicole Mylan	Director of Care Coordination	Gay, lesbian, bisexual, transsexual
Care for the Homeless	Doug Berman	Director of Policy	Homeless
Coalition for the Homeless	Lindsey Davis	Director of Crisis Services, formerly in advocacy	Homeless
Coalition for the Homeless	Shelly Nortz	Deputy Executive Director for Policy	Homeless
Community Voices Heard	Sondra Youdelman	Executive Director	Low-income
Fifth Avenue Committee	Amanda Frick	Single Stop Program Coordinator	Low-income
Fortune Society	Andre Garcia	Entitlement Specialist	Formerly incarcerated
Getting Out and Staying Out	Paul Gutkowski	Director of Social Services	Formerly incarcerated youth (18-24 years old)
Health Insurance Enrollment Program, Astoria, Public Health Solutions	Kadrije Burhani	Senior Facilitated Enroller	Low income
Health Insurance Enrollment Program, Bay Ridge, Public Health Solutions	Nansy Bekhit	Senior Facilitated Enroller	Low-income
Lenox Hill Neighborhood House	Lina Ngo	Health Care Advocate	Low-income, homeless, and low income community college students

Organization	Name	Title	Populations Served
Make the Road	Sara Cullinane	Health Care Advocate	Low-income
MetroPlus	Thelvis Alston	Associate Director of Marketing	Medicaid and Family Health Plus eligible
Metropolitan Council on Jewish Poverty	Karen Ginnis and Lisa Gaon	Director of Community Network and Program Director, Child and Family Health Plus	Low-income
New York Immigration Coalition	Adam Gurvitch and Jenny Rejeske	Director of Health Advocacy and Health Advocacy Associate and Membership Coordinator	Immigrants
NYC Health and Hospitals Corporation	Nina Sporn	Senior Director, Corporate Planning Services	HHC consumers
Seedco	Anna Verdiyan	Senior Program Associate, Community-Based Employment Initiatives (Single Stops)	Low-income
Seedco	Jessica Nathan	Program Manager, Community-based initiatives (Fatherhood Initiative)	Non-custodial parents, mostly men
Single Stop, Kingsborough Community college	Heidi Lopez	Single Stop Coordinator	Low-income community college students
Urban Justice Center	Dara Wilensky	Legal Advocate	Homeless
Westside Campaign Against Hunger	Holly Park	Program Director	Low-income

Appendix B: Interview Guide

The interviews followed an interview guide; however, the interviewer allowed the discussion to flow based on the experience and perspective of the interview subject. The interviews took one and a half to two hours each, and the interviewer took simultaneous notes.

1. Who is the population? Clarify population that you work with
2. How do you encounter this population?
    a. Meet same clients repeatedly?
    b. Walk-in? scheduled sessions? Related to other events/services?
    c. Discuss health care?
    d. Discuss benefits?
3. Who among your population are the eligible but not enrolled adults? Do different sub-populations have different reasons for not enrolling?
    a. Age?
    b. Ethnic background?
    c. Immigration status?
    d. Work status?
    e. Health status?
    f. Mental health/substance abuse?
4. What comes to mind as the main reasons they are not enrolled?
5. Are these people who have been on and off public health insurance? Private health insurance?
6. Where/How do they get their health care?
7. Do many of your clients go on and off Medicaid? Do they go on and off other insurances also?
8. Do most of them know what Medicaid is?
9. Do most of them know what the eligibility requirements are?
    a. Do most of them know that you can get it without being on public assistance?
10. What are your clients attitudes about having health insurance?
    a. Preventive care?
    b. Chronic care?
    c. Visiting doctors?
    d. Emergencies?
    e. Value in relation to other needs?

11. What are your clients' experiences with enrollment?
    a. Confusing
    b. Rude people
    c. Embarrassing
    d. Language barriers
    e. Difficult to produce papers
        i. Date of birth
        ii. residency
        iii. Proof of income
        iv. Resources
        v. Citizenship
    f. Poor customer service? (hours, long wait)
    g. What percentage of your clients need help with application? Could they do it on their own if there were no face-to-face requirement?
    h. At hospitals and health care clinics — are they getting accurate info?
12. Do you think your clients begin the process and fail to complete it?
13. Do many of your clients lose coverage at renewal time?
    a. Does this happen to one subset of the population more than others?
    b. Has mail-in recertification made a big difference?
    c. What percentage of your clients need help with renewal?
14. What are the attitudes of clients who have been on Medicaid about the quality of health care on Medicaid?
15. To what extent are mental health issues barriers?
16. I am going to ask my earlier question again, What comes to mind as the main reasons they are not enrolled?
17. What solutions come to mind? Enrollment? Recertification?

Appendix C: Focus Groups

The focus groups were conducted at sites where key informants were interviewed. In each case, the organizer was asked to screen participants to ensure that they were childless adults who are eligible for and not enrolled in public health insurance or childless adults who recently had a period in which they were eligible for and not enrolled in public health insurance.

Description of Focus Group Participants, by Focus Group Host Organization

	Getting Out and Staying Out	Fifth Avenue Committee	Make the Road	Coalition for the Homeless	Coalition for the Homeless	Seedco, NYC Workforce One	Seedco, Citizens Advice Bureau	Care for the Homeless — Susan's Place	**TOTALS**
Total Participants	**12**	**10**	**9**	**2**	**2**	**9**	**10**	**11**	**65**
Gender									
Women	0	2	2	0	0	0	0	11	15
Men	12	8	7	2	2	9	10	0	50
Health Insurance Status									
With Health Insurance	0	4	2	2	1	1	2	7	19
Without Health Insurance	0	6	7	0	1	8	7	3	32
Didn't Know Health Insurance Status	12	0	0	0	0	0	1	1	14
Other Characteristics									
Homeless	0	0	0	2	2	0	0	11	15
Ex-Offenders	12	0	0	0	0	0	0	0	12
Non-Custodial Fathers	0	0	0	0	0	9	10	0	19
Participated Through Translator	0	0	7	0	0	0	1	0	8

Information is based on how participants self-identified or were identified by the host organization.

Appendix D: Focus Group Guide

Each focus group lasted between 60 and 90 minutes. The focus groups were recorded and transcribed for analysis. What follows is the guide that was used; however, the focus group leader allowed the discussion to flow naturally.

General Knowledge about Public Health Insurance

Please tell me what you know about health insurance in general? Public health insurance?

What do you know about Medicaid? How many of you have been on Medicaid?

Family Health Plus?

Is Family Health Plus for people with kids? Without kids?

Do you think you are eligible?

Do you think of Medicaid or Family Health Plus as related to Food Stamps? Public Assistance?

Do you consider Medicaid or Family Health Plus to be something you want? Why? Why not?

Is there anyone here who does not have health insurance? Why not? Have you tried to get it?

Was anyone here recently without health insurance? Why?

How important is health insurance compared to other things you worry about?

What are the benefits to having health insurance? Disadvantages?

What are the benefits and disadvantages to NOT having health insurance?

Do you have a bad association with getting Medicaid?

Are you embarrassed to have Medicaid?

Experience with Public Health Insurance

If you've had it, have you used your health insurance?

Was it helpful to have it?

If you are comfortable telling me, how is your health?

Did you receive good quality health care?

Did you have a health insurance card? How was that?

When you have been without health insurance, where do you go for medical care? How does that work for you? Which is preferable (if you've also had health insurance)?

Experiences with Public Health Insurance Enrollment

If you have ever had Medicaid or Family Health Plus, what were your experiences with it?

What were your experiences with signing up for it? Where did you sign up? Did anyone help you?

Was it hard? Easy? What was hardest about it?

Did you ever apply and not get the benefit? Do you know what happened?

Are you sometimes approached on the street and asked to sign up for health insurance? What do you think about that? Do you see the vans or tables set up in your neighborhood? What do you think? Have you used them?

Have you ever been to a Medicaid Office? What was that like?

Did you have to produce documents? Was that a problem?

Did someone help you enroll? Was that helpful? Could you have done it alone?

Recertification

If you have had public health insurance, do you know about the "recertification" process, also sometimes called renewal? (If not, describe what it is.)

Did you have to go through that process? Did you find it difficult? Were you successful?

Future

If there are those that were completely unaware of eligibility, explain what they are eligible for and how to get it.

Do you plan to apply? Do you know where to go?

What makes it hard for you? What are your questions? Why are you not sure?

What could make it easier for you?

What could make it easier for folks to maintain coverage?

What else can be done to make sure more people who are eligible get coverage?

Appendix E: Advisory Board

In 2001, the United Hospital Fund convened representatives of community-based organizations, consumer advocacy groups, legal advocacy groups, the Coalition of New York State Public Health Plans, and other grantees to address urgent matters of eligibility and coverage through public insurance related to Disaster Relief Medicaid. The group has continued to meet for information sharing and connecting to policymakers on these issues as appropriate. Current members include:

Susan Dooha, Center for Independence of the Disabled, NY
Kinda Serafi and Swapna Reddy, Children's Defense Fund of NY
Judy Wessler, Commission on the Public's Health System
Elisabeth Benjamin, Community Service Society of NY
Trilby de Jung, Empire Justice Center
Gwen O'Shea, Health and Welfare Council of Long Island
Lisa Sbrana, Legal Aid Society
Patti Boozang, Manatt Phelps & Phillips, LLP/Coalition of NYS Public Health Plans
Lara Kassel, Medicaid Matters NY/Center for Disability Rights of NYS
Jenny Rejeske, New York Immigration Coalition
Alice Berger and Carmina Bernardo, Planned Parenthood of NYC
Val Bogart, Selfhelp Community Services, Inc.
Danielle Holahan, United Hospital Fund

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