

NEW YORK'S DISASTER RELIEF MEDICAID: WHAT HAPPENED WHEN IT ENDED? A FOCUS GROUP STUDY

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ABSTRACT: In September 2001, following the terrorist attacks on the World Trade Center, New York State launched a temporary health care program called Disaster Relief Medicaid (DRM). During the four-month enrollment period, 342,000 New Yorkers enrolled in DRM to obtain Medicaid benefits. As their eligibility for DRM expired, enrollees could apply for standard Medicaid benefits; however, only 38 percent did so. This focus group study examines what happened to those who did not enroll in Medicaid. The report cites a number of reasons for DRM participants' failure to apply for continuing coverage through Medicaid, including confusion over what to do once their DRM eligibility expired, lack of adequate communications from Medicaid following enrollment in DRM, and the perceived hassles of applying for Medicaid, from long waits in line to the numerous documents required.

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EXECUTIVE SUMMARY

In September 2001, following the terrorist attacks on the World Trade Center, New York State launched a temporary health care program called Disaster Relief Medicaid (DRM). During the four-month enrollment period, 342,000 New Yorkers enrolled in DRM to obtain Medicaid benefits. As their eligibility for DRM expired, enrollees could apply for standard Medicaid benefits. However, only 38 percent did so. Our focus group study sought to discover what happened to those who did not enroll in Medicaid.

In a 2002 study for the Kaiser Commission on Medicaid and the Uninsured and the United Hospital Fund, New Yorkers reported mostly positive experiences with DRM.² Other than citing the long lines, enrollees praised the enrollment process and the quality of services they received. It was a positive aspect of what was otherwise a difficult period in the city's history.

This raises the question: Why did so many enrollees fail to make the transition to standard Medicaid? Some have suggested that these enrollees should not have received DRM benefits but were approved because of the simplified application and approval system.³ Therefore, when they applied for standard Medicaid, the more detailed process revealed that they were ineligible for benefits and they were thus denied coverage. However, our research indicates that the reasons are much more complex.

Several factors prevented DRM recipients from enrolling in Medicaid. First, many were confused about what to do when their DRM eligibility expired. They did not know if they needed to begin the Medicaid application process anew, or if there was another process for those who had been in DRM. Many enrollees had applied for DRM at hospitals and community centers. Some did not know whether they were supposed to return to those sites or go to a regular Social Services site to apply for standard Medicaid.

There was also confusion about the program for which they should apply. Enrollees did not know if DRM would be extended, a similar program would become permanent, or if their only recourse was to apply for standard Medicaid.

¹ Assembly Committee on Health and the City Council Committees on Health, General Welfare, and Oversight and Investigations, "Evaluating Disaster Relief Medicaid and Family Health Plus," January 10, 2003.

² New York's Disaster Relief Medicaid: Insights and Implications for Covering Low-Income People. Kaiser Commission on Medicaid and the Uninsured and United Hospital Fund, August 2002.

³ Kathryn Haslanger, "Radical Simplification: Disaster Relief Medicaid in New York City," Health Affairs 22 (January/February 2003): 257.

Second, poor communication may have added to the confusion. Most focus group participants did not receive any communications from Medicaid after they enrolled in DRM. In particular, few participants received a letter to inform them that their DRM eligibility was about to end and instruct them how to continue coverage. Many of the Chinese Americans who did receive such a letter could not read it because it was written in English and Spanish only.

Third, many DRM enrollees appear to have determined on their own that they were not eligible for Medicaid or any other public health care program. Enrollees made this decision based on previous experiences with Medicaid or on hearsay from friends and family. Indeed, almost no one in the focus groups had accurate information on income eligibility levels for Medicaid.

Fourth, some DRM enrollees report that they did not want to go through the hassle of applying for Medicaid—enduring long waits in line, providing numerous documents, having eligibility workers ask about their personal affairs, and then waiting up to three months before being informed about eligibility.

Finally, some DRM enrollees applied for Medicaid but were found to be ineligible. This was often due to a change in circumstances, such as an applicant having a higher income or new job.

KEY FOCUS GROUP FINDINGS

Many enrollees do not see improvement in their situation since September 11.

Focus group participants feel their current situation is uncertain and unstable. Many have lost jobs or had their work hours cut. Few are finding work, and there is a lot of competition for jobs that are available. This leaves them feeling hopeless about the future.

Many enrollees appreciated the Disaster Relief Medicaid program.

DRM was a popular program among New Yorkers. Many who enrolled gained a sense of security from having it available to them, whether or not they used it. In addition, many availed themselves of care, using a wide range of medical and dental services. Some had longstanding health issues addressed, others received routine check-ups, and many had prescriptions filled. Some obtained treatment for acute illnesses.

Communication regarding the end of DRM was inconsistent.

Many focus group participants did not receive notification that DRM coverage was ending. Many believed that, prior to the end of their DRM eligibility, they would receive

a letter instructing them how to continue coverage. Some learned that their coverage had expired only when they tried to use services. When this happened, many participants left the doctor's office because they could not afford the bill. Moreover, all correspondence from Medicaid is in English or Spanish—languages that many Cantonese speakers can not understand.

Awareness and usage of programs post-DRM seems low.

Many participants were unaware that they could apply for Medicaid while enrolled in DRM. They reported that no one told them about the procedure. Some first learned about this possibility when they received the letter notifying them that DRM was ending. Many did not even try to apply for Medicaid when DRM ended, thinking that they would not be eligible based on their experience or what others told them. Some did not want to go through the hassle of applying. A few younger participants felt they did not need the coverage because they were in good health. Many Chinese-American participants felt they would be denied coverage based on their savings.

The Medicaid application experience continued to be negative.

Many who applied for Medicaid reported long waits, long lines, and inconsiderate staff and said that too many documents and too much personal information were required for application. After losing DRM coverage, many participants rely on their own resourcefulness or the emergency room for their health care needs. Many participants self-medicate using over-the-counter medications, home remedies, or homeopathic medicines. They say they will do almost anything they can to avoid incurring a doctor bill. Those on medications who cannot afford to pay for them rely on physicians for samples, take lower doses than prescribed, get the prescription filled in a friend's name, or resort to buying medications on the street or the black market. Some do without their medication.

Participants like Family Health Plus but feel it is not designed to help them.

Awareness of Family Health Plus (FHP) is low. Some participants had heard of the program but few had applied for it. Most participants like the benefits offered through the program but feel the income eligibility levels are too low. Some feel that FHP compares poorly with Child Health Plus (CHP). While the benefits in the two programs are similar, the eligibility requirements are not.

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ABOUT DISASTER RELIEF MEDICAID

Disaster Relief Medicaid (DRM) was created after the September 11th terrorist attacks on New York City. The city's Medicaid computer system was damaged during the attacks, making it impossible to process applications electronically. DRM was developed as a temporary solution to this problem.

But DRM was more than a quick fix for computer problems; it was an experiment in providing health coverage to needy people in a time of crisis. It used a shortened and simplified application—only one-page long and requiring just one form of identification. Additionally, those who applied in a Medicaid office could be approved for DRM on the spot. Those who applied at a community site could receive approval in four to seven days. In both cases, the process was much shorter than the typical wait of 30 days or more for standard Medicaid. Information about the program spread through word of mouth. In all, 342,000 New Yorkers applied for this temporary health coverage.⁴

In addition, there were two significant changes in eligibility rules. First, the New York Court of Appeals ruled in *Aliessa v. Novello*, that legal immigrants were eligible for Medicaid coverage regardless of their entry date into the United States. Previously, only legal immigrants that arrived in the United States prior to August 22, 1996, had been eligible for Medicaid coverage. The new rules for determining immigrant eligibility were put in place with the advent of DRM.

Second, instead of using Medicaid income guidelines, DRM eligibility was determined using the higher levels set forth in Family Health Plus (FHP).⁶ Under the new FHP income eligibility guidelines, the level for parents was set at 133 percent of federal poverty levels (FPLs), compared with 87 percent of FPL for Medicaid. For single adults or

⁴ Enrollment for DRM began in late September 2001 and ended January 31, 2002. Coverage was slated to last for 120 days. However, for those who applied for standard Medicaid, coverage was extended until the date of their initial application interview. Because of the large number of DRM enrollees, application interviews ran until November 2002.

⁵ June 5, 2001, New York Court of Appeals.

⁶ FHP is an expansion of the Medicaid program that was implemented in October 2001 outside New York City. It could not be implement in New York City because of the damage to the computer system resulting from the September 11 attacks. FHP was put into service in March 2002 in New York City.

childless couples, eligibility levels were increased from 50 percent of FPL under Medicaid to 100 percent of FPL under FHP. In addition, FHP does not require an asset test.

Methodology

To capture the experiences of New Yorkers with DRM, Lake Snell Perry & Associates conducted 10 focus groups with former recipients of DRM between June 11 and August 27, 2003 (Table 1). We recruited participants from all five boroughs of New York City. We held three groups with Hispanics, two of which were conducted in Spanish. We conducted three groups with African Americans. We convened two focus groups with Chinese Americans, both of which were conducted in Cantonese. We also held two discussions with whites. Discussions that were not conducted English were translated simultaneously for the benefit of observers.

Table 1. Focus Group Specifics

Location	Date	Participants	Language
Bronx	6/11/03	Hispanic	English
		African American	English
Manhattan	7/10/03	Chinese American	Cantonese
		Chinese American	Cantonese
Manhattan	8/25/03	Hispanic	Spanish
		Hispanic	Spanish
Manhattan	8/26/03	African American	English
		African American	English
Manhattan	8/27/03	White	English
		White	English

Health plans in New York City helped identify potential study participants. Only those who said they were willing to participate in follow-up interviews when they enrolled in DRM were invited to participate in this study. All participants had to be DRM enrollees. Participants were told that participation in the study would not affect the status of their current enrollment or an application they may have pending and given a \$75 honorarium for their time. Table 2 provides demographic details about the focus group participants.

Table 2. Focus Group Participants

		Total
Total participants		96
Gender	Male	35
	Female	61
Race/Ethnicity	Hispanic	29
	Chinese American	16
	African American	29
	White	21
	Other	1
Marital status	Married	29
	Single	35
	Divorced	17
	Living as married	4
	Separated	9
	Widowed	1
	No answer	1
Education	1st grade–11th grade	18
	High school graduate	33
	Some college	27
	College graduate	15
	Other	3
Household income	<\$10,000	15
	\$10,000-\$14,999	20
	\$15,000-\$19,999	26
	\$20,000-\$29,999	20
	\$30,000+	10
	No answer	5
Borough	Bronx	31
	Brooklyn	29
	Manhattan	28
	Queens	6
	Staten Island	2
Born in the United States	Yes	66
	No	30
Parenting children under 18	Yes	54
	No	41
	No answer	1

Finally, the findings reported here are based on qualitative research, which means they are not representative of the opinions of all DRM enrollees. Although this report identifies trends within this population and generates hypotheses for further research, quantitative research is needed to test these findings.

CURRENT SITUATION

Many focus group participants feel gloomy about their current situation and future prospects. Many continue to be concerned about September 11 and its aftermath. Events such as the blackout in August 2003 heighten these concerns.

Many participants mentioned mental health concerns, such as anxiety and apprehension about another attack, which they attribute to the attacks of September 11. Some report respiratory ailments that they attribute to the attacks.

Additionally, participants are worried about New York's economy. They feel it was severely damaged because of the terrorist attacks and they do not see it rebounding. Many have had difficulty finding steady employment since the attacks. As one woman stated, "Things are going poorly for me. I've been unemployed for a long time. I'm quite depressed about the situation. I have been going on interviews, and when I go to the interviews you see a pile of resumes from desk to ceiling, for one position ... It's frustrating. I really want to work."

HEALTH SERVICES USE UNDER DRM

Many focus group participants took care of routine medical issues while enrolled in DRM, including having a physical, eye exam, teeth cleaning, or dental exam. Others used DRM to address longstanding medical conditions such as high blood pressure or back pain.

Those with children used DRM for routine medical concerns and chronic issues, as well as for treatment of typical childhood maladies such as coughs, colds, and flu.

In contrast, some participants enrolled in DRM for the peace of mind they got from having a safety net during the uncertain days after September 11. Many of them not utlize any services under the program. As one white man noted, "It was a cushion basically, you had coverage. You don't have to worry about anything."

"Since September 11 and even the blackout, and the news, and Israel, life will never really be the same. And I'm a little angry that we have to live like that."

White woman

"I got my eyes checked, my teeth checked, and an annual check-up at the doctor."

Hispanic woman

A few participants thought that they were supposed to use their DRM coverage only if an illness was related to September 11th.

Whether or not they took advantage of health services, enrollees were appreciative of the coverage. As one white woman said, "God forbid, you got sick or the kids got sick, I can go to the doctor and be seen."

Interestingly, some Chinese Americans considered DRM more trouble than it was worth. They said they had difficulty finding providers who would accept DRM. As one person stated, "I think most doctors didn't take 9/11 Medicaid ... I mean [Chinatown] doctors. This is the biggest problem."

WHEN DRM ENDED

Notification of Benefits Ending

Most participants said they were told they would receive a letter prior to the end of their DRM eligibility that would tell them what they needed to do to continue their coverage. However, few reported actually receiving such a letter. A handful reported that they received the letter after their DRM had expired.

Some enrollees said they were told when they applied that their coverage would end on a certain date. Many simply stopped using their DRM card on that day.

Some discovered that their coverage had ended only when they were rejected for services at their doctor's office or pharmacy. When this happened some enrollees were left owing a bill that they could not afford. Others walked out of the doctor's office or pharmacy when they found out their coverage had expired because they did not have the cash to pay for the services or medication. A Chinese-American woman related, "I remember one or two days after the expiration I went to see the doctor and then I got some medication. The drugstore said, 'You are already expired.' I said, 'What a coincidence.'"

Cantonese-speaking enrollees had even more difficulty because of the language barrier. Many said that they do not read English so they were not aware if they received a letter or not. Even among those who had "I was told that it was going to be a notification mailed to you when it was time to reapply."

Hispanic woman

"I do not know
English so I don't
know what letters I
have received."

Chinese-American woman

received a letter and understood that their coverage was expiring, many did not understand the instructions provided for continuing coverage.

Some Cantonese-speaking enrollees were able to ask a child or friend to translate the letter for them. Nevertheless, receiving correspondence in English or Spanish is problematic for this group.

Awareness of Medicaid Availability

Many focus group participants were not aware they could apply for Medicaid while enrolled in DRM. They reported that no one told them about this procedure. Instead, they believed that they had to wait for their DRM coverage to end before they applied. Many found out about the procedure for making the transition to Medicaid only when they received the letter notifying them that their DRM coverage was ending. If they did not receive the letter, they often relied on their friends for information about what to do. Some, especially those with children, went to a Medicaid office to see what other programs were available to them.

Applying for Medicaid

For a variety of reasons, many focus group participants did not apply for Medicaid when their DRM coverage ended. Some thought they would not be eligible for Medicaid based on their previous experience or what they heard from friends. Others thought they might be eligible, but they did not want to go through the hassle of applying. A few younger enrollees decided not to apply for Medicaid because they were in good health and they felt they did not need the coverage.

Cantonese speakers believed they would be denied coverage because of their savings, even if their income was low.

Participants with children were more likely to apply for Medicaid. They felt they needed Medicaid to cover basic health services for their children, such as physical and dental exams. Several noted that children are prone to illness and accidents and they wanted to make sure they could take their child to the doctor when necessary. Many parents said that they are willing to forgo medical care for themselves when they are sick as long as they can get care for their child. As an African-American woman stated, "It is really important to me, basically for my kids. They come first before

"I heard so many people talk about income level. That is why I didn't apply for it. It is so troublesome."

Chinese-American woman

me. I would just sit there and be sick as a dog, but I'll still take them to the doctor."

Focus group participants with chronic medical conditions such as asthma, diabetes, and hypertension were somewhat more likely to have applied for Medicaid. They know that they need to monitor their condition and pay for needed medications.

Application Experience

Focus group participants who applied for Medicaid after DRM reported that they had negative experiences with the application process. These included long lines, long waiting times, and rude and inconsiderate eligibility workers. They also said that there too many documents and too much personal information were required. If any documents were missing, participants reported that they had to retrieve these and then endure another long wait to continue the application process. A Chinese-American participant related, "Too many customers and not enough staff. Also, they ask for so much information. They ask for this and ask for that. It looks like they are trying to find something to reject you. They would say, 'You don't have enough information,' and you have to come back again. I feel like they are trying to reject me. When I come back the trouble is just too much."

Focus group participants also felt that the processing time of 30 days or more required for an application was too long.

Several participants said that when their application for Medicaid was denied in the past they were not given an explanation or they did not believe the explanation they were given.

Overall, participants felt that the standard Medicaid application process is inferior to the application process for DRM.

Health Care for Those Denied Medicaid

After their DRM eligibility ended, focus group participants who did not obtain Medicaid or other coverage have relied on their wits and the emergency room (ER) for their health care. Many participants self-medicate with over-the-counter medications, home remedies, homeopathic

"I was there for five hours and they treated me like garbage."

Hispanic man

medicines, or simple bed rest. They do whatever they can to avoid incurring a doctor bill because they know they will be unable to pay.

If their illnesses do not improve, participants resort to the ER. They choose the ER because they know they will not be turned away due to lack of health insurance, while a physician might require a payment in advance for services.

Participants who are on maintenance medications reported many different ways of coping. These include getting samples from physicians, taking a lower dose than prescribed to stretch out their prescription, getting their physician to write a prescription without a name on it that they have an insured friend fill, buying prescriptions on the street or the black market, or not taking their medication at all.

"I do the best to avoid seeing a doctor. I try to avoid feeling sick. Maybe I try to get some medicine over the counter."

Chinese-American woman

FAMILY HEALTH PLUS

Awareness of Family Health Plus

Many focus group participants say they were not aware of Family Health Plus (FHP). Some had heard of the program by name, but knew nothing about it. A few participants said they had applied for FHP.

Chinese Americans were more likely than others to be aware of FHP. This is apparently due to the mobile unit that visits Chinese-American neighborhoods to promote FHP and take applications for the program. One Chinese-American participant stated, "I went to Canal Street and there was a truck parked on the side of the street and some people came up to you and they asked if you are interested in applying for Family Health Plus. I told them, 'Of course.' I filled out the paper, but I didn't have my identification with me. The next time I brought my passport, my tax return, and my bank statements."

"The syringes I use [for insulin], it's very embarrassing to say, but I'll say it. I've used the syringes over again when I'm not supposed to."

White man

Family Health Plus Benefits

Focus group participants like the array of benefits that FHP offers. As an African-American man remarked, "You can't ask for nothing better. This is too good to be true though."

However, when participants saw the income levels for eligibility, they thought few New Yorkers would qualify. They pointed out that

income levels are unrealistically low for New York City, where even a modest apartment rents for \$1,000 per month. In response to the income eligibility chart a Hispanic woman stated, "That is really sad. That's not even enough money to pay for child day care."

Those most disappointed were participants who were aware of Child Health Plus. They felt that the name Family Health Plus indicates that the program is similar to Child Health Plus. But they were disappointed—and a few even angry—that the FHP eligibility requirements were not the same as those for CHP. Ultimately, rather than feeling encouraged by learning about FHP, most participants felt discouraged that there is no program available for people in their circumstances.

"They want you to be broke!"

African-American man

IMPLICATIONS

Disaster Relief Medicaid was a good program that served the needs of many New Yorkers after September 11.

Even if they never used medical services under DRM, focus group participants appreciated the safety net that it provided. Many participants were able to address longstanding health issues, take care of routine health care needs, or receive care for an illness while enrolled in DRM.

Participants also appreciated the shorter, simpler application forms, courteous and helpful staff, and quicker eligibility determinations. Overall, these changes made the application process easier and less impersonal than the standard Medicaid application procedure.

Experiences with Disaster Relief Medicaid can help the Medicaid system improve.

Many participants feel that applying for Medicaid is a humiliating and adversarial experience. Such perceptions of the application process keep potentially eligible people from applying or completing the application process.

It is important to publicize the new Model Offices initiative, which has shortened and streamlined the application process for the state's public insurance programs.

Additionally, DRM experiences suggest that reduced paperwork would make the process less onerous and invasive for applicants. Also, fostering a courteous and helpful attitude among Medicaid eligibility workers would make applicants feel that the system was working for them rather than against them. According to a previous study, participants pointed to the helpfulness of staff members as one of the most positive aspects of DRM.⁷

Good communication with enrollees and potential enrollees is critical.

Many focus group participants did not receive the letter that they had been promised reminding them that their DRM eligibility was ending and telling them what they needed to do if they wanted to continue with regular Medicaid coverage. Such basic communication is crucial to ensure that enrollees understand their benefits and the procedures they need to follow.

⁷ New York's Disaster Relief Medicaid: Insights and Implications for Covering Low-Income People, Kaiser Commission on Medicaid and the Uninsured and United Hospital Fund, August 2002.

Many participants do not have a clear understanding of the income eligibility levels for New York's public health programs. Their understanding often was based on what a friend or family member tells them. Word of mouth is not an accurate source of information, especially for technical issues such as eligibility requirements. Also, many participants were unaware that a new program like FHP would have different guidelines (e.g., FHP has no asset test) that could affect their eligibility. Medicaid administrators should make efforts to clarify such issues in order to reduce the spread of inaccurate information.

Additionally, it is important to have basic forms and documents available in languages other than English and Spanish. In New York, a large Chinese-speaking population now receives communications from Medicaid that they cannot read. Making standardized communications available in additional languages, including Cantonese, would alleviate some of these barriers. Another option would be to make translators available by phone to those who cannot read the documents. Notices in appropriate languages on all documents would be needed to inform enrollees about translation services.

Family Health Plus may need more publicity.

Awareness of Family Health Plus among focus group participants was low. If this is an indication of awareness in the population at large, additional publicity about the program is needed. This is especially important because once participants heard about FHP, they were very interested in it—even though they were disappointed to learn about income eligibility limits.

According to participants, the mobile units that visit neighborhoods to pass out literature and take applications are the most effective means of publicizing FHP. Other community-based publicity efforts may be needed to make target audiences aware of the program.

Participants' economic situations are fluid—keep lines of communication open.

At the time of the focus groups, some participants did not think they were eligible for Medicaid or FHP. However, even minor changes in their financial circumstances—not to mention major changes such as job losses, reduced work hours, or illnesses—could make them eligible.

Therefore, it is important to inform applicants that changes in their status can affect their eligibility and to encourage them to reapply when their status changes. They should understand that a denial is not permanent. If applicants are denied, it is important to inform them of other options they may have. Keeping lines of communication open and active will help potential enrollees stay aware of when it might be worthwhile for them to reapply.

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#546 Health Coverage for Immigrants in New York: An Update on Policy Developments and Next Steps (July 2002). Deborah Bachrach and Karen Lipson, Kalkines, Arky, Zall & Bernstein LLP. This field report examines the way in which federal welfare reform restricted legal immigrants' access to Medicaid and how a New York State Court of Appeals' decision provides coverage for those previously denied.

#507 Lessons from a Small Business Health Insurance Demonstration Project (February 2002). Stephen N. Rosenberg, PricewaterhouseCoopers LLP. This report finds that the recently concluded pilot project, the Small Business Health Insurance Demonstration, launched by New York City in 1997, was successful in providing a comprehensive, low-cost insurance option for firms with two to 50 workers. But poor implementation and marketing, plus flaws in product design, prevented the program from catching on among small businesses.

#485 Implementing New York's Family Health Plus Program: Lessons from Other States (November 2001). Rima Cohen and Taida Wolfe, Greater New York Hospital Association. Gleaned from research into the ways 13 other states with public health insurance systems similar to New York's have addressed these matters, this report examines key design and implementation issues in the Family Health Plus (FHP) program and how Medicaid and the Child Health Plus program could affect or be affected by FHP.

#484 Healthy New York: Making Insurance More Affordable for Low-Income Workers (November 2001). Katherine Swartz, Harvard School of Public Health. According to the author, Healthy New York—a new health insurance program for workers in small firms and low-income adults who lack access to group health coverage—has so far been able to offer premiums that are substantially less than those charged in the private individual insurance market.

#458 Expanding Access to Health Insurance Coverage for Low-Income Immigrants in New York State (March 2001). Deborah Bachrach, Karen Lipson, and Anthony Tassi, Kalkines, Arky, Zall & Bernstein, LLP. This study of health insurance coverage among New York State's legal immigrants finds that nearly 170,000 low-income adults who would otherwise be eligible for public insurance programs are denied coverage solely because of their immigration status.

#444 Creating a Seamless Health Insurance System for New York's Children (February 2001). Melinda Dutton, Kimberley Chin, and Cheryl Hunter-Grant, Children's Defense Fund-New York. New York has recently brought Medicaid and Child Health Plus together, making the two programs more compatible. This paper takes a comprehensive look at both these programs in order to identify areas of continued programmatic disparity and explore ways to bridge differences.