

**THE NEW YORK STATE  
MANAGED CARE CONSUMER ASSISTANCE  
PROGRAM (MCCAP)**

*1999 - 2000 ANNUAL REPORT*

A Report by  
The Office of the Attorney General's  
Health Care Bureau

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**EXECUTIVE SUMMARY**

This report describes and analyzes the accomplishments of the Managed Care Consumer Assistance Program (MCCAP), the statewide network of organizations created to provide information and assistance to managed care consumers, during its first year of operation. The Attorney General's Health Care Bureau<sup>1</sup> and participating MCCAP organizations have established an infrastructure to educate consumers about managed care issues and help them to access the care and coverage they need. Based on a review of the calls and complaints received by participating MCCAP organizations, this report also identifies patterns of managed care problems New Yorkers are currently encountering, such as:

- Obtaining out-of-network referrals;
- Accessing prescription drug coverage;
- Understanding inadequate denial notices from health plans;
- Challenging a health plan's denial of care; and
- Understanding rights and protections under the state's Managed Care Bill of Rights.

MCCAP, established to respond to rising managed care enrollment and a corresponding increase in consumer confusion and complaints, is funded by the New York State Legislature and administered by the New York State Attorney General's Health Care Bureau to:

- Empower consumers to make informed choices among managed care plans;
- Educate consumers about their rights and responsibilities as health plan enrollees; and
- Resolve consumer and provider complaints about health plans.

Charged with distributing \$150,000 from the Legislature, the Attorney General's Health Care Bureau formulated a Request for Proposals and reviewed submitted proposals and selected the following organizations for funding based on experience and proven ability:

1. Medicare Rights Center (Award Amount: \$40,000)
2. Public Policy and Education Fund-Binghamton (Award Amount: \$30,000)

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<sup>1</sup> In addition to administering MCCAP, the Attorney General's Health Care Bureau operates a hotline that has received over 20,000 managed care complaints since its inception in 1997 and more than 5,700 calls so far this year from consumers seeking reliable information about their health care rights or help in accessing care or coverage for care.

3. Research and Education Project of Long Island (Award Amount: \$30,000)
4. Puerto Rican Family Institute (Award Amount: \$30,000)
5. Community Service Society (Award Amount: \$20,000)

In MCCAP's first year, MCCAP organizations have provided direct assistance to consumers through telephone hotlines and produced a variety of educational materials and programs on a broad range of managed care issues for both consumers and the professionals who assist them, including consumer brochures, training manuals and community presentations.

**Recommendations.** MCCAP proposes legislative or regulatory reforms to address identified common managed care problems:

- ? Lack of prescription drug coverage for persons under 65 enrolled in Medicare due to disability could be addressed by expanding the eligibility criteria of the State's Elderly Pharmaceutical Insurance Coverage (EPIC) program;
- ? Denials of out-of-network referrals to specialists could be addressed by allowing consumers access to the external appeals process to review such denials;
- ? Inadequate denial notices can be addressed by better enforcing existing requirements and mandating a model claim denial notice for use by all plans; and
- ? Failure to comply with Managed Care Consumer Bill of Rights requirements can be addressed by providing statutory penalties for violations.

**The Future of MCCAP:** As more New Yorkers are becoming aware of MCCAP, the demand for information and assistance has grown. Given that managed care enrollment in New York is predicted to increase in the coming years,<sup>2</sup> the success of MCCAP's first year demonstrates that it is vitally important to ensuring that consumers have assistance in navigating the confusing array of managed care options and restrictions. Consequently, MCCAP will require increased funding in order to ensure that the growing number of managed care consumers in New York are (i) made aware of their rights under the state's landmark Managed Care Bill of Rights and (ii) assisted in accessing the care they need and to which they are entitled.

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<sup>2</sup> The Kaiser Changing Health Care Marketplace, August 1998, p.21, *citing* data from National Research Corporation's Health Care Market Guide Survey, 1997 published on American Association of Health Plan website at [www.aahp.org](http://www.aahp.org).

## ESTABLISHMENT OF MCCAP TO ASSIST NEW YORK CONSUMERS

### 1. Managed Care: Increasing Enrollment in New York State

Enrollment in managed care plans in New York has been increasing dramatically. As of June 2000, more than 53% of New York's insured population was insured by a managed care plan.<sup>3</sup>

New York's private employers increasingly are offering their employees only a choice of managed care plans, and fewer are offering traditional fee-for-service health coverage.<sup>4</sup> In addition, Medicaid managed care enrollment has risen rapidly.<sup>5</sup> As of December 2000, more than 680,000 Medicaid recipients were enrolled in managed care plans through the New York State Medicaid Managed Care program.<sup>6</sup> The New York State Department of Health has established a goal to eventually have 89% of the more than 2 million eligible Medicaid recipients enrolled in a Medicaid Managed Care plan.<sup>7</sup> While the Medicare HMO enrollment gains of the 1990s have stagnated, more than 480,000 New Yorkers with Medicare are enrolled in Medicare+Choice managed care plans (commonly and herein referred to as "Medicare HMOs").<sup>8</sup>

### 2. Managed Care: Confusing Array of Options and Restrictions

In the past few years, the managed care industry has experienced three dramatic shifts. First, while group and staff model health maintenance organizations ("HMOs") have grown at a steady pace, the network and mixed model HMOs as well as independent practice association (IPA) models have expanded rapidly. Meanwhile, two types of health plans, participating

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<sup>3</sup> Enrollment figures and percentages based on New York State Department of Health (DOH), Office of Managed Care, *Quarterly Enrollment Report*, June 2000 and US Census Bureau population and uninsured estimates. Figures do not include enrollment in Preferred Provider Organizations (PPOs) other than New York State Health Insurance Plan (NYSHIP), as this information is not reported to DOH.

<sup>4</sup> The Kaiser Changing Health Care Marketplace Project, August 1998, p.18, *citing* KPMG; The Wall Street Journal, Health & Medicine, *Is Health Care Ailing?*, February 21, 2001.

<sup>5</sup> New York State Department of Health, *Quarterly Enrollment Report*, New York State Office of Managed Care, June 2000.

<sup>6</sup> *Id.*

<sup>7</sup> New York State Department of Health, *Report on Recipients Eligible for Enrollment In Managed Care: Enrollment Status by Aid Category and County, and Total Percent Enrolled by Provider Plan*, February 2001.

<sup>8</sup> New York State Office for the Aging, [www.aging.state.ny.us](http://www.aging.state.ny.us).

provider networks (PPOs) and point of service (POS) plans, have entered the market place aggressively.<sup>9</sup>

As a result, the term “managed care” or “managed care organization” now includes a variety of different forms of health plans and the laws, rules and regulations that apply to each often vary. For convenience, we will use the term “health plan” to refer to the many variations of managed care plans and organizations.

The nuances of health plans are not always obvious to those who work in the field, let alone consumers who have no health care training or background. “Even people with high levels of education -- and certainly people in high-risk health populations -- find the health care marketplace very perplexing today as new health plan products, and newly reorganized health systems, offer choices and limitations that never existed before.”<sup>10</sup> In New York, for example, many people with Medicare have been confused by the advent of Medicare HMOs. Some New York seniors have enrolled in Medicare HMOs, mistakenly believing that they were only enrolling in a Medicare supplemental policy or prescription drug plan. They were completely unaware that they had effectively terminated their traditional Medicare coverage and now had to use the HMO’s network of providers in order to have coverage for the Medicare-eligible care they received.

New Yorkers with Medicaid, among our most vulnerable citizens, have had to adjust to a new Medicaid managed care landscape. Numerous counties require Medicaid recipients to enroll in a managed care plan unless they are eligible for an exemption to maintain their traditional Medicaid. Many recipients are not aware that they meet the requirements for an exemption. The burden of proving eligibility for an exemption falls upon the recipient and sometimes involves extensive paperwork. On the other hand, Medicaid recipients who are not exempt and residing in mandatory enrollment counties are automatically enrolled in a managed care plan if they do not voluntarily select one. Many of these enrollees are unaware of their rights and responsibilities or experience difficulty accessing care within the parameters of an HMO because of the complexity of managed care options and procedures. New Yorkers with Medicaid need assistance and information to understand their rights, select a health plan to fit their needs and make fully informed decisions when accessing care.

New York managed care consumers, whether covered by a commercial, Medicare or Medicaid health plan, must become informed consumers in order to maximize their care. First,

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<sup>9</sup> *The Variety and Growth of Primary/Acute Managed Care*, New York State Office for the Aging citing Miller, Robert H. and Luft, Harold S. 1994. Also, *Managed Care Plan Performance Since 1980: A Literature Analysis*, Journal of the American Medical Association, 271: 1512-9.

<sup>10</sup> Ronald Pollack, Executive Director and Vice President, Families USA.

they must choose which health plan is best, or simply find one that is affordable, by sifting through marketing and other materials. Once enrolled, they must learn to navigate their way through plan benefits, exclusions, networks, providers and levels of coverage applicable to them. And, if a problem or a disagreement with the health plan occurs or if the plan denies care or coverage, informed consumers must learn to negotiate their way through the grievance or appeals process to resolve their claims.

Given the complexity of health plan rules, it is not surprising that 51 percent of insured American adults under age 65 report having some type of problem with their health plan over the period of a year.<sup>11</sup> In addition, Americans report similar levels of stress for dealing with their health insurance company (34% say “some” or “a lot”) as for doing their taxes (36%) and dealing with their auto mechanic (30%). They report lower levels of stress for dealing with auto insurance (19%).<sup>12</sup>

### **3. Managed Care: Growing Need for Information and Assistance**

New York’s landmark Managed Care Bill of Rights (MCBOR)<sup>13</sup> was intended to help New Yorkers resolve problems with their health plans. MCBOR, among other things, mandates full disclosure of a health plan’s benefits and services and grants the right to appeal a health plan’s decision. However, many New Yorkers are still unaware of their rights and responsibilities or lack the knowledge to appeal a plan’s decision and cannot take advantage of the protections accorded to them.

In June 2000, a national survey found that 89 percent of the consumers surveyed did not know the name of the state agency that regulates HMOs and other health plans. Forty percent said they were unaware of their right to appeal a health plan decision to the state or to an independent medical expert. In the 21 states (including New York) where consumers did have that right at the time of the survey (33 states provide for such a right now), 54 percent said they did not have that right, did not know, or did not answer the question.<sup>14</sup>

The Attorney General’s Health Care Bureau assists thousands of confused consumers every year who are seeking reliable information on their health care rights or referrals to other

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<sup>11</sup> Kaiser Family Foundation, *National Survey of Consumer Experiences with Health Plans*, June 2000.

<sup>12</sup> *Id.*

<sup>13</sup> *Managed Care Reform Act of 1996* (L.1996, ch.705), commonly referred to as the “Managed Care Consumer Bill of Rights.”

<sup>14</sup> Kaiser Family Foundation, *National Survey of Consumer Experiences with Health Plans*, June 2000.

government agencies or consumer service organizations for further assistance. Since its inception, in spring 1997, the Health Care Bureau has received more than 20,000 consumer and provider complaints about managed care and other health care plans. More than 5,700 calls have been received on the Bureau's Healthcare Hotline so far this year, demonstrating that the hotline provides a valuable service to consumers. The New York State Department of Insurance and the New York State Department of Health have also engaged in a number of ongoing initiatives to educate and protect managed care consumers.

Despite the Health Care Bureau's success in helping New Yorkers access the care and coverage they need, additional resources are needed to ensure that every managed care consumer has access to information and help. While consumers could always take their questions or complaints to the Health Care Bureau, other government agencies, their employer's benefits office or even their managed care plan, a study on managed care assistance programs reported that the government, the private sector, and community-based organizations were simply not prepared for the giant leap in managed care enrollment projected for New York State.<sup>15</sup> MCCAP is New York's innovative and bold attempt to meet the needs of New York's managed care consumers in navigating a complex and constantly changing managed care landscape.

#### **4. MCCAP: Meeting the Needs of Managed Care Consumers**

The complexity of managed care options and procedures, combined with the increase in managed care enrollment, created a clear need for education and assistance to help New Yorkers become savvy, well-informed managed care consumers. In 2000, the New York State Legislature, recognizing the needs of New York's managed care consumers, established MCCAP to:

- Assist consumers by: (a) helping them navigate issues and answer questions regarding health plans; (b) educating them about their rights and responsibilities as health plan enrollees; and (c) providing them with information so that they can make an informed choice among health plans;
- Resolve consumer and provider complaints about health plans or, where appropriate, refer consumers requiring assistance to an appropriate community-based organization (CBO), the Attorney General's Health Care Bureau or other government agency;
- Provide statistical reports and analysis of consumer complaints and trends in managed care; and

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<sup>15</sup> New York City Task Force on Medicaid Managed Care Ombudsman Program Feasibility Study, *Ombudsprograms: Lessons From the State and Private Sector*, July 21, 1997, p. 6.



- Propose legislative and regulatory reform.

Appropriating \$150,000 in fiscal year 2000 for MCCAP, the Legislature directed the Office of the Attorney General (OAG) to:

- ? Administer the MCCAP grant making process, including development of and solicitation of applicants through a request for proposal (RFP) process;
- ? Establish standardized data collection and reporting mechanisms for MCCAP grant recipients;
- ? Provide technical support to MCCAP grant recipients;
- ? Collect data from MCCAP grant recipients and publish an annual report based on such data; and
- ? Identify consumer problems and current trends in managed care and recommend responses through litigation or legislative and regulatory reform.

Although the OAG itself did not receive any funding to administer MCCAP, existing staff in the OAG's Health Care Bureau were assigned to implement and manage MCCAP. The Health Care Bureau distributed the MCCAP RFP in November 1999. To select the organizations to participate in MCCAP, the Health Care Bureau requested proposals from New York State not-for-profit organizations with consumer service experience. Health Care Bureau staff reviewed the proposals and selected organizations based on experience and proven ability in the following areas:

- Consumer complaint investigation and resolution;
- Consumer education and counseling expertise on health matters;
- Resolution of disputes, appeals and grievances;
- Representation in matters pertaining to health care or social services benefits and entitlements; and
- Community outreach and communication.

Following a careful review of submitted proposals, the following five organizations were awarded MCCAP funds:

1. Medicare Rights Center (MRC)
2. Public Policy and Education Fund - Binghamton (PPEF)
3. Research and Education Project of Long Island (REP-LI)
4. Puerto Rican Family Institute (PRFI)
5. Community Service Society (CSS)

Of these five MCCAP organizations, only MRC had a managed care consumer service program, with trained staff and a well-advertised and reputable hotline, established prior to MCCAP. Because of MRC's experience in consumer education and assistance, and its established reputation, MRC staff were able to provide services as soon as they received MCCAP funding.

The remaining MCCAP organizations, while not possessing MRC's staffing and telecommunications infrastructure, did have considerable experience in providing education and assistance to consumers. Consequently, these organizations developed their MCCAP infrastructure by leveraging their existing experience and training volunteers to serve as managed care advocates, establishing a database to record their efforts, and advertising their new MCCAP services. By the end of MCCAP's first year, all of the MCCAP organizations had established successful managed care consumer assistance programs.

## **MCCAP'S FIRST YEAR: PUTTING THE PIECES IN PLACE**

### **MCCAP's EDUCATION, INFORMATION AND ASSISTANCE PROGRAMS**

#### **MEDICARE RIGHTS CENTER**

MRC assists New Yorkers with Medicare, both senior citizens and people with disabilities, through its direct consumer assistance, education and public policy programs. MRC informs people with Medicare about their health care rights and attempts to ensure that they get the health care to which they are entitled. MRC was awarded a \$40,000 MCCAP grant to enhance the services MRC provides to New Yorkers with Medicare who are enrolled in Medicare HMOs. MRC provided MCCAP services to more than 150 professionals and over 4,500 consumers.

#### **Educational Services**

MRC developed educational tools and distributed them to consumers, 55 New York State Health Insurance, Information, Counseling and Assistance Program (HIICAP) offices, members of the New York State Assembly and Senate Committees of Aging, Health and Insurance, the Attorney General's Health Care Bureau, as well as the other MCCAP organizations. The new educational publications include:

- ? *Medicare Watch*: a bi-weekly fax update on Medicare issues and health care developments impacting people with Medicare and their care givers;

- ? *HMO Flash*: a Medicare HMO reference guide consisting of 28 counseling tip sheets;
- ? *Let's Learn Medicare*: a Medicare Training and Reference Guide which includes eight training modules about the Medicare program that can be used to conduct training programs for consumers; and
- ? *Online services*: MRC made substantive changes to its website to include Medicare managed care information specific to New York State, including information for consumers terminated from their Medicare HMOs.

### **Direct Assistance**

- ? *Toll-free Hotline*: MRC maintains several toll-free counseling telephone numbers, one available nationally and a second available only to New York residents. Assistance to callers residing in New York State ranged from answering general questions about Medicare HMOs or enrolling and disenrolling in an HMO to providing New York State-specific information to seniors choosing their Medicare coverage.

As a result of consumer complaints received on its hotline, MRC worked with the Health Care Bureau in its investigation of Aetna/US Health Care's ("Aetna") pattern of denials of specialty care treatment for its Medicare HMO members. Aetna had been denying specialty care referrals despite the existence of a valid referral from the members' primary care provider. In February, the Attorney General and Aetna signed an Assurance of Discontinuance, which required Aetna to take remedial steps to correct its specialty referral claims process and to review claims that may have been improperly denied. It was, in part, because of the cooperation and work of MRC that the Attorney General was able to proceed against and settle with Aetna.

In July 2000, the Centers for Medicare and Medicaid Services (CMS), the federal agency formerly known as HCFA that administers the Medicare program, reported that 65 Medicare HMOs across the nation were opting to terminate their Medicare contracts. In addition, 53 managed care companies reduced their service areas, affecting a total of more than 934,000 Medicare beneficiaries nationwide. In New York State, 64,000 people with Medicare were faced with the termination of their Medicare HMO coverage. In Suffolk County, for example, five Medicare HMOs pulled out and, of the remaining plans, one increased premiums significantly, while another decreased prescription drug coverage and increased premiums. As a result, MRC was flooded with calls from hundreds of seniors enrolled in Medicare HMOs who needed

immediate help in understanding their rights and their remaining health care options. Through its MCCAP hotline, MRC provided immediate information and assistance to those being terminated from their Medicare HMOs.

### **MCCAP MRC Case Histories**

Mr. R called the MRC hotline because he was unable to access care from the specialists his HMO had allowed him to see. When Mr. R called MRC, he had an ulcerated open wound the size of a tennis ball on his leg and had passed out due to convulsions the previous day. Mr. R. was in need of both a plastic surgeon and a rheumatologist. Mr. R. was wheel-chair bound and did not have access to transportation that could take him to the doctors his HMO had approved. MRC staff discovered that Mr. R's HMO had "pre-authorized" visits to a set of specialists, all of whom were located approximately an hour away from his home. An MRC staff attorney explained to Mr. R's HMO that federal regulations require Medicare HMOs to provide primary care and hospital services within 30 minutes of a member's home, and specialty services within 30 minutes or 30 miles of travel from a member's home. Since the HMO did not have specialists within the required geographic distance, MRC staff persuaded the HMO to cover Mr. R.'s visits to local specialists who were out-of-network.

Mr. B, 72, called MRC when his health plan repeatedly denied his appeals for access to chiropractic care. Mr. B had been diagnosed with severe osteoarthritis by his chiropractor, who had been treating him on a weekly basis for six months. According to Mr. B, the severity of his neck and lower back pain prevented him from turning his head from side-to-side or performing daily activities, and continuity of treatment was critical to his well-being. Mr. B's HMO denied coverage for chiropractic care stating it was "not medically necessary." Mr. B appealed the decision and was denied a second time on the grounds that he had exceeded the allowed number of yearly visits. After appealing again, he was given yet another reason for denial: his condition was chronic and therefore not covered by Medicare. MRC represented Mr. B at an Administrative Law Judge (ALJ) hearing where MRC presented evidence that the service was medically necessary and that his condition was not chronic. The ALJ overturned the HMO's denial and ordered it to cover Mr. B's treatment.

Ms. G, a 98-year-old resident of the Bronx, called the MRC hotline after her HMO denied her prescriptions for two different drugs. The first prescription for osteoporosis was denied because it had been removed from her HMOs formulary – a list of drugs an HMO covers. The second prescription, for a sleeping disorder, was denied because she had ordered a higher quantity than that allowed under her drug plan. Since Medicare does not cover prescription drugs, Medicare HMOs can decide for themselves how much, if any, prescription drug coverage

they will offer. An MRC counselor advised Ms. G to apply to New York's Elderly Prescription Insurance Coverage (EPIC) program for coverage of her osteoporosis medication and to ask her doctor to write a prescription for a smaller quantity of her sleep disorder pills.

## **THE PUBLIC POLICY AND EDUCATION FUND OF NEW YORK -- Binghamton**

PPEF is a state-wide research and education organization that has focused primarily on consumer health care issues, and been instrumental in establishing and expanding both the Child Health Plus Program and the Managed Care Bill of Rights. PPEF's Managed Care Project, which began five years ago, has become a leader in educating New York consumers about managed care protections with distribution of over 60,000 copies of its *Consumers' Guide to New York's Managed Care Bill of Rights*. The Managed Care Project is a leading trainer on consumer rights for consumer assistance organizations in the state and, through its Story Bank Project, helps consumers with their health insurance problems.

PPEF -- Binghamton was awarded a \$30,000 MCCAP grant provide the following managed care assistance and educational services to residents of Broome, Tioga and other counties in central New York. PPEF estimates that it has provided MCCAP services to more than 2,500 people.

### **Educational Services**

- ? *Local Referrals Guide*: a fifteen-page resource list to serve as a guide for consumer referrals. PPEF trained its volunteers to follow-up with consumers on all referrals to make sure that their complaints are properly addressed;
- ? *Referrals Advisory Group*: an advisory group of professionals who met quarterly to evaluate and provide assistance on providing appropriate referrals;
- ? *Educational Presentations*: managed care education presentations were made by PPEF staff for a number of community organizations, including the Muscular Dystrophy Support Group, the Managed Care Users Group and United Health Hospitals;
- ? *MCCAP Brochure*: an educational brochure which explains the purpose and the goals of the MCCAP program. The brochure has been widely distributed to area health care providers, health care consumer assistance agencies, the Binghamton Free Medical Clinic and local public libraries; and

- ? *Community Outreach:* PPEF distributed its MCCAP brochure and other informational materials to consumers at the Health and Fitness Expo at the Binghamton Arena and placed articles in the *Appalachian Community Press* and *Tioga Pennysaver*. Additionally, coverage of PPEF MCCAP's activities in the *Binghamton Press* and *Sun Bulletin* and on a local TV newscast reached thousands of consumers.

### **Direct Assistance**

- ? *Toll-free Help line:* PPEF used MCCAP funds to create a toll-free help line for consumer complaints with 24-hour voice mail service. PPEF trained eleven volunteers, supervised by a part time staff person, to provide assistance to consumers who have problems accessing care through their managed care plans. The volunteers are also required to attend monthly meetings to evaluate call information and receive ongoing training from local community agencies.

### **MCCAP - PPEF Case Histories**

Mr. B called PPEF when he received a bill from a local hospital for a CT Scan ordered by his HMO's primary care physician. PPEF volunteers assisted in making the necessary calls to the hospital, physician and HMO and determined that the HMO did not pay for the CT Scan because of a billing error by the hospital. Because of PPEF's intervention, the HMO reversed its denial, the claim was paid and Mr. B did not receive any further bills.

Ms. F complained about a problem that began when she discovered she was carrying a fetus that had died. In November 1999, she had a dilation and curettage, an operation to remove the fetus. Her HMO repeatedly denied her claim based on a lack of pre-authorization. Ms. F made many phone calls and wrote many letters without success. Finally, she called PPEF's MCCAP hotline where a volunteer informed her about her rights under the Managed Care Bill of Rights, which, in part, provides that any pregnancy-related surgery can be performed without prior authorization. Ms. F sent one final letter to her HMO quoting the Managed Care Bill of Rights and, within one week, received word from the HMO that it would pay for the care she had received.

### **RESEARCH AND EDUCATION PROJECT OF LONG ISLAND**

REP-LI is a 15-year-old organization dedicated to research, public education, community revitalization, health, education, enhancement of human dignity, environmental preservation and

social justice. For the past ten years, REP-LI and its affiliate organization, Long Island Progressive Coalition (LIPC), have worked on issues related to health care.

REP-LI was awarded a \$30,000 MCCAP grant to provide managed care education and assistance to Long Island consumers. REP-LI estimates that it provided MCCAP services to more than 1,500 Long Island residents.

## **Educational Services**

- ? *Referral Guide:* REP-LI staff created a fourteen-page resource guide for consumer referrals;
- ? *Sample Appeal Letters:* REP-LI staff drafted and distributed sample letters to consumers to assist them in filing their own appeals. The letters were also distributed to REP-LI staff to use in assisting consumers;
- ? *Brochure:* REP-LI developed and distributed an informative and attractive brochure which explains services provided by REP-LI MCCAP; and
- ? *Community Outreach:*
  - P REP-LI successfully completed several community presentations informing consumers about MCCAP services at locations such as the 2000 Suffolk County Transitional Housing Resources United, National Alliance for the Mentally Ill, Hispanic Task Force, Sagamore Children's Psychiatric Center, the Nassau Department of Senior Affairs, the Health Care Fair with the Heart Council of Long Island, Cancer Care, Pulmonary Rehabilitation Center at the Winthrop Hospital Emergency Room, Lupus Foundation, Hempstead Senior Center and the Adelphi Breast Cancer Program;
  - P REP-LI staff and volunteers distributed 400 copies of PPEF's *A Consumer's Guide to New York's Managed Health Care Bill of Rights*; 3,000 MCCAP brochures to local health care clinics and hospitals; and 200 flyers offering MCCAP services in local libraries, supermarkets, emergency rooms and doctor's offices; and
  - P REP-LI placed articles in local publications such as *Pennysavers* to advertise MCCAP services.

## **Direct Assistance**

- ? *Hotline Services:* REP-LI used MCCAP funds to establish a hotline with 24-hour voice mail. Eight volunteers were trained and educated to respond to consumer calls and complaints. REP-LI also enlisted the help of a local attorney to provide technical assistance, including help in filing external appeals.

## **MCCAP - REP-LI Case Histories**

Ms. S contacted REP-LI after receiving a denial of coverage for infusions. She filed an appeal, but was again denied when the plan determined that her treatment was “experimental.” With assistance from MCCAP volunteers and the MCCAP pro-bono attorney, Ms. S was able to get her decision overturned and get coverage for the care she needed.

After receiving notice that her father’s Medicare HMO premium had increased 100%, Ms. J called REP-LI, who explained that her father resided in Nassau County but the HMO was billing him as a New York City resident. REP-LI assisted Ms. J in contacting the HMO, and her father’s Medicare HMO premium returned to the lower correct rate.

## **PUERTO RICAN FAMILY INSTITUTE**

Founded in 1960, PRFI is a multi-program, family-oriented social service and health agency whose primary mission is to prevent family disintegration. PRFI is a health and human service organization that combines casework and psychiatric counseling with a variety of support services. For over 30 years, PRFI has offered a comprehensive array of linguistically and culturally relevant programs to promote and protect the interests of children and families.

PRFI was awarded a \$30,000 MCCAP grant to provide health care education and assistance to the Puerto Rican community. PRFI estimates that it has provided MCCAP services to more than 250 community members and professionals.

## **Educational Services**

- ? *Focus Groups and Workshops:* PRFI conducted several focus groups and consumer assistance workshops in order to develop elements of the MCCAP program that would respond directly to the needs of the community. PRFI used MCCAP funds to hire two part-time staff people to assist with the workshops and



focus groups. During the focus groups, PRFI asked the mostly Latino participants to identify issues they dealt with that affect their access to health care. Responses included:

- excessive waiting periods for doctor's appointments ;
- gaps in specialist services due to the need to obtain a referral for specialty care;
- delays in the approval process for specialist referrals; and
- cumbersome systems complicated by language barriers.

When asked to identify strategies to improve managed care services, participants included consumer education on the list. According to PRFI, consumers reported that their ability to understand and navigate managed care increased as a result of PRFI's consumer assistance workshop;

- ? *Brochure:* PRFI developed and distributed a pamphlet in Spanish explaining the services available through MCCAP. Over 100 copies of the pamphlet were distributed at the Manhattan-wide Resources Fair in Harlem and additional brochures were distributed at various community events; and
- ? *Educational Workshops:* PRFI conducted workshops to educate participants about their rights and responsibilities in today's managed care environment.

### **Direct Assistance**

- ? *Telephone Assistance:* PRFI used MCCAP funds to operate a telephone helpline to answer consumer questions and provide assistance. The coordinator of the PRFI MCCAP received managed care training so that she would be better able to assist consumers.

## **COMMUNITY SERVICE SOCIETY OF NEW YORK**

Since 1995, CSS has provided education and training on Medicaid managed care to both consumers and community organizations throughout New York City. CSS has assisted 15,000 Medicaid beneficiaries through its workshops and telephone help line.

MCCAP funding (\$20,000) was awarded to CSS to enable it to provide workshops to consumers and community organizations in Westchester, Suffolk and Nassau counties. During

the contractual period, CSS informed the Health Care Bureau that it would not be able to implement this program. Consequently, the Health Care Bureau is sending out a Request for Proposals in December 2001 in an effort to award this \$20,000 to another organization that will provide MCCAP services.

## **COMMON MANAGED CARE PROBLEMS: REFORM PROPOSALS**

As required by the terms of the MCCAP appropriation, MCCAP has identified patterns of consumer problems in managed care through its work with consumers and proposes the following legislative and regulatory reforms to address these problems.

### **1. Prescription Drug Coverage**

MCCAP organizations have been receiving a high number of complaints from some of the most vulnerable New Yorkers -- seniors and people with disabilities -- related to prescription drug coverage. Medicare does not provide outpatient prescription drug coverage, and many of New York's seniors and people with disabilities with Medicare must pay out-of-pocket for their prescriptions. New York's EPIC program helps many low- and middle-income New Yorkers over age 65 with their prescription drug costs, but disabled New Yorkers with Medicare are not eligible to join. Here is an example of the effect of this exclusion:

Mr. B, a 42-year-old disabled person living in Oswego County, called MRC's Hotline for help paying for his prescription drugs. Just eligible for Medicare, Mr. B had been prescribed a number of different medications that cost well over \$1,000 a month. He feared he would go broke paying for his prescriptions. Because there are no Medicare HMOs in Oswego and Mr. B did not qualify for Medicaid, the MRC counselor presented him with his limited options: apply to the drug manufacturers for free or discounted drugs, contact discount mail order companies, buy an expensive Medigap policy with limited drug coverage, or apply for a Medicaid spend-down.

**Recommendation.** Expand EPIC's eligibility criteria so that people with disabilities covered by Medicare can receive the affordable prescription drug coverage they so desperately need.

## 2. Denials of Out-of-Network Referrals

The Managed Care Bill of Rights (MCBOR)<sup>16</sup> provides consumers with a right to request a referral to an out-of-network health care provider if their health plan does not have a participating provider with experience and expertise in the treatment or service needed (Public Health Law § 4408[1][k]). An out-of-network referral is usually sought when (i) the enrollee's condition is unusual or unusually serious and (ii) the enrollee's condition calls for either an uncommon medical service or a provider with unusual training and expertise, which can not be found in the health plan's network.

In recent years, a debate has emerged over whether denials of out-of-network referrals necessarily involve medical judgment, or whether they are administrative in nature. The distinction is important because denials based on judgments about the medical necessity of a health service are governed under a separate law, the Utilization Review Law (Article 49 of the Public Health Law and Article 49 of the Insurance Law), which provides greater protections to consumers. The most important of these protections are (1) a guarantee that all decisions at the initial stage and on appeal are made by properly qualified medical professionals and (2) a right to an external appeal. Denials that are not based on medical necessity are handled as grievances, according to rules and procedures set out in Public Health Law, § 4408-a(1), which can not be externally appealed.<sup>17</sup> For example:

Mrs. K, a 57-year-old New Yorker with end-stage emphysema, was referred by her HMO-participating specialist to an out-of-network provider in Boston with expertise in lung reduction. The HMO denied the request and sent her to one of its in-network providers in New York City with little experience in lung reduction. She filed a grievance but again her HMO denied her request. Unable to pay for the out-of-network provider on her own, she was left with no choice but to receive treatment from a physician she considered inexperienced.

Under the current statutory scheme, denials of out-of-network referrals are not medical-necessity determinations. Appeals of such denials are therefore handled as grievances. MCCAP organizations agree, however, that a health plan's decision not to authorize out-of-network care is almost always medical in nature. This is because a disagreement between a provider and a health plan over whether a consumer's condition is unusual or unusually serious, or whether the consumer's condition calls for an uncommon medical service or a provider with unusual training and expertise, requires the exercise of professional medical judgment. A consensus has emerged

<sup>16</sup> Managed Care Reform Act of 1996 (L.1996, ch.705), commonly referred to as the "Managed Care Consumer Bill of Rights."

<sup>17</sup> The time frames and procedures for grievances and appeals are found in Public Health Law Section 4408-a, whereas the time frames and procedures for utilization review are found in Public Health Law Section 4903, et. seq.

among MCCAP organizations that consumers and providers who request out-of-network referrals should be assured that the decision will be made by properly qualified medical personnel and that they have access to an external appeal.

**Recommendation.** Amend Article 49 of the Public Health Law and Article 49 of the Insurance Law to require that denials of referrals to out-of-network providers be treated as adverse determinations under the Utilization Review Law, requiring eventual access to the external appeals process.

### **3. Inadequate Denial Notices**

MCCAP organizations have found that consumers regularly complain about the form and content of HMO denial notices. In particular, MCCAP organizations believe that the health plans could do a much better job of explaining why a service has been denied, as well as make it clearer how a consumer can appeal the denial. Review of MCCAP consumer complaints and calls related to inadequate denial notices reveals that both the form and content of denials vary from plan to plan, with some HMOs giving more detailed information while others give only very general information. For example:

Ms. K received a denial letter from her HMO that stated only that her visits to a mental health provider were “not medically necessary.” The letter provided her with no information about the criteria that the HMO used in making its decision and, therefore, Ms. K and her provider could not adequately respond to the denial through the appeal process.

State law requires that certain information be contained in the denial notice, in particular a statement of the reasons and clinical rationale for a medical-necessity denial. However, it does not specify any exact language that a notice must contain (Public Health Law §§ 4900, 4903, & 4408-a). The lack of clear guidance about what a denial notice should contain has meant that health plans have each developed different denial notice forms, some of which are inadequate, thereby confusing consumers and hampering their ability to access their appeal rights.

**Recommendation.** First, health plans should take positive steps to make their denial letters more informative with respect to appeal rights, appeal procedures, time-frames and other protections. The agreements recently signed between the Attorney General and six of the state's largest health plans provide an excellent model. In these agreements, the health plans agreed to the following improvements to denial notices and other correspondence with consumers and providers:

- ? Each medical-necessity denial letter will:
  - P state the reasons and clinical rationale for the denial, with specific reference to the clinical data about the patient that the plan relied on for its decision.
- ? When a consumer or doctor appeals, the plan will send an acknowledgment letter, and this letter will:
  - P state that the plan has to decide the appeal within 60 days;
  - P state that the plan has to communicate the result of the appeal in writing within two business days of the decision; and
  - P state that, if the plan doesn't make a decision within the applicable time period, the initial adverse determination is automatically reversed. [The law already provides this protection, but nothing in the law required plans to tell consumers and their providers about it.]
- ? If a plan misses the deadline for deciding the appeal, it will write a new letter to the party that appealed, stating that the adverse determination has been reversed and that the health service will be covered.

Second, health plans should use a standard State-mandated denial form for all denials. Such a form could be similar to the one required by CMS for Medicare denials and, ideally, would include a statewide toll-free telephone number and the phone number of the local MCCAP office for assistance.

#### **4. Inadequate Information Disclosure**

MCCAP organizations have been receiving a very high number of calls from consumers who are unaware of the rights and protections they enjoy under the MCBOR. For example, it seems that most consumers are unaware that they have a right:

- ? to receive information about their health care plan, including details about health services it covers and the health plan's procedures for approving care;
- ? to appeal a decision by the plan that a health service was or is not medically necessary;
- ? to see the clinical review criteria on which such a denial was based;
- ? to initiate an external appeal of such a denial; and
- ? to file a grievance regarding any other kind of decision made by the plan.

MCCAP organizations devote significant resources to providing information to consumers about their rights, in addition to direct assistance in navigating a health plan's

complaint processes, but clearly there is a great need for further effort in this area. More resources are required to make sure that all New Yorkers know about their rights and how to exercise them.

**Recommendation.** First, expand MCCAP, through additional funding for existing MCCAP organizations and the creation of new MCCAP organizations to serve geographic, cultural and linguistic communities that are not being reached by the existing MCCAP network. Second, amend the MCBOR to prescribe statutory penalties for violations of its provisions.

## CONCLUSION

In its debut year, MCCAP organizations established and executed groundbreaking consumer education and assistance programs. The program has provided direct assistance and support to thousands of New Yorkers seeking help with managed care. MCCAP organizations successfully started the program from scratch and developed the infrastructure and experience to provide direct consumer assistance by answering questions and providing education and assistance. MCCAP organizations also identified common managed care problems and suggested possible solutions.

As more people became aware of the MCCAP services available, the demand for those services has increased. This is encouraging, given that the number of New Yorkers enrolled in managed care is predicted to increase.<sup>18</sup> Fortunately, the Legislature has continued funding MCCAP for fiscal year 2001. MCCAP organizations are dedicated to working closely with each other and with the Attorney General's Health Care Bureau in an effort to make a statewide MCCAP network of managed care advocates. The Health Care Bureau looks forward to another successful year of the Managed Care Consumer Assistance Program.

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<sup>18</sup> The Robert Wood Johnson Foundation predicts that 90% of people with private insurance will be members of some type of managed care organization by the year 2010 (*Health and Health Care 2010: The Forecast, The Challenge*, Chapter 4).