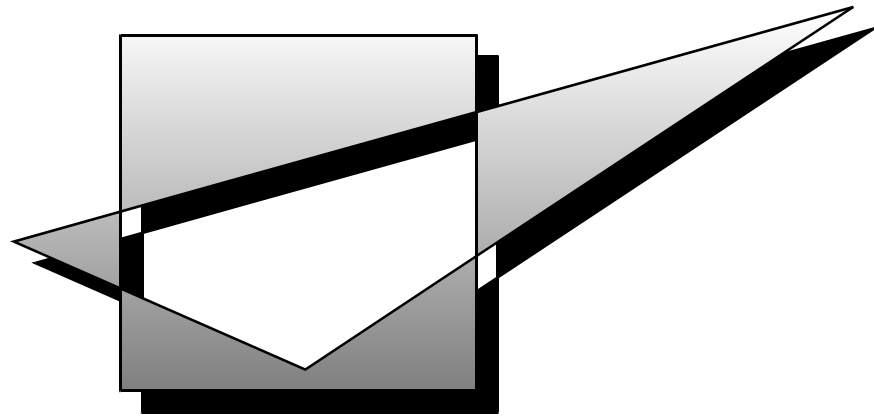


# Recommendations for Making the Consumers' Voice Heard in Medicaid Managed Care:



## A Guide to Effective Consumer Involvement



**April 1999**

National Health Law Program, Inc.

# **Recommendations for Making the Consumers' Voice Heard in Medicaid Managed Care**

---

## **A Guide to Effective Consumer Involvement**

Prepared by:

Kristi Olson, J.D., and Jane Perkins, J.D., M.P.H.  
National Health Law Program  
211 N. Columbia Street  
Chapel Hill, NC 27514  
<http://www.healthlaw.org>

This guide was funded by The Pew Charitable Trusts and the Center for Health Care Strategies.  
The opinions expressed in this guide are those of the authors and do not necessarily  
reflect the views of the Foundations.

© 1999 National Health Law Program, Inc.

*The National Health Law Program (NHeLP) is a nonprofit civil rights organization working for justice in health care on behalf of low-income and under-represented individuals. For thirty years, NHeLP has worked with community-based organizations, legal services programs, the private bar, policymakers, providers, and individuals to preserve a health care safety net for low-income people.*

## **A**cknowledgments

---

The extent to which consumers are being involved in the design, implementation, monitoring, and evaluation of Medicaid managed care programs has not received a great deal of attention. As an organization working on behalf of Medicaid beneficiaries and other low-income individuals, the National Health Law Program has explored both the need for and the possibilities of various consumer involvement mechanisms as part of a project entitled, *Making the Consumers' Voice Heard in Medicaid Managed Care*.

The goal of the project was to take an in-depth look at how consumers are being involved in the design, implementation, monitoring, and evaluation of Medicaid managed care programs and to make recommendations for effective consumer involvement. This guide represents the culmination of the project, offering a catalogue of suggestions for stakeholders to consider as Medicaid managed care programs are implemented and improved.

We are very much indebted to The Pew Charitable Trusts and the Center for Health Care Strategies for making this project a reality. We also are extremely grateful to the Consumer Involvement Working Group participants who have shared so much of their valuable time, energy, and resources with this project. While many people have contributed to this project and we are grateful to all of them, we particularly wish to acknowledge and thank Elisabeth Benjamin, New York City Task Force on Medicaid Managed Care; James Jackson, Health Action New Mexico; Gene King, Ohio State Legal Services; Richard Seckel, Kentucky Legal Services; and Janet Varon, The Children's Alliance (Seattle, WA). In addition, we would like to express our gratitude to the Medicaid administrators who not only saw the value of consumer involvement, but who worked with us to find the best mechanisms. Thank you also to Tonya Pate for her research assistance. It is safe to say that this project could not have been accomplished without the help of everybody involved.



# Contents

---

<b>Instructions for using this guide</b> .....	1
<b>Section I: Background and Methodology</b> .....	3
Why consumer involvement? .....	5
Project methodology .....	9
<b>Section II: Recommendations for Consumer Involvement</b> .....	15
Guiding principles .....	17
Outreach and education .....	21
Public meetings and community forums .....	27
Boards and committees .....	31
Focus groups .....	37
Recipient employees .....	43
Member advocates .....	47
Consumer surveys .....	51
Hotlines .....	57
Consumer assistance programs .....	61
Complaint processes .....	67
<b>Section III: Legal Requirements and Model Provisions</b> .....	71
Boards and committees .....	73
Recipient employees .....	75
Member advocates .....	79
Hotlines .....	81
Consumer assistance programs .....	83
Complaint processes .....	87
<b>Section IV: The Consumer Involvement Action Plans</b> .....	105
Kentucky .....	IV-3
New Mexico .....	IV-65
New York City .....	IV-87
Ohio .....	IV-93
Washington .....	IV-121



## Instructions for Using this guide

The reader should use this guide in conjunction with the first report of this project, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*. The first report provides an in-depth discussion of the various consumer involvement mechanisms, including an assessment of the legal requirements for implementing these mechanisms.

This guide is organized into four sections:

**Section I** provides the background and methodology. It discusses why consumer involvement is needed and explains the process through which the recommendations in this report were developed and tested.

**Section II** is organized as a catalogue which the reader can use to consider a range of consumer involvement mechanisms, including:

- # Guiding principles
- # Outreach and education
- # Public meetings and community forums
- # Boards and committees
- # Focus groups
- # Recipient employees
- # Member advocates
- # Consumer surveys
- # Hotlines
- # Consumer assistance programs (ombudsprograms)
- # Complaint processes

The discussion of each mechanism includes specific recommendations, sample illustrations, and a reference list of “how-to” guides and resources.

**Section III** contains legal requirements and sample legislative and contract language for various mechanisms.

**Section IV** reproduces the “Consumer Involvement Action Plans” which were developed as part of this project. As part of the process of developing the recommendations, five pilot sites were asked to test initial recommendations by creating individualized Consumer Involvement Action Plans. These Plans provide insight into the final recommendations contained in this guide.





# **S**ection I: Background & Methodology

---

<b>Why Consumer Involvement?</b> .....	5
Reasons for consumer involvement .....	5
Who is a consumer? .....	5
Is consumer involvement feasible? .....	6
<b>Project Methodology</b> .....	9
Background .....	9
The project .....	10
The Consumer Involvement Action Plans .....	11



# Why Consumer Involvement?

---

*“The genius of the United States is not best or most in its executives or legislature, nor in its ambassadors or authors or colleges or churches or parlors, nor even in its newspapers or inventors – but always in the common people.”*

- Walt Whitman

---

This guide is about how to involve consumers in the design, implementation, monitoring, and evaluation of Medicaid managed care programs. There are a number of compelling reasons to involve consumers. As a starting point, consumer involvement is required under a number of federal and state laws. But, beyond the law, consumer involvement offers a number of benefits.

## Reasons for consumer involvement

- ◆ *Improve public confidence.* Consumer involvement can increase public confidence in the health care system, in the policies being developed and implemented, and in government and health plan staff.
- ◆ *Share knowledge and opinions.* Consumer involvement provides an opportunity not just to solicit consumer input, but to provide information to consumers. It also provides an opportunity for various stakeholders to communicate in a cooperative environment.
- ◆ *Increase consumer satisfaction.* Studies have demonstrated that consumer involvement increases consumer satisfaction.
- ◆ *Foster accountability.* Consumers involved in the health care system have valuable information which, if brought to light, can play a large role in monitoring the system’s accountability to the public and the people it serves.
- ◆ *Enhance decision-making.* Consumers bring new insights and first-hand information to the table which, though frequently overlooked, are often at the crux of the matter. Consumer involvement allows decisions to be made with more complete information and a wider representation of view points.

## Who is a consumer?

Considerable debate has surrounded the issue of who is a consumer. For example, should consumer advocates be considered “consumers”? Should former Medicaid beneficiaries be included or only current beneficiaries?

---

*Fortunately, with most consumer involvement mechanisms, an “either/or” choice does not have to be made; in most cases, there is no reason why all interested persons cannot be involved.*

---

Former participants bring a unique value to the table. Unlike current beneficiaries who may fear reprisal, former participants may be more open about their experiences and insights. Including former participants also promotes long-term involvement. Since many Medicaid beneficiaries are only enrolled for brief periods of time, they have very little time during which to become involved. By the time they have figured out how to navigate the system, they may lose their eligibility.

Good reasons also exist to include consumer advocates. While nobody can replace the first-hand experiences and insights of actual beneficiaries, consumer advocates bring their own experiences and knowledge to the table. Advocates are often more readily available and easier to identify as desiring participation than are consumers. Including advocates may be a first step towards identifying and including actual beneficiaries. In addition, advocates may represent broader constituencies and may have knowledge about the experiences of large groups of consumers. They are often paid to be consumer advocates, and therefore may be on a more equal playing field with other paid professionals. They also may be more familiar with legal requirements and technical issues.

Nonetheless, it is important to recognize that neither former participants nor consumer advocates can substitute for current participants. Efforts need to be taken to ensure that current participants are involved. Fortunately, however, with most consumer involvement mechanisms, an “either/or” choice does not have to be made; in most cases, there is no reason why all interested persons cannot be involved.

## **Is consumer involvement feasible?**

Attaining real consumer involvement can be a challenge. Yet, it is a challenge which can be overcome, if there is a commitment to real consumer participation.

One of the greatest obstacles to consumer participation is a lack of commitment on the part of other stakeholders. If the involvement is a mere token or is done merely to comply with legal requirements without a genuine interest in consumer input, it will be very difficult to sustain

involvement. Throughout this project, numerous consumers and consumer advocates expressed frustration that nothing came from their participation. Not surprisingly, consumers who felt that their participation was not valued were unlikely to continue to participate.

A second obstacle to consumer participation is the failure to involve consumers in planning the mechanisms for participation. Consumers are much more likely to be invested in participation if they have a shared role in the promotion and planning of the mechanism. Thus, consumer involvement cannot be approached from the top; it needs to include all stakeholders at all stages.

A third obstacle is lack of funding. Meaningful and ongoing consumer involvement requires not just a commitment by all participants, but the financial resources behind that commitment. Over the course of this project, a number of funding sources were identified, including general state revenue appropriations, state and federal Medicaid dollars, adjustment of capitation rates to cover consumer involvement, tithing by managed care organizations, private foundation grants, individual donors, and local business and medical trade association support. In-kind donations and volunteer assistance, including grocery and department store certificates, transportation services, babysitting services, and church and community volunteers, also were identified and used.

Most of the various sources of funding came with both strengths and weaknesses. For example, funding by government actors conveyed a sense of commitment by the government agency which was viewed as important. A similar argument could be made for funding by managed care organizations. By funding the consumer involvement, they had a greater stake and a greater commitment to it. On the other hand, for some mechanisms, government and managed care organization funding was seen as compromising the independence of the participants.

Foundation funding, because of its perceived neutrality, was favored in those situations where stakeholders were most concerned about inappropriate influence. One concern with foundation funding was the difficulty in obtaining multi-year funding to ensure stable and ongoing consumer involvement. Nonetheless, foundation funding was

considered particularly valuable in time-limited projects and in supporting consumer involvement during transition periods.

Despite these obstacles, it is clear that consumer involvement is possible. This guide was written based, in large part, on the experiences of various stakeholders, as they have been conveyed to us. These experiences vividly demonstrate that true consumer involvement is, indeed, feasible.

## **P**roject Methodology

---

*Consumers, government entities, managed care organizations, and providers all will be better served by a system that involves consumers structurally in the design and ongoing implementation, monitoring, and evaluation of Medicaid managed care.*

---

## **B**ackground

To control Medicaid expenditures and expand access to health care, states are rapidly implementing managed care programs. As of June 1997, more than 15 million beneficiaries — 48 percent of the Medicaid population — were enrolled in managed care plans — a dramatic increase from the 2.7 million beneficiaries enrolled in 1991. In twenty-nine states and the District of Columbia, more than half of all Medicaid beneficiaries were enrolled in managed care. This trend is likely to continue, particularly in light of provisions of the Balanced Budget Act of 1997 which increased state flexibility to require beneficiaries to enroll in managed care programs.

Questions have arisen regarding the appropriate role for consumers to play as Medicaid managed care programs are introduced and as they mature. As recipients of public assistance, should beneficiaries be passive users of the health care system? Or, should they be involved in program design, implementation, monitoring, and evaluation?

It is now increasingly accepted that consumer involvement across the range of program activities is desirable. Consumer feedback can help improve the quality of managed care programs, monitor compliance, and, ultimately, promote the health of consumers. Consumer understanding and involvement can improve health access and delivery, avoid unnecessary spending, and increase consumer satisfaction. Consumers, government entities, managed care organizations, and providers all will be better served by a system that involves consumers structurally in the design and ongoing implementation, monitoring, and evaluation of managed care.

Clearly, the benefits of consumer involvement are not limited to Medicaid settings. However, specific aspects of the Medicaid program make it vitally important that consumer involvement in Medicaid managed care occur. First, the public responsibility and funding for the Medicaid program demand an open process with maximum sharing of information. Second, navigating managed care is a demanding and confusing process for most consumers. To complicate matters, Medicaid beneficiaries are more likely to encounter unique barriers in accessing health care. For



some Medicaid beneficiaries, barriers such as limited literacy, limited English proficiency, and the lack of money for transportation, childcare, and telephone services may detract from their ability to participate actively. Moreover, low-income consumers have fewer resources available with which to obtain out-of-network care. Increasingly, they are locked into health plans and do not have the option of seeking care elsewhere. These circumstances not only make it more essential that Medicaid beneficiaries have ongoing input about their health care delivery arrangement, but they also present unique challenges for consumer involvement.

## **The Project**

In April of 1996, the National Health Law Program, along with the Cecil G. Sheps Center for Health Services Research, initiated a comprehensive project to examine how consumers can be better involved in the design, implementation, monitoring, and evaluation of Medicaid managed care. The first report of the project, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, was published in December 1996. The report described the need for consumer involvement, examined the federal and state provisions requiring consumer involvement, and summarized ideas from the academic literature and interviews with interested persons at the state and local levels.

Following publication of the first report, the National Health Law Program and the Sheps Center began to focus on developing recommendations for consumer involvement in Medicaid managed care. An interdisciplinary technical advisory group was convened to provide reactions and suggestions. In addition, site visits were made to California, Kentucky, New York City, Ohio, and Washington. During each of the site visits, surveys were conducted of consumers, advocates, health plans, and state administrators. In each site, focus groups and meetings with Medicaid beneficiaries were held to obtain their recommendations on how consumers can be more effectively involved in Medicaid managed care.

In designing their Consumer Involvement Action Plan, each site was asked to answer the following five questions:

- # Why were certain consumer involvement mechanisms chosen and not others?
- # How were the mechanisms modified to better address the needs and political realities of the site?
- # Are there mechanisms included in the site's Plan that were not included in the draft best practice recommendations and, if so, what led to their development?
- # What will be the "value-added" by the selected mechanisms?
- # Where in the system are these mechanisms expected to result in change?

## The Consumer Involvement Action Plans

Using the first report, the findings from the site visits, and the suggestions of the interdisciplinary panel, the National Health Law Program developed a draft set of best practice recommendations for making the consumers' voice heard in Medicaid managed care. Five sites — Kentucky, New Mexico, New York City, Ohio, and Washington — were selected to review the draft best practice recommendations and to use them as a template for designing "Consumer Involvement Action Plans" tailored to meet their local needs.

At the time of their selection, all of the sites exemplified: (1) a broad range of approaches to consumer involvement; (2) the existence of a strong non-profit consumer organization with an established capacity to work effectively with the Medicaid agency; and (3) demonstrated interest by the Medicaid agency in developing practical approaches for obtaining consumer input. The five sites were selected to ensure geographic and demographic diversity and a range of new and more mature managed care programs. In each site, we invited a consumer representative and a government representative to form a team to develop a Consumer Involvement Action Plan. All of the teams were asked to involve various stakeholders in the development of the Plan and to keep them involved through feedback loops. The consumer representative in each site was provided a small grant to enable consumer participation.

The Consumer Involvement Action Plans were to reflect the sites' best thinking for how to involve consumers in ongoing mechanisms that seek to maintain and improve the quality of health care in managed care settings. The Action Plans were prepared through a collaborative effort involving consumer advocates, Medicaid consumers, and, in all sites except New York City, the Medicaid agency. The sites were asked to use a team of a consumer representative and a Medicaid managed care administrator to lead the effort to develop the Plan. All of the teams were asked to involve various stakeholders in the development of the Plan and to keep them involved through feedback loops.

Apart from these requirements, the National Health Law Program gave the study sites maximum flexibility to tailor

---

*Development of a Consumer Involvement Action Plan is not a “cookie cutter” process; plans will vary depending on the populations to be served and the political landscape of the region.*

---

the plan process to meet their local situations. Indeed, the processes that the sites used to develop their Consumer Involvement Action Plans varied greatly among the sites. A few of these variations are highlighted below.

# **Geographic scope.** Some sites used a state-wide approach (e.g., Kentucky); other sites chose to focus their efforts on selected regions. Ohio, for example, selected two counties, both of which had strong traditions of social, labor, and political organizing. This approach allowed Ohio to compare and contrast different localities.

# **Formation of the working group.** The process of forming the working group also varied from site to site. In Kentucky, for example, a planning committee composed of a consumer, an advocate, and a Medicaid representative met and agreed on a set of premises to guide the working group process. Among other things, the premises specified that the membership of the working group should be at least half current or former Medicaid beneficiaries or low income community representatives and that advocates and social service agency staff who serve on the committee should bring one or two low income community members into the process as the “ticket” for their own participation. In contrast, New York City established their Consumer Involvement Workgroup as a subcommittee of an existing and highly active consumer coalition, the New York City Task Force on Medicaid Managed Care, a coalition of nearly 200 individuals and organizations.

# **Development of the Action Plan.** At least two of the sites — New Mexico and Washington — used trained facilitators to lead discussions. Several sites (e.g., Kentucky, New Mexico, and Washington) included in their processes a discussion of how the site had already implemented federal and state requirements for consumer involvement. Kentucky Working Group members also carried out “field assignments” to find out what was happening on the ground. Most of the sites used a prioritizing process to decide which recommendations should be addressed or emphasized. In Washington, for example, members of the Working Group voted on the mechanisms they thought would be the best means to reach the goal of meaningful consumer

involvement. After developing a draft plan, the Washington Working Group circulated it to over one hundred interested individuals around the state, including consumers, members of Medicaid managed care oversight committees, consumer groups, health plans, providers, community agencies, advocacy groups, and state and county health agencies. Feedback from these individuals was incorporated into the final plan. The New Mexico Working Group developed two action plans, the second one building on the recommendations of the first plan.

The full Consumer Involvement Action Plans for each site are reproduced in Section IV of this guide.



## **Section II: Recommendations for Consumer Involvement**

Guiding principles .....	17
Outreach and education .....	21
Public meetings and community forums .....	27
Boards and committees .....	31
Focus groups .....	37
Recipient employees .....	43
Member advocates .....	47
Consumer surveys .....	51
Hotlines .....	57
Consumer assistance programs .....	61
Complaint processes .....	67

*“We began with an inventory of the kinds of consumer involvement mechanisms that members of the groups have been involved in. We discussed some of the best and worst experiences we have had with these mechanisms, and the causes of these particularly good and bad experiences. In light of this discussion, members of the group voted on the mechanisms they thought would be the best means to reach the goal of ‘meaningful’ consumer involvement.”*

- Washington Consumer Involvement Action Plan

## Guiding Principles

### Quick Checklist

- # Are consumers valued as consultants?
- # Are consumers involved in developing consumer involvement mechanisms?
- # Is consumer involvement sought at all stages – design, implementation, monitoring, and evaluation?
- # Are a variety of mechanisms used?
- # Are opportunities for involvement well-advertised? Are they advertised in the languages spoken by the community?
- # Do the mechanisms seek diverse representation, recognizing that one consumer cannot represent the interests of all consumers?
- # Are there feedback loops?

The specific mechanisms for involving consumers in Medicaid managed care programs will depend to a great extent on each site's structural arrangements for managed care; government, health plan, and other stakeholder interest in involving consumers; and activity by consumers and consumer advocates to involve themselves in the process. As a result, consumer involvement will take different forms from one place to the next. The Consumer Involvement Action Plans developed by the study sites illustrate this. However, regardless of the specific mechanisms used to include the consumers' voice in Medicaid managed care, there are a number of general principles that should be considered.

The guiding principles listed below have been repeated consistently by Medicaid beneficiaries, consumer advocates, state administrators, and health plans as being critical to successful consumer involvement. As a first step, these principles should be reviewed and stakeholders should come to a consensus regarding the guiding principles that will be used.

### Recommendations

- ◆ Consumer involvement efforts should aim to increase the number of informed, empowered consumers and enable them to participate more in their own health care.
- ◆ A variety of consumer involvement mechanisms are needed. One effort will not tap the range of consumers' views or their ability to participate. Mechanisms should be used to seek consumer involvement at all stages — during the design, implementation, monitoring, and evaluation of the program.
- ◆ Efforts to improve consumer involvement in Medicaid managed care should be consumer-driven. Creating a role for a consumer co-coordinator for each consumer involvement mechanism being used would contribute greatly to a shared partnership and vision between consumers, the Medicaid agency, and the health plans. Consumers and consumer advocates should be involved in the development of the mechanisms at all stages.



---

*Notices of opportunities to participate should be made available in the languages spoken by the community and in alternative formats.*

---

- ◆ Consumer involvement mechanisms should recognize the important role that trust plays. In practice, Medicaid beneficiaries will turn first to sources they trust. Thus, these sources should be identified and included in the planning of consumer involvement mechanisms.
- ◆ Consumers should be viewed as valued consultants. Consumers should be reimbursed for their expenses and compensated for their time, thus reflecting the fact that they are consultants. Local businesses and grant-making entities can be approached to contribute financially to this effort, thus assuring that consumers remain entirely “independent thinkers.” The state should ensure that reimbursement does not affect eligibility for benefits.
- ◆ Participating consumers, advocates, community-based organizations, mass mailings, and health fairs should be used to identify and recruit additional consumers for involvement. Stakeholders also should advertise and make presentations on opportunities for consumer involvement. Notices of opportunities to participate should be made available in the languages spoken by the community and in alternative formats.
- ◆ Ask consumers and advocates how the agency/health plan can increase consumer participation and how to identify and recruit potential consumer members. New plans, in particular, can benefit from listening to advocates and community-based organizations. There should be follow-up with consumers who stop participating to find out why.
- ◆ Feedback loops should be included to ensure that various stakeholders are informed. Health plans and state and local Medicaid administrators should be accountable to consumers for the information they receive from them.
- ◆ Recommendations that are accepted should be acknowledged as such, and those that are not implemented should be responded to as to why that recommendation was not adopted.
- ◆ Representativeness and a diversity of perspectives are important. The Medicaid agency and health plans should comply with Title VI of the Civil Rights Act, 42 U.S.C. § 2000d, regarding cultural and linguistic requirements,

and with the Americans with Disabilities Act, 42 U.S.C. § 12101 *et seq.* Consumer involvement mechanisms should seek diversity with regard to race, ethnicity, age, health status, geography, and type of medical assistance program. Accommodations should be made to allow and encourage full participation for all individuals.

- ◆ Extend the period of guaranteed eligibility. This allows consumers to stay involved for longer periods of time and increases the likelihood that they will find it worthwhile to participate. Former Medicaid beneficiaries also can play an important role.
- ◆ Effective efforts to involve consumers should be recognized and shared with other communities.

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction* (Dec. 1996) (available from NHeLP, 310-204-6010).

Hans Bleiker and Annemarie Bleiker, *Citizen Participation Handbook for Public Officials and Other Professionals Serving the Public*, 1999 (available from the Institute for Participatory Management and Planning, 831-373-4292).

Gordon Bonnyman for Family Voices, *Managed Care and Children with Special Health Care Needs: Consumer Leadership and Participation* (July 1997) (reproduced at <http://chcs.org/fambonny.htm>).

David Mathews, *Politics for People: Finding a Responsible Public Voice* (University of Illinois Press, 1994).

The Office of Consumer Technical Assistance of Oregon, *How-to Tips* (visit <http://www.orocta.org> or call 503-231-3052).

*“Project participants agreed for the most part that whatever may be the impact of it, consumer education is singularly important. Any educational endeavors should leave consumers with appropriate resources and phone numbers to call for more information or assistance with a problem. If nothing else, if a consumer knows how to begin the process of problem solving, a great purpose will be served.”*

- Ohio Consumer Involvement Action Plan

## Outreach & Education

---

*Well-informed stakeholders of all types are necessary to ensure that consumer rights are recognized and protected.*

---

### Quick Checklist

- # Are there ongoing educational efforts?
- # Are consumers involved in the development of informational materials?
- # Is the information field-tested?
- # Is the information available in appropriate formats for people with disabilities, people with limited literacy, and people with limited English proficiency?

As noted by the Ohio Consumer Involvement Working Group, the best way to increase consumer participation, protection, and satisfaction is to ensure that consumers, consumer advocates, providers, and state and health plan personnel are well-informed. Well-informed consumers are better able to participate, are more likely to take advantage of available protections, and will be more successful at accessing health care — resulting in higher satisfaction. Well-informed advocates, providers, and state and health plan personnel are better able to assist consumers and are better advocates on behalf of consumers. Well-informed stakeholders of all types are necessary to ensure that consumer rights are recognized and protected.

## Recommendations

- ◆ There should be ongoing educational efforts for consumers, consumer advocates, providers, and state and health plan personnel. The content needs to be targeted to the timing of the outreach. Time spent educating consumers and other stakeholders, particularly early on, may prevent problems from occurring.
- ◆ Information should be easy to understand, provided in a variety of formats, up-to-date, translated, accessible to people with disabilities, locally-tailored, and broadly disseminated.
- ◆ Consumers should be involved in the development and field-testing of information prior to distribution. Focus groups, discussed later, are an excellent way to obtain consumer input into the development of informational material and also to verify that the information is clearly conveyed.
- ◆ Any educational endeavor should provide appropriate follow-up resources and phone numbers for stakeholders to call for more information or assistance with a problem.
- ◆ Efforts should be made to avoid jargon, initials, and bureaucratic language. The consumer involvement process should include up-front and ongoing explanations to demystify the language.

- ◆ Efforts should be made to seek out consumers' concerns and interests and to reflect these concerns in program design. The Medicaid agency should widely distribute draft documents, including requests for applications, federal waiver proposals, proposed regulations, and policy directives to consumer organizations and advocates for comment. Copies should be posted on the agency website, along with the names of contact persons, and made available on disk. The agency should maintain a consumer mailing list, so that notices of the availability of the draft documents can be sent to these groups. Copies of documents should be distributed at public meetings. It is important that this outreach occur early in the process, so that the consumer input can be maximized as documents are developed and before they are finalized.
- ◆ The managed care contracting effort should encourage bidding health plans to reach out to and cultivate ties with consumers and consumer organizations. As in New Mexico, each health plan should be required to document in their contract bid which consumer clients and advocates they worked with as the bid was developed, identify these consumers and advocates by name and organization, and state how the proposal reflects the input received. Health plans would then be scored on this response and receive contracting points for maximizing inclusion of their potential members' interests.

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction* (Dec. 1996) (available from NHeLP, 310-204-6010).

Jane Root and Sue Stableford, *Write It Easy-To-Read: A Guide to Creating Plain English Materials (Especially for the Medicaid Market)* (available from the University of New England Health Literacy Center, 207-283-0171, ext. 2337).

Vicky Pulos and Lisa Gallin Lynch, *Outreach Strategies in the State Children's Health Insurance Programs* (June 1998) (<http://www.familiesusa.org/OUT2.HTM>).

The Secretary of Health and Human Services, *Report to the President: Interagency Task Force on Children's Health Insurance Outreach* (June 1998) (reproduced at <http://www.hcfa.gov/init/chiprpt.htm>).

Jeanne McGee, *Field Testing to Improve Information Materials for Consumers: A Do-it-Yourself Guide*, 1995 (available from McGee & Evers Consulting, Inc., 360-574-4744).

Community Service Society of New York, *Medicaid Managed Care Education Project* (visit <http://www.cssny.org> or call 212-614-5400).

---

## *Ohio*

### *Putting Education First*

The Ohio Consumer Involvement Working Group considered the education of consumers and communities to be the best way to increase the effectiveness of consumer protections. The Working Group recommended providing people with accurate and helpful information and education about health plans from the beginning. If a person makes a choice about a health plan based on a good understanding of the delivery system and health plan options, that person will be better matched to the capacity of the plan and will be less likely to need to use the grievance system. In addition to educating consumers, a community must be educated about the changing delivery system and what it means to providers, social service agencies, advocates, and consumers. Information can be shared through a variety of mechanisms and should include, but not rely exclusively on, written materials. Having an informed community, regardless of whether people like or dislike managed care, can increase the effectiveness of consumers accessing health care. *For further information, contact Gene King, Ohio State Legal Services, 614-299-2114.*

---

---

## **Washington**

### *Establishing a Mentorship Program*

The Washington Consumer Involvement Working Group determined that establishing a mentorship program is a key mechanism for achieving consumer involvement. Mentoring involves sharing knowledge, ideas, feedback, and resources, and provides mutually-supporting relationships. Mentorship is a nationally-recognized method of educating and supporting people to become more effective in their work. Mentors should include interested and committed state agency staff, other state and local agency staff, consumers, advocates, and others. The Medicaid agency will benefit from the implementation of this mechanism by having a ready pool of consumers to draw from with the skills and information needed to provide meaningful input. In addition, the success and sustainability of consumer involvement will be improved. *For further information, contact Janet Varon, The Children's Alliance, 206-328-0615.*

### *Hub and Spoke Information System*

The Washington Working Group also recommended establishing a clearinghouse of consistent information and answers to consumer questions. The information bank for Medicaid managed care applicants and enrollees would serve as a “hub” to disseminate information to regional and local “spokes.” The Medicaid agency would designate one organization or group in each region or local area to serve as the lead information resource for that area; these would be the “spokes” that connect to the central Medicaid agency “hub.” These “spokes” would, in turn, work with their communities, including school districts and other systems, to disseminate information and gather input on this information from consumers. *For further information, contact Janet Varon, The Children's Alliance, 206-328-0615.*

---

---

*New Mexico*  
*Educated Educators*

The first report of the New Mexico Consumer Involvement Working Group included the following recommendations to ensure effective informational efforts: Individuals who handle customer service should be adequately trained and have access to superiors who can give quick, correct, and binding information that can be passed on to consumers. In addition, information about the program should be available at community centers, hospitals, clinics, and other places where Medicaid clients are likely to be when they have eligibility or service-related inquiries. Some of this could be provided through volunteer workers, or by providing additional outreach workers, or, probably best of all, beneficiaries could be hired as consultants to provide this information at appropriate sites. Managed care organizations which do not respond quickly and accurately to inquiries from subscribers should be penalized by the state, and the Medicaid contracts should be amended to provide for such penalties. The New Mexico Working Group also recommended that the state conduct advocacy training for anyone interested in doing Medicaid advocacy work, including state personnel and managed care providers. Medicaid beneficiaries should be provided with advocacy training so they can work effectively with individual providers, the Medicaid agency, and with the state legislature. *For further information, contact James Jackson, Health Action New Mexico, 505-323-8394.*

---



*“Partnerships [Kentucky’s managed care providers] should attend or co-host periodic community forums with key local partners and their constituencies quarterly over the next year, bringing managers to respond to policy questions and member services staff to begin to solve individual problems. Medicaid agency staff should attend, too.”*

- Kentucky Consumer Involvement Action Plan

# Public Meetings & Community Forums

## Quick Checklist

- # Is there a commitment to consumer input?
- # Have consumers been involved in planning the meeting or forum?
- # Is the meeting held at a convenient time and place?
- # Is it well advertised?
- # Have special accommodations been made?
- # Is there a way for participants to comment on the meeting process?
- # Is there a mechanism to provide feedback to participants on how their input was used?

A number of states have held public meetings and community forums during the development of their Medicaid managed care programs. While state Medicaid administrators almost uniformly found these forums to be quite valuable, consumers and consumer representatives were frequently discouraged. The following recommendations were suggested by consumers and consumer representatives to improve the success of public meetings and community forums.

## Recommendations

- ◆ There should be a commitment to listening to consumers and to ensuring that their voices are not silenced by other stakeholders.
- ◆ Meetings should be held at locally convenient locations and during accessible times. Ask consumers (in focus groups, surveys, etc.) to recommend the best times and places for meetings.
- ◆ Consumers and other stakeholders should be involved, early on, in the meeting planning process. Consumers and advocates should have input into the purpose and topics of meetings.
- ◆ Consumers and consumer groups should be given adequate prior notice of the meeting, and it should be well advertised. Ask consumers to review the notice to ensure that it is understandable and meaningful. Advertisements should be given in the languages spoken in the community and in alternative formats.
- ◆ The site should be accessible to people with disabilities and special needs. Let participants know that the site will be accessible to people with disabilities and ask in advance if other accommodations, such as sign language or interpreter services, are needed. Include the following notice, with a toll-free telephone number, when advertising the meeting:

*“Let us know by <date> if you need any special accommodations.”*

---

*Meetings should be designed to both obtain input and to provide information. Informational materials, proposed rules and policies for comments, and a toll-free telephone number for further information should be disseminated at the meeting.*

---

- ◆ Childcare, refreshments, and transportation should be provided. Include the following notice, with a toll-free telephone number, when advertising the meeting:

*“Let us know by <date> if you need childcare at the meeting or transportation.”*

- ◆ Meetings should be held on an ongoing basis to gain input at the various stages – i.e., design, implementation, monitoring, and evaluation.
- ◆ Meetings should be designed to both obtain input and to provide information. At the meeting, distribute informational materials, proposed rules and policies for comment, and a toll-free telephone number for further information.
- ◆ Consider using a trained facilitator to keep the meeting focused and to ensure that all participants have an opportunity to be heard.
- ◆ Minutes of meetings should be provided to attendees and posted on the convener’s website.
- ◆ There should be a structure to provide feedback to consumers about how their input has been used.
- ◆ Notice of the meeting and other meeting materials should include information on how to provide additional input for consumers unable to attend the meeting or who wish to provide input outside of the meeting.

## **Resources**

NHeLP and Cecil G. Sheps Center, *Making the Consumers’ Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 77-80 (Dec. 1996) (available from NHeLP, 310-204-6010).

Hans Bleiker and Annemarie Bleiker, *Citizen Participation Handbook for Public Officials and Other Professionals Serving the Public*, 1999 (available from the Institute for Participatory Management and Planning, 831-373-4292).

Cindy Lakin Morley, *How to Get the Most Out of Meetings* 1994 (available from the Association for Supervision and Curriculum Development, 1-800-933-2723).

Deb Richter, *How to Organize a Town Hall Meeting in Eight Weeks* (available from Nurses United CWA Local 1168, 716-852-2511).

---

### *Kentucky Town Meetings*

The Kentucky Consumer Involvement Working Group supported the use of consumer forums to enable consumers to contribute ideas during all phases of managed care, from planning to evaluation. The Working Group felt that it is useful to use a town meeting approach which allows people to have their say. In addition, the staff of the Medicaid agency and the Partnerships [Kentucky's managed care providers] must be present to hear questions and concerns and begin follow-up with the persons who raised them. A meeting where problems can be worked on has a different tone than one where they are simply aired. *For further information, contact Richard Seckel, Kentucky Legal Services, 606-233-3057.*

---

*“The Consumer Involvement Group identified the development of a state level consumer advisory board as a key mechanism for achieving meaningful consumer involvement in medical assistance issues.”*

- Washington Consumer Involvement Action Plan

# Boards & Committees

## Quick Checklist

- # Does the state have an active Medical Care Advisory Committee that focuses on managed care?
- # Do the health plans have active advisory and/or governing boards?
- # Is there a commitment to consumer participation on the boards?
- # Are consumers reimbursed for their time and expenses?
- # Are board meetings open to the public?
- # Are board meetings held at accessible sites and times?
- # Is there training and orientation for board members?
- # Are recommendations of the board used for program improvement?

Most states, some counties, and many health plans involve consumers and/or consumer representatives on boards created to address Medicaid managed care issues. Typically, boards initiated by the state or by health plans are in response to federal or state requirements. Although these boards tend to function as *advisory* boards, some boards, particularly at the plan-level, are *governing* boards and thus have greater authority and responsibility. Consumers and advocates also have formed their own committees to address Medicaid managed care — such as the New York City Task Force on Medicaid Managed Care and Health Action New Mexico. While various boards have different degrees of authority and responsibility, they all share an important role in consumer involvement.

## Recommendations

- ◆ Each state should have a functioning Medical Care Advisory Committee (MCAC) which devotes significant time to Medicaid managed care issues. As required under federal law, the MCAC should include consumers and consumer-oriented groups, such as labor unions and traditional safety-net providers. The MCAC should seek ways to further consumer involvement.
- ◆ The board should be used as a forum for information sharing. Board members should identify their concerns and informational needs. The Medicaid agency, in conjunction with other partners, should provide needed information and education.
- ◆ The role of the board should be defined, up-front, and made clear to all participants. It is critical for the board's authority and role to match the expectations of board members. Projects undertaken by the board should be well-defined, meaningful projects that reinforce the board's purpose and design.
- ◆ The board should respond to inquiries and requests from the state or local agency, health plans, consumers, and consumer advocates and also set its own agenda. The board should select its own chair. Meetings should be conducted in a way that encourages participation of all members.

---

*Individuals with decision making authority should be involved with and attend board meetings. They should report back to the board on how recommendations are being implemented, or, if they are not being implemented, they should explain why not.*

---

- ◆ The board should use subcommittees addressing specific issues or special populations, including children with special needs, persons receiving mental health or substance abuse services, and individuals with developmental disabilities.
- ◆ The board should work with partners to create clear channels of communication to and from membership, community stakeholders, and state representatives and health plans.
- ◆ The role of the consumer on the board should be taken seriously. There needs to be an ongoing commitment to consumer input.
- ◆ Individuals with decision-making authority should be involved in the board meetings and should report back on how the board's recommendations are being implemented or why the recommendations are not being adopted.
- ◆ The board should include consumer representation by both Medicaid beneficiaries and consumer advocates. Ask experienced board members to partner with and mentor new members.
- ◆ Board membership should reflect the cultural, ethnic, linguistic, and racial composition of the Medicaid population and should be chosen based on the recommendations of consumer- and community-based organizations.
- ◆ Board meetings should be open to the public and advertised in advance of the meeting. Openness is a critical aspect of improving trust and cooperation. Each meeting should include a reserved time to hear comments and questions from members of the public and a time to report on how comments/concerns raised at previous meetings have been addressed.
- ◆ Consider implementing a casual dress policy.
- ◆ The board should be active and involved both during and after the early stages of the Medicaid managed care program, recognizing that new issues will arise

---

*Ongoing education in substantive managed care issues should be made available to all board members.*

---

throughout design, implementation, monitoring, and evaluation.

- ◆ Board meetings should be held at accessible sites, such as community centers and public housing sites, and at accessible times. Ask consumers to suggest the most convenient times and locations. Accommodations (e.g., sign language interpreters) should be made if needed to ensure that all people can attend and participate.
- ◆ The agency, health plan, or other stakeholders should provide initial and ongoing training and orientation for board members. Briefing and debriefing sessions should be available before and after meetings for interested consumers. Ongoing education in substantive managed care issues should be made available to all board members.
- ◆ Consumer members should be reimbursed for travel, childcare, and other expenses. Reimbursement should be provided at the time of the meeting. Transportation and on-site childcare should be provided. Ask consumers to recommend a caregiver whom they know and trust.
- ◆ Consumers should be viewed as valued consultants and compensated for their value and expertise as consumers (or “community advisors”).
- ◆ The initial board should help to define future membership criteria, develop recruitment plans, and help recruit future members. The initial board also should investigate and secure funding to reimburse members for their time and expenses.

## **Resources**

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 23-25, 41-50 (Dec. 1996) (available from NHeLP, 310-204-6010).

Office of Medical Assistance Programs, Department of Public Welfare, Commonwealth of Pennsylvania



*Request for Proposal for a Mandatory Medical Assistance Program for Bucks, Chester, Delaware, Montgomery, and Philadelphia Counties* (April 22, 1996) (sample contract provision) (reproduced in Section III).

California Department of Health Services, *Boilerplate Agreement Between Department of Health Services and Contractor* (entered into under the provisions of Section 14087.3, Welfare and Institutions Code) (November 7, 1995) (sample contract provision) (reproduced in Section III).

Hans Bleiker and Annemarie Bleiker, *Citizen Participation Handbook for Public Officials and Other Professionals Serving the Public*, 1999 (available from the Institute for Participatory Management and Planning, 831-373-4292).

A. Fleming Bell, II, *Suggested Rules of Procedure for Small Local Government Boards*, 1998 (available from The Institute of Government, 919-966-4119).

Andrew Swanson, *Building a Better Board: A Guide to Effective Leadership* (The Taft Group, Washington, DC, 1984).

---

## ***New York***

### *The Functions of an Advisory Council*

The New York City Task Force identified four key functions to be filled by an advisory council. The council would: 1) update all the key stakeholders on the status of implementation and solicit input and recommendations regarding implementation; 2) monitor the implementation of mandatory managed care; 3) provide the Medicaid agency with “stories from the field” reflecting beneficiaries experiences with the Medicaid managed care program; and 4) advise the enrollment broker.

Within the advisory council, the Task Force recommended using workgroups to focus on various specialized issues. This has been successful in the past. For example, the Medicaid agency brought plans and consumer advocates together in a workgroup to design Americans with Disabilities Act Guidelines for Managed Care Organizations. The Task Force recommended reconvening a workgroup to review how these guidelines have been implemented and to assess their efficacy. *For further information, contact Elisabeth Benjamin, New York City Task Force on Medicaid Managed Care, 212-577-3386.*

---

---

***Washington***  
*A Consumer-Driven Board*

The Consumer Involvement Working Group identified the development of a state level consumer advisory board as a key mechanism for achieving meaningful consumer involvement in medical assistance issues. The board is a forum for consumers to proactively advise on planning, policies, and procedures so that the state Medicaid agency gains an improved understanding of how to increase the success of its medical programs. Although other advisory and oversight groups exist, the unique contribution of this Board is that it would be consumer-driven, would prioritize issues most important to consumers, and would emphasize establishment of a safe and respectful environment. The Working Group identified the following key elements, among others:

- The Board should ensure that consumers constitute the majority of the members, with composition defined and articulated in the bylaws.
- Board members should represent a wide range of medical assistance programs and should bring diverse perspectives.
- Information, mentorship, and support should be provided to board members at the initiation of and throughout their participation.

*For further information, contact Janet Varon, The Children's Alliance, 206-328-0615.*

---

*“There was a strong feeling that by just asking people their opinions, one can learn much about how things are going. This kind of feedback or participation can happen in a number of ways: through formal focus groups; through informal gatherings with Medicaid consumers at social service agencies; through member luncheons sponsored by health plans; and through interviews with consumers/members.”*

- Ohio Consumer Involvement Action Plan

# Focus Groups

## Quick Checklist

- # Is there a commitment to consumer input?
- # Has there been adequate preparation?
- # Is there a trained and knowledgeable moderator?
- # Is there a written moderator's guide?
- # Is the focus group held at a convenient time and place?
- # Have measures been taken to ensure confidentiality?
- # Are consumers reimbursed for participation and expenses?
- # Is there a structure in place to respond to the feedback provided in the focus group?
- # Are consumers told how their input is used?

In focus groups, a small number of Medicaid beneficiaries are invited to meet with a facilitator and share their experiences and impressions. The information obtained from the groups is summarized, reported to interested parties, and used to improve services to enrollees. Focus groups are a little used, but favorably perceived, method of obtaining information from Medicaid beneficiaries and promoting their participation in managed care programs. One of the advantages of focus groups is that, unlike other mechanisms, focus groups do not require long-term commitments. As a result, focus groups may be a good way to get information from and to consumers who would not otherwise be involved.

## Recommendations

- ◆ There should be adequate groundwork prior to the focus group to ensure consumer attendance.
- ◆ Consumers and advocates should be involved in the planning of the focus groups. Consumers and advocates can help to identify and recruit participants, to suggest specific times and locations, and to identify appropriate uses of focus groups (e.g., to field-test informational materials).
- ◆ Consumers should be reimbursed for expenses and compensated for their participation. Compensation may be in the form of a grocery or department store certificate. Transportation and childcare should be available. Reimbursement should be made at the time of the focus group.
- ◆ The focus groups should be tailored to the local community and held at convenient locations (where the people already are) and times (focusing on the needs of the particular group of participants).
- ◆ Focus group participants should be assured that their names will be kept confidential. The group should use first names only and summaries of focus groups should not refer to any participants by name or disclose other identifying information.

---

*Information obtained should be made public (with safeguards to ensure confidentiality). Public reporting will help the consumer movement gain confidence in Medicaid managed care, inform stakeholders about issues facing consumers, and provide another opportunity for public input into the managed care program.*

---

- ◆ State and county agencies and health plans should utilize focus groups that are tailored to specific populations being served (e.g., people with disabilities, families with children, limited-English speaking populations).
- ◆ The facilitator for the focus group should be well-prepared and not perceived as biased by consumers. To the extent possible, the facilitator should use objective open-ended questions.
- ◆ Focus groups should be used continuously throughout the process — during design, implementation, monitoring, and evaluation stages.
- ◆ Focus groups should be used to identify consumers who wish to participate in other areas (e.g., as board members) and to learn from consumers what it would take for them to become involved in other mechanisms.
- ◆ State and health plan personnel attending focus groups should be rotated so that more plan and state administrators have the opportunity to hear and learn from consumers.
- ◆ Information obtained should be made public (with safeguards to ensure confidentiality). Individual participants should receive information on what was done with their input. Public reporting will help the consumer movement gain confidence in Medicaid managed care, inform advocates, community-based organizations, and other stakeholders about issues facing consumers, and provide another opportunity for public input into the managed care program.
- ◆ Time should be reserved for participants to fill out a questionnaire evaluating the focus group and asking for additional suggestions. If time is not adequate, participants should leave the focus group with a stamped envelope addressed to the convener of the focus group.
- ◆ Focus groups also can be used as a way to inform Medicaid beneficiaries and to distribute information. Participants should be provided with a telephone number to call if they have additional comments or questions.

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 66-70 (Dec. 1996) (available from NHeLP, 310-204-6010).

David L. Morgan and Richard A. Krueger, *The Focus Group Kit* (Sage Publications, Thousand Oaks, CA 1998).

Thomas L. Greenbaum, *The Handbook for Focus Group Research* (Sage Publications, Thousand Oaks, CA, 1998).

Richard A. Powell and Helen M. Single, *Methodology Matters-V: Focus Groups*, 8 *International Journal for Quality in Health Care* 499 (Oct. 1996).

Christy L. Beaudin and Luc R. Pelletier, *Consumer-Based Research: Using Focus Groups as a Method for Evaluating Quality of Care*, 10 *Journal of Nursing Care Quality* 28 (Apr. 1996).

Gilmore Research Group, *Focus Group Moderator's Guide*, 1996 (available from Gilmore Research Group, 206-726-5555).

Alfred E. Goldman and Susan Schwartz McDonald, *The Group Depth Interview: Principles and Practice* (Prentice-Hall, Englewood Cliffs, NJ, 1987).

Joseph M. Viladas, *The Book of Survey Techniques* (Havemeyer Books, Greenwich, CT, 1982).

Jeannine Coreil, *Group Interview Methods in Community Health Research*, 16 *Medical Anthropology* 193 (July 1995).

---

**Ohio**  
*Consumer Feedback Sessions*

The Ohio Working Group felt that focus group-type activity offered the best promise for ongoing consumer feedback. The Working Group felt the most successful approach is to identify pre-existing groups of consumers and join them in a casual meeting to ask some open-ended questions. It was preferable to be able to offer some kind of “thank you” such as a gift certificate to a grocery store. By taking advantage of pre-existing groups, transportation and childcare are not as much of an issue. If, however, they become an issue, most members felt it important to provide transportation and childcare.

Focus groups already are occurring in some areas of Ohio. In Cuyahoga County, for example, the Joint Advisory Council Consumer Subcommittee has been conducting “consumer feedback sessions” every other month. In these sessions, a subset of the full committee meets with a group of consumers and asks a standard set of questions to see how managed care is working for them. The County Department of Human Services has provided \$20 certificates for a local grocery store as a thank-you to participants. This nominal gratuity does not affect eligibility for any benefits. The consumer feedback sessions have provided insight into the impact of managed care. In addition to providing feedback, participants have received information about how best to use their primary care physicians. This has had an impact on members’ use of the emergency room. The sessions have helped advocates, the state agency, and the managed care plans identify the issues of greatest importance to consumers. *For further information, contact Gene King, Ohio State Legal Services, 614-299-2114.*

---

---

***New Mexico***  
*Tailored Focus Groups*

The Consumer Involvement Working Group recommended that focus groups be established to address issues as they are identified during implementation of Medicaid managed care. Beneficiaries should be trained to facilitate focus groups. Focus groups should be held at times and places convenient to consumers in rural and tribal communities. They should be coordinated with feast days, community events, and rural work schedules which may differ from those of urban residents. Existing programs and community groups can be used to convene focus groups. Tribal and Indian Health Service staff should participate in the focus groups. The focus groups should be funded by the Human Services Department Medical Division and managed care organizations. *For further information, contact James Jackson, Health Action New Mexico, 505-323-8394.*

---



*“A project which hires community members for outreach or member services can tap into a high level of commitment in its hires. Commitment communicates itself to the people served and helps build trust.”*

- Kentucky Consumer Involvement Action Plan

# Recipient Employees

## Quick Checklist

- # Is the state complying with federal requirements for recipient employees?
- # Is this effort being coordinated with welfare-to-work requirements?
- # Is there adequate initial and ongoing training?
- # Are recipient employees involved in monitoring accountability?
- # Is there a mechanism to obtain feedback from recipient employees?

As a condition of federal financial participation, the Medicaid Act requires state Medicaid agencies to provide for the training and effective use of beneficiaries and other persons of low income in providing services to applicants and beneficiaries. While the use of recipient employees has been virtually non-existent, this is likely to change with the implementation of welfare-to-work requirements. Notably, each of the study sites recognized the future role that hiring of recipient employees can have in this effort.

## Recommendations

- ◆ Recipient employee programs should be developed and emphasized as a part of states' work programs for welfare recipients. The program should include opportunities for career advancement and professional training and development.
- ◆ Recipient employees should receive adequate training. Responsibilities and caseloads should be appropriate. Absent intensive training and professional supervision, responsibilities should not involve medical skills (e.g., health screening, monitoring medications).
- ◆ Recipient employees should reflect the cultural, racial, and linguistic diversity of the population being served.
- ◆ Recipients should be involved in monitoring the accountability of state and local agencies and health plans. For example, recipients can monitor hotlines for response time, accuracy of information, and helpfulness. They can monitor health plan compliance with federal, state, and contract requirements, such as whether well-child visits are available within accepted time limits. And, they can "test run" complaint procedures to ensure that the systems are responsive.
- ◆ Recipient employees should be involved with the design, implementation, monitoring, and evaluation of other consumer involvement mechanisms. For example, recipient employees can sit on boards, recruit consumers for focus groups and other mechanisms, and participate in designing, implementing, and evaluating surveys.

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 25, 74-76 (Dec. 1996) (available from NHeLP, 310-204-6010).

The Medicaid Act and Regulations, 42 U.S.C. § 1396a(a)(4) and 42 C.F.R. § 432.31 and 432.32 (legal requirements for recipient employees) (reproduced in Section III).

Office of Medical Assistance Programs, Department of Public Welfare, Commonwealth of Pennsylvania, *Request for Proposal for a Mandatory Medical Assistance Program for Bucks, Chester, Delaware, Montgomery, and Philadelphia Counties* (April 22, 1996) (sample contract provision) (reproduced in Section III).

*Lay Health Advisors: A Critical Link to Community Capacity Building*, 24 Health Education & Behavior (Special Issue, Aug. 1997) (Sage Periodicals Press).

Anne Witmer, *et al.*, *Community Health Workers: Integral Members of the Health Care Work Force*, 85 American Journal of Public Health 1055 (Aug. 1995).

Paul T. Giblin, *Effective Utilization and Evaluation of Indigenous Health Care Workers*, 104 Public Health Reports 361 (July/Aug. 1989).

Eva J. Salber, *The Lay Advisory as a Community Health Resource*, 3 Journal of Health Politics, Policy and Law 469 (Winter 1979).

Community Service Society of New York, *Medicaid Managed Care Education Project* (visit <http://www.cssny.org> or call 212-614-5400).

---

***New York City***  
*Consumer Monitors*

The New York City Task Force recommended that consumer monitors be employed to provide “real time” program monitoring about consumers’ experiences. The Task Force suggested that 10 to 30 enrollees per plan be randomly selected and trained to monitor and record their experiences. Each enrollee would be provided a stipend or receive workfare credit, babysitting money, carfare and possibly be recruited for permanent positions. Additional consumers with special health care needs would be identified to underscore the issues that arise for people with special health needs. *For further information, contact Elisabeth Benjamin, New York City Task Force on Medicaid Managed Care, 212-577-3386.*

***New Mexico***  
*Medicaid Beneficiaries as Eligibility Workers*

The Consumer Involvement Working Group recommended that the state should develop a corps of Medicaid eligibility workers who are also Medicaid beneficiaries. Alternatively, employees of New Mexico’s managed care program and their family members should be required to get all of their personal health care through the Medicaid program; this would make them more aware of the problems (and the advantages) of the program, and it would make them more able to respond to inquiries about it. The Working Group also recommended building on the experiences of the Promatora program (a program working in communities composed of predominantly undocumented workers and their citizen children) by employing and training beneficiaries to demonstrate that information, advocacy, and assistance can result in improved health and better use of services provided through the Medicaid managed care program. *For further information, contact James Jackson, Health Action New Mexico, 505-323-8394.*

***Kentucky***  
*Kentucky Homeplace Family Health Care Advisors*

The Cabinet for Health Resources in Kentucky has funded a demonstration program, called Kentucky Homeplace, to train current and former welfare beneficiaries as community outreach workers called Family Health Care Advisors (FHCAs). The FHCAs receive extensive training, including several months of field experience serving low-income families who request help. During the home visit, the FHCAs: provide health information appropriate to the families’ needs; encourage families to use appropriate preventive services; inform families about available services; facilitate families’ use of such services (e.g., making referrals, advocating, accompanying on appointments); and provide follow-up. Early evaluations of the program have been extremely positive and have demonstrated substantial cost savings. *For further information, contact Richard Seckel, Kentucky Legal Services, 606-233-3057.*

---

*“Most oft-mentioned, and of greatest concern, was the difficulty in finding adequately informed customer service representatives who could help Medicaid recipients with individual questions.”*

- New Mexico Consumer Involvement Action Plan

# Member Advocates

## Quick Checklist

- # Did consumers participate in defining the role and qualifications of member advocates?
- # Did consumers participate in the selection/hiring process?
- # Are the member advocates readily available, on site and by phone, to assist consumers?
- # Do the member advocates have sufficient authority to assist consumers? If not, do they have ready access to somebody who does have that authority?
- # Is there a mechanism to obtain feedback from consumers about the member advocates?

A growing number of health plans are hiring “member advocates,” distinct from member services employees and distinct from independent ombudsprograms, to advocate for Medicaid beneficiaries enrolled in the plan. While there is some concern about the member advocate’s lack of independence from the plan, this mechanism generally is perceived by plans, state purchasers, and consumer representatives as a valuable means for maintaining consumer satisfaction and assuring some amount of consumer protection. The degree to which member advocates are helpful will depend upon adequate staffing, the qualifications of the person(s) filling the position, and the degree to which the member advocate is accountable and responsive to plan members.

## Recommendations

- ◆ The qualifications of the member advocate should be clearly defined and consumer oriented. Consumer advocacy groups, consumers, and the ombudsprogram, if operating, should help define these qualifications and participate in the selection/hiring process.
- ◆ Member advocates should help members navigate the managed care system. Core responsibilities should include ensuring that members are informed of their rights and responsibilities, providing education and training to plan staff and provider networks on member rights, monitoring and commenting to plan administrators on changes in provider networks, reviewing and approving informational materials prior to distribution, conducting community outreach, and investigating and resolving access and cultural sensitivity issues. The member advocate also should review and comment on draft policies of the plan and the Medicaid agency.
- ◆ Persons employed as member advocates should have experience in health care and experience advocating for consumers. They should be culturally and linguistically diverse and sensitive to the needs of people with disabilities and people with low-incomes. Plans should consider hiring current and former Medicaid beneficiaries who have worked in health care.

---

*Member advocates should have frequent communication with plan administrators who have the authority to require corrective action.*

---

- ◆ The ratio of member advocates to plan members should be sufficient to allow meaningful use of the service. Where individuals with disabilities or special needs are included in mandatory enrollment, staffing should include dedicated member advocates. The health plan should consider hiring additional member advocates during start-up periods and periods of transition. The adequacy of staffing levels should be monitored on an ongoing basis.
- ◆ Member advocates should have frequent communication with plan administrators who have the authority to require corrective action. The member advocate should be responsible for providing input to plan management on how changes in provider networks will affect consumer access.
- ◆ Member advocates should conduct community education and outreach, through such means as attending health fairs and holding focus groups.
- ◆ Member advocates should sit on health plan and state advisory boards and committees. They should participate in public meetings and community forums and should meet regularly with other member advocates and the state or county ombudsprogram.
- ◆ The member advocate program should be readily accessible both on-site and by telephone and well-advertised. The member advocate should have a toll-free telephone number with live pick-up during business hours and 24-hour answering services, with immediate help for emergencies. Outreach to advertise the member advocate program should include wide distribution of the toll-free number and attendance by the member advocate at various community events, including health fairs and public forums. The plan should display posters in provider reception areas with the advocate's name, picture, and information on how to contact the advocate.
- ◆ The costs associated with member advocates should be included among the administrative costs recognized in the state rate-setting methodology.

- ◆ Member advocates should meet regularly with other member advocates and the public to provide reports of their activities. Plans also should consider rotating member advocates. This allows greater independence and accountability of member advocates.

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 64-66 (Dec. 1996) (available from NHeLP, 310-204-6010).

Bureau for Medical Services, West Virginia Department of Health and Human Resources, *Request for Application* (January 19, 1996) (sample contract provision) (reproduced in Section III).

NHeLP, *Ombudsprograms and Member Advocates: Consumer-Oriented Approaches to Problem-Solving in Medicaid Managed Care* (Sept. 1998) (available from NHeLP, 310-204-6010).

---

### *New Mexico*

#### *Rotating Member Advocates Among Plans*

The New Mexico Consumer Involvement Working Group recommended using member advocates to address the needs of New Mexico's consumers. The Working Group recommended, among other things, rotating member advocates among plans, ensuring that member advocates are trained and sensitive to underserved populations, using a consumer council to develop job descriptions for member advocates, and ensuring that the role of member advocates is well-explained to consumers. The Working Group decided that if resources could not pay for both member advocates and recipient employees, then recipient employees could be used as member advocates. SALUD! [New Mexico's managed care program] could employ and train recipient employees to serve in this role. *For further information, contact James Jackson, Health Action New Mexico, 505-323-8394.*

---



*“An important way to monitor the quality of the Managed Care Program is to assess measures of consumer satisfaction.”*

- Ohio Consumer Involvement Action Plan

# Consumer Surveys

## Quick Checklist

- # Are consumers involved in the design, implementation, and evaluation of the survey and in the analysis and presentation of results?
- # Is the survey conducted by an independent entity?
- # Is the survey instrument available in the languages spoken in the region being surveyed and made available in alternative formats, e.g., braille and oral?
- # Is there an opportunity for consumers to provide feedback on the survey instrument, the administration of the survey, and the presentation of survey results?
- # Are survey results publicized in a useable and understandable format?
- # Are survey results used to improve the program?

Consumer satisfaction surveys are conducted in the vast majority of states and are required under federal law if the health plan uses financial incentives that place physician groups at substantial financial risk. Despite their prevalence, however, beneficiaries and consumer advocates interviewed for this project rarely viewed surveys as among the more effective mechanisms for consumer involvement. And according to a 1997 report of the Department of Health and Human Services Office of Inspector General, "Surveys have yet to provide beneficiaries with information to help them choose a plan. . . . In general, little is known about what information beneficiaries would like to have when faced with a choice of plans." While the field of consumer surveys is progressing rapidly, at this point in time it is not recommended that consumer surveys be emphasized as the primary means of consumer involvement. Nonetheless, surveys are still useful, and it is likely that their utility will increase as more is learned about what consumers want to know and what information surveys can provide.

## Recommendations

- ◆ Surveys should be conducted by an external entity, independent of the state and health plan.
- ◆ Surveys should be used throughout the design, implementation, monitoring, and evaluation phases.
- ◆ Consumers should be involved in the development of the survey instrument, in implementation decisions, and in the analysis, presentation, and utilization of results.
- ◆ The survey instrument should be readable at a fifth-grade level and should be consumer tested prior to distribution. Each question should be a complete question so that respondents do not need to refer back to introductory phrases for multiple questions.
- ◆ The survey should be preceded by advance mailings and mailed under separate cover from eligibility information. The survey and advance mailing should explain that responses will not affect eligibility or services, how the data will be used and by whom, and that identifying information will not be disclosed.

---

*Survey results should be published in a consumer-friendly manner, printed in local newspapers, and provided to consumers at the time of enrollment or re-enrollment.*

---

- ◆ Questions should be relevant to the experience of Medicaid consumers.
- ◆ The survey should be focused to meet a limited number of objectives. To the extent possible, the survey should be short and user-friendly.
- ◆ Sample sizes should be large enough that, after allowing for non-responses, the results are still statistically significant.
- ◆ Sample sizes of vulnerable subgroups, including individuals with specific health care needs, minority populations, and adolescents, should be large enough to ensure adequate representation.
- ◆ Surveyed populations should include both current enrollees and those who have disenrolled.
- ◆ Surveys should be administered in appropriate languages.
- ◆ Surveys should be conducted both orally and in writing. Both methods should be well utilized so that neither beneficiaries without telephone services nor beneficiaries with limited reading and writing abilities are systematically excluded.
- ◆ Survey instruments, methodology, and reporting should be uniform for all plans.
- ◆ Survey results should be published in a consumer-friendly manner, printed in local newspapers, and provided to consumers at the time of enrollment or re-enrollment. Consumers should field-test the presentation of results prior to distribution.
- ◆ Survey results should be used to hold the system accountable, to improve quality, and to monitor individual managed care plans/providers. For example, states should develop and monitor corrective action plans for health plans scoring below a certain level of beneficiary satisfaction (e.g., 80%).

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 31, 70-73 (Dec. 1996) (available from NHeLP, 310-204-6010).

Jeanne McGee, et al., *Making Survey Results Easy to Report to Consumers: How Report Needs Guided Survey Design in CAHPS*, 37 *Medical Care* MS32 (1999 Supp.)

NHeLP and Center for Health Care Rights, *Making Sense of Managed Care Quality Information*, 6.1-6.13 (Nov. 1998) (available from NHeLP, 310-204-6010).

Christine Edlund, *An Effective Methodology for Surveying a Medicaid Population: The 1996 Oregon Health Plan Client Satisfaction Survey*, 20 *Journal of Ambulatory Care Management* 37 (1997).

State of Oregon, Department of Human Resources, Office of Medical Assistance Programs, *1996 Consumer Satisfaction Survey* (Oregon Office of Medical Assistance Programs, 1996).

Connecticut Children's Health Project, *Client Utilization and Satisfaction Survey*, 1996 (available from the Children's Health Project, 860-548-1661).

Harris M. Allen, Jr. & William H. Rogers, *Consumer Surveys of Health Plan Performance: A Comparison of Content and Approach and a Look to the Future*, 22 *Journal of Quality Improvement* 775 (Dec. 1996).

Research Triangle Institute, *Design of a Survey to Monitor Consumers' Access to Care, Use of Health Services, Health Outcomes, and Patient Satisfaction* (Mar. 1995).

---

***New Mexico***  
*Cultural Adaptation of Surveys*

The Consumer Involvement Working Group recommended that a variety of tools should be used for various populations when conducting surveys. For example, Pueblo languages are not written. Thus, trusted persons should administer and read the survey orally. The surveys should be administered on a one-on-one basis during clinic visits or on home visits in rural areas. Consumers should be involved in developing the surveys. *For further information, contact James Jackson, Health Action New Mexico, 505-323-8394.*

***New York***  
*Surveying Accountability*

The New York City Task Force recommended the use of surveys to test the job of the enrollment broker. Consumers should be used by the enrollment broker to field test current materials and in the subsequent creation of their final materials. This would prevent situations, like the one witnessed in upstate New York, in which consumers received information about exemptions, but were not informed that they actually had to do something affirmative in order to activate their exemption. Consumers should be surveyed after they have used the enrollment broker's services to learn: was the enrollment broker effective in providing counseling; did consumers actually know about their right to private, individualized face-to-face counseling; what did the consumers think about their packets; could they understand the information they received; and, did the enrollment broker provide adequate services to consumers who speak languages other than English or who have disabilities. *For further information, contact Elisabeth Benjamin, New York City Task Force on Medicaid Managed Care, 212-577-3386.*

---

---

***Kentucky***  
*The Trust Factor*

The Kentucky Working Group identified several key considerations in the design and implementation of a survey. First, people planning surveys need to consider the time it takes to fill them out. As a general rule, people do not have time for surveys. It is important, on phone surveys, to say up front how much time it will really take. In addition, the Working Group stressed that it makes a difference *who* does a face-to-face survey. Community members and community-based groups may be better received. The Group also recognized that in a face-to-face setting, open-ended questions can be used which may bring forth valuable and sometimes unexpected information. By contrast, written surveys tend to be close-ended and reflect the ideas and perceptions the surveyors already had. *For further information, contact Richard Seckel, Kentucky Legal Services, 606-233-3057.*

---

*“The state should create a well staffed 800 number to answer Medicaid questions from around the state.”*

- New Mexico Consumer Involvement Action Plan

# Hotlines

## Quick Checklist

- # Are consumers involved in the design, implementation, monitoring, and evaluation of hotlines?
- # Are hotline staff knowledgeable about the range of problems consumers face?
- # Are calls answered, by a live voice, within a reasonable time period?
- # Is the hotline well advertised?
- # Does the hotline include a TTY line and staff fluent in the languages spoken in the region being served?
- # Are there routine accountability checks to verify that the hotline is functioning smoothly?
- # Is data about the calls collected, made publicly available (maintaining confidentiality), and used to make system changes?
- # Is there a mechanism to obtain feedback from callers?

Toll-free hotlines are in place for the majority of state Medicaid managed care programs and in many health plans. While hotlines are critical as a safety net measure, our interviews revealed a high level of frustration with hotline services. In general, hotlines have not realized their full potential. The Tennessee hotline is a notable exception — advocates have found that the hotline can often identify systemic problems before the state can identify the problem through other methods. The Tennessee hotline and other hotlines that are successful share some or all of the following characteristics:

## Recommendations

- ◆ Hotlines should be adequately funded and staffed. Staff should be knowledgeable about the Medicaid managed care program and capable of answering questions accurately and promptly.
- ◆ Calls should be answered, preferably by a live voice, within a reasonable time period. The hotline should be monitored for: (1) the number of overflow calls (calls not answered due to a busy signal); (2) the average length of time between the first ring and conversation between the caller and hotline staff (including time spent on hold); (3) the number of hang-ups prior to reaching a live voice; (4) the average duration of each call; (5) the total number of calls handled per day/week/month; (6) the busiest area code; (7) the busiest day by the number of calls; and (8) the busiest hours during the day by the number of calls. Most of these items can be monitored by the telephone company. Resource allocation and staffing should be adjusted accordingly.
- ◆ Staff should be knowledgeable, courteous, and helpful. Staff should have experience working with the populations being served. State agencies should consider rotating workers from field offices to state-operated hotlines (e.g., in six-month cycles).
- ◆ Staff should be culturally and linguistically diverse. Telephone messages should be recorded in English, Spanish, and other languages spoken in the area being served. The hotline also should include a TTY line.



- ◆ Telephone numbers should be local and toll-free. The hotline should be available 24 hours a day. If this is not feasible, at a minimum, an emergency number should be available at all times with immediate response.
- ◆ Data regarding the content of calls should be collected, analyzed, and made publicly available (maintaining confidentiality) for quality assessment and improvement and for consumer choice purposes.
- ◆ The hotline should be monitored by and work closely with a consumer advisory board. The hotline should report regularly to the board. The board should be responsible for reviewing and evaluating this information and making recommendations for improvement.
- ◆ There should be ongoing efforts to publicize the hotline to beneficiaries. Member handbooks from the state and health plans should print the hotline number at the bottom of each page. Stuffers regarding the hotline should be included, periodically, in Medicaid eligibility mailings.
- ◆ Follow-up “quality-control” calls should be made to hotline users to discuss the nature of the services provided by the hotline. The consumer advisory board and a designated state or plan administrator should review reports generated by the hotline and verify ultimate resolution of the problem.
- ◆ State personnel and consumer testers should call both state and health plan hotlines periodically to ensure that they are accessible to English and non-English speaking beneficiaries and to people who are hearing impaired and that the information being provided is accurate. Corrective action plans should be developed and implemented immediately if problems are uncovered during the investigation.

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 50-53 (Dec. 1996) (available from NHeLP, 310-204-6010).

TennCare Consumer Advocacy Program, *Scope of Services: 1996/97* (sample contract requirements) (reproduced in Section III).

Community Service Society of New York, *Medicaid Managed Care Education Project Telephone Assistance Hotline* (visit <http://www.cssny.org> or call 212-614-5400).

---

### *New Mexico Customized Hotlines*

The Consumer Involvement Working Group recommended the following elements for successful hotlines: Staff should be culturally and linguistically diverse and sensitive. When consumers are put on hold, there should be informational recordings on system issues and the recordings should be available in several languages. The state should study the TennCare hotline as one of the few successful efforts and adapt the findings to New Mexico. The hotlines should be used to identify systemic problems and trends and ensure that the information is fed into the systems change mechanisms. Finally, there should be a process for consumer input into hotline functions. *For further information, contact James Jackson, Health Action New Mexico, 505-323-8394.*

---

*“Establishing an on-going dialogue with the consumer assistance programs, to the extent they exist now and as more go ‘live’ over the next few months, will be a remarkable opportunity for government to keep a pulse on issues affecting consumers in a timely way.”*

- New York City Consumer Involvement Action Plan

# Consumer Assistance Programs

## Quick Checklist

- # Are consumers involved in the design, implementation, monitoring, and evaluation of the program?
- # Is the program operated independent of state and local government and health plans?
- # Are program staff appropriately trained and knowledgeable?
- # Is help readily available, both on-site and by phone?
- # Does the evaluation of the program include consumer testers?
- # Is there a mechanism to obtain feedback from consumers who use the program?
- # Is information from the ombudsprogram, including identification of systemic problems, used for program improvement?

An increasing number of states are using ombudsprograms (or consumer assistance programs) to assist enrollees in Medicaid managed care programs and to monitor the quality of care delivered in managed care settings. An ombudsprogram is an entity which engages in independent investigation of individual complaints and issues recommendations. Typically, the program does not have enforcement powers. Nonetheless, these programs can play a critical role in inspiring consumer confidence in the system by making available a watchdog for consumers who will hold governments and health plans accountable and by providing consumers with an impartial agent at no charge. Ultimately, these programs can improve the administration of managed care itself. The specific characteristics of the ombudsprograms which are currently operational vary greatly. However, ombudsprograms generally are perceived as helpful in remedying individual problems and in identifying systemic problems.

## Recommendations

- ◆ The ombudsprogram should be operated and housed independent of state/local government and health plans. Programs that are not independent are not true ombudsprograms.
- ◆ The ombudsprogram should have clear goals and responsibilities, rules of program conduct, and the authority to implement its responsibilities. The first-and-foremost goal should be to serve the interests of individual beneficiaries. Goals and responsibilities should be reevaluated periodically to accommodate changes. Goal-setting processes should include input from consumers, consumer organizations, plans, providers, and the state.
- ◆ The program should have adequate funding and adequate staff to meet the needs of beneficiaries free of charge. A range of funding sources should be explored, from general state revenues to private foundation grants to tithing by managed care organizations. The program should have adequate time and funding for planning and design. Because of the costs associated with initiating the program and to allow for the development of

---

*Information should be collected and analyzed, made available to the public, the Medicaid agency, the state legislature, and the health plans, and used to identify and address systemic problems.*

---

expertise, funding should be guaranteed for a minimum of three years.

- ◆ Staff should be well-trained and have advocacy backgrounds. Staff should have experience serving the population and should include individuals who are representative of the cultures and language needs of the Medicaid beneficiaries being served. Staff should have experience serving people with special health care needs. Staffing levels should be monitored on an ongoing basis.
- ◆ The program should include local offices for face-to-face contact and walk-in visits. If the program operates statewide, there should be one central office to serve as a clearinghouse for the service sites.
- ◆ The ombudsprogram should be well-advertised and readily accessible both by telephone and in-person. The program should use a toll-free telephone number that is widely advertised to beneficiaries (e.g., on Medicaid eligibility cards).
- ◆ The program should develop and serve as a clearinghouse for objective educational materials for consumers, participate in consumer education, investigate and solve problems, and engage in systemic advocacy, including compiling reports on the status of Medicaid managed care and making recommendations to state and local agencies and plans. The program should refer consumers to free legal assistance.
- ◆ The program should not assume responsibilities that have been designated to other participants in the managed care system. Rather, the ombudsprogram should be used as a mechanism to ensure that the system works effectively. For example, the ombudsperson should not act as a case manager or care coordinator since this function is the responsibility of the state and health plans.
- ◆ Through its database of calls and requests for assistance, information should be collected and analyzed, made available to the public, the Medicaid agency, the state legislature, and the health plans, and used to identify and address systemic problems. All reports should maintain confidentiality of information about individual

beneficiaries. Ombudspersons should hold regular meetings with consumers, advocates, health plans, and state and local personnel to discuss activities and problems.

- ◆ Consumer needs should be identified through periodic needs assessments.
- ◆ The program should engage in outreach, with particular attention to vulnerable populations. The program should publish an annual report which contains information about program activities and statistical information on complaints received and resolved.
- ◆ The ombudsprogram should be evaluated, both internally and by an independent entity. Self-evaluation should include follow-up calls to enrollees who used the program to verify case closure and to review the enrollee's satisfaction with the ombudsprogram. The external evaluation factors should be determined prior to the initiation of the ombudsprogram, with input from consumers and consumer advocacy organizations. Consumer "testers" should be involved in the evaluation process.

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 59-64 (Dec. 1996) (available from NHeLP, 310-204-6010).

NHeLP, *Model Ombudsprogram* (model contract and legislative provision) (reproduced in Section III).

Hans Bleiker and Annemarie Bleiker, *Citizen Participation Handbook for Public Officials and Other Professionals Serving the Public*, 1999 (available from the Institute for Participatory Management and Planning, 831-373-4292).

NHeLP, *Ombudsprograms and Member Advocates: Consumer-Oriented Approaches to Problem-Solving in Medicaid Managed Care* (Sept. 1998) (available from

NHeLP, 310-204-6010).

New York City Task Force on Medicaid Managed Care, *Ombudsman Feasibility Study* (a series of four reports) (available from The Legal Aid Society, 212-577-3386).

Peter V. Lee & Carol Scott, *Managed Care Ombudsman Programs: New Approaches to Assist Consumer and Improve the Health Care System* (Dec. 1996) (available from the Center for Health Care Rights, 213-383-4519).

Sam Zagoria, *The Ombudsman: How Good Governments Handle Citizens' Grievances* (Seven Locks Press, 1988).

Health Consumer Alliance (a consumer assistance program in California) (visit <http://healthconsumer.org> or call 415-732-5750).

Massachusetts Managed Care Consumer Advisory Board Ombudsman (visit <http://www.state.ma.us/ombud/> or call 617-753-8618).

---

### *New York City*

#### *Keeping a Pulse on Issues Affecting Consumers*

The Task Force's major recommendation is to implement an ombudsprogram. The Task Force suggests that the Medicaid agency identify "point people" to deal with concerns that arise as consumers navigate the managed care system and to resolve individual cases in an informal way. Reports and data that reflect trends should be shared so that systemic problems can be "nipped in the bud" as they are identified. Establishing an on-going dialogue with existing consumer assistance programs will be a remarkable opportunity for the agency to keep a pulse on issues affecting consumers in a timely way. *For further information, contact Elisabeth Benjamin, New York City Task Force on Medicaid Managed Care, 212-577-3386.*

---

---

*Kentucky*  
*A Local Presence*

The Kentucky Working Group recommended that the medicaid agency contract with community-based organizations to create a local presence for a managed care ombudsprogram in each active Partnership [Kentucky's managed care providers] region. The local programs should be linked in a network, to each other, and to a Frankfort base or resource center. Members of the Working Group felt that a local presence helps build trust and that ombudspersons at local levels would be better able to get to the facts of individual cases and complaints. A local presence also makes sense in light of the variations in Kentucky's managed care program from region to region. The Working Group also mentioned that care should be taken in the design of the local presence to make sure that the ombudsperson is not "captured" by the regional Partnership. Program staff must understand the appeals process and due process rights. Experience as a consumer advocate should weigh heavily in the qualifications for ombudsprogram staff. *For further information, contact Richard Seckel, Kentucky Legal Services, 606-233-3057.*

---



*“In the transition to managed care in Kentucky, many aspects of the complaint procedure have been addressed. Yet while we have the right structures on paper, it will take several years and a big commitment to build a world in which consumers feel informed, empowered and safe when they take on the system.”*

- Kentucky Consumer Involvement Action Plan

# Complaint Processes

## Quick Checklist

- # Are consumers involved in the design, implementation, monitoring, and evaluation of the complaint processes?
- # Are government and health plan personnel appropriately trained and knowledgeable about federal and state requirements?
- # Are there structural safeguards to ensure the accountability of the process?
- # Is the process well advertised, in an understandable fashion?
- # Are consumers notified of sources of help, including free legal assistance?
- # Is there a mechanism to obtain feedback from consumers who use the process?
- # Is data about complaints collected, made publicly available (maintaining confidentiality), and used to make system changes?

The phrase “complaint process” is being used here to describe both the in-plan grievance process and the state-level fair hearing process. While federal Medicaid laws require all states to have formal complaint procedures at both the state and the plan levels, key informants expressed a high degree of confusion and dissatisfaction with complaint procedures, describing them as “existing on paper, but nonfunctional in practice.” The following characteristics were identified as critical to the success of the complaint process:

## Recommendations

- ◆ State and local agency and health plan personnel should be knowledgeable about federal law requirements. Personnel who work with the complaint process should have a readily accessible copy of the grievance and fair hearing requirements.
- ◆ Efforts should be taken to make the process user-friendly. Consumers and consumer advocates should be involved in the design, implementation, monitoring, and evaluation of the process.
- ◆ Consumers should be appointed to monitor and test the grievance system. Plans that are aware that they are being tested and monitored may make additional efforts to ensure that the process works as smoothly and as fairly as possible. Consumers who have used the complaint process should be asked to evaluate the process and make recommendations for improvement.
- ◆ There should be a uniform grievance process from plan to plan, with specified time frames. The terms used to describe the complaint process should be simplified and used uniformly.
- ◆ Consumers, advocates, and other community members should participate on committees hearing grievances. Public participation on grievance committees will improve public accountability and public trust.
- ◆ Ongoing educational efforts should be undertaken to ensure that consumers are aware of and understand the

---

*Consumers should be involved in monitoring and testing the grievance system. Plans that are aware that they are being tested and monitored may make additional efforts to ensure that the process works as smoothly and as fairly as possible.*

---

plan- and state-level procedures at the time they enroll and at the time of a denial, reduction, or termination of services or eligibility. Member handbooks should explain all of the options. Consumers and consumer organizations should field-test this information to ensure that it accurately and effectively conveys the intended information.

- ◆ State and community-based personnel should be available to assist consumers with complaints. As part of the plan's grievance procedures, a person should be available, by telephone and on-site, to provide assistance in filing complaints.
- ◆ Consumers should be notified of the availability of free legal assistance, such as Legal Aid and Protection and Advocacy programs.
- ◆ Consumers should be able to pursue state fair hearings without exhausting plan grievance procedures and should be notified of their right to do so.
- ◆ Where services are terminated or reduced, benefits should be continued pending a final decision, in accordance with federal law.
- ◆ Consumers should have access to second opinions.
- ◆ Complaints should be filed directly with the state where they should be logged and returned to the health plan for resolution, allowing the state to monitor content and complaint resolution. Any urgent complaints should be resolved immediately by the state. Consumers should be notified of the time frames and availability of an expedited review process.
- ◆ Complaint data should be monitored, made available to the public (maintaining confidentiality), reported to the state, and utilized by the state and health plans in creating corrective action plans. Complaint data should be used during contract renewal, in determining the need for sanctions, and for internal quality improvement purposes.
- ◆ Health plans and the state agency should report on the number, nature, and resolution of complaints during

consumer advisory board meetings. The consumer board should review and evaluate the information and make suggestions for improvement.

## Resources

NHeLP and Cecil G. Sheps Center, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction*, 25-27, 54-58 (Dec. 1996) (available from NHeLP, 310-204-6010).

The Medicaid Act and Regulations, 42 U.S.C. § 1396a(a)(3) and 42 U.S.C. § 1396u-2(b)(4); 42 C.F.R. §§ 431.200 - 431.250; 42 C.F.R. § 434.32 (legal requirements for complaint processes) (reproduced in Section III).

NHeLP, Model Complaint Processes (Jan. 1999) (reproduced in Section III).

General Accounting Office, *Medicare Managed Care: Greater Oversight Needed to Protect Beneficiary Rights* (Apr. 1999) (available from the GAO, 202-512-6000).

Joanne Rawlings-Sekunda, *Addressing Complaints and Grievances in Medicaid Managed Care* (Jan. 1999) (available from National Academy for State Health Policy, 207-874-6524).

NHeLP and Center for Health Care Rights, *Making Sense of Managed Care Quality Information*, 5.1-5.11 (Nov. 1998) (available from NHeLP, 310-204-6010).

Families USA and NHeLP, *A Guide to Complaints, Grievances, and Hearings Under Medicaid Managed Care* (Jan. 1998) (available from Families USA, 202-628-3030).

James T. Ziegenfuss, *Patient-Client-Employee Complaint Programs: An Organizations Systems Model* (1985).

---

## *Kentucky*

### *Developing a Consumer-Oriented Complaint Process*

Upon drafting contract language, the agency posted it on its website for general comment. Consumer groups reviewed, commented on, and met with the state agency on multiple occasions regarding contract provisions dealing with the grievance process. What resulted is a model complaint process that includes, among other things, a process for evaluation of patterns of complaints, a process for changing policies and procedures in response to problems, and provision of complaint data to state and plan level Recipient Access Advisory Committees (required for all plans). These committees are composed of plan members, advocates, and public health recipients. The Consumer Involvement Working Group added the following specific ideas:

- Consumers should get a pocket-sized card listing the services covered by their plan. On the back, the card should give a summary of consumer rights, plus key phone numbers for questions, complaints, and grievances. This should include the state 800 line.
- Providers and Partnerships should have concrete incentives to observe due process rights, including sanctions for failure to observe them and rewards for doing so.
- Information about complaints, grievances and the response must be gathered and evaluated by Partnerships, including consumer advisors and board members. The current structure requires this, but several Working Group members were interested in monitoring to make sure it happens.

*For further information, contact Richard Seckel, Kentucky Legal Services, 606-233-3057.*

---

## **S**ection III: Legal Requirements and Model Provisions

---

<b>Boards and Committees</b> .....	73
Pennsylvania’s Request for Proposals .....	73
California’s Local Authority Contract .....	74
<b>Recipient Employees</b> .....	75
The Medicaid Act and Regulations .....	75
Pennsylvania’s Request for Proposals .....	77
<b>Member Advocates</b> .....	79
West Virginia’s Request for Applications .....	79
<b>Hotlines</b> .....	81
TennCare Consumer Advocacy Program .....	81
<b>Consumer Assistance Programs</b> .....	83
National Health Law Program Model .....	83
<b>Complaint Process</b> .....	87
The Medicaid Act and Regulations .....	87
National Health Law Program Model .....	95



## **Boards and Committees: Pennsylvania's Request For Proposals**

OFFICE OF MEDICAL ASSISTANCE PROGRAMS, DEPARTMENT OF PUBLIC WELFARE, COMMONWEALTH OF PENNSYLVANIA REQUEST FOR PROPOSAL FOR A MANDATORY MEDICAL ASSISTANCE PROGRAM FOR BUCKS, CHESTER, DELAWARE, MONTGOMERY, AND PHILADELPHIA COUNTIES (April 22, 1996) [Eff. date: 11/1/96 - 10/31/99].

### **Part II, § E.3 (p. 36) Education and Outreach**

The HMO must establish and maintain a Health Education Advisory Committee that includes members and providers of the community to advise on the health education needs of managed care members. Representation on this Committee shall include, but not be limited to, women, minorities, and persons with special needs and at least one (1) person with expertise on the medical needs of children with special needs. . . . HMOs shall also work with the Department to ensure that their respective Health Education Advisory Committees are provided with an effective means to consult with each other and, when appropriate, coordinate efforts and resources for the benefit of the entire HealthChoices population or populations with special needs. The Department strongly encourages the inclusion of physicians on the HMO's Health Education Advisory Committee.

### **Part II, § M.5 (pp. 79-80) Consumer Advisory Committee**

Each HMO must send knowledgeable staff to attend a regularly scheduled advisory meeting. The Committee shall advise the Department on related issues such as:

- Review of HMO networks, e.g., number of pediatricians, PCPs acting as specialists, providers specializing in the care of persons with HIV and other conditions, pediatric specialists, provider capacity for new enrollees, etc.
- Review standards of care for adults, children, home care, etc., and particularly for evolving treatment for HIV and where standards of HMOs have not kept pace with evolving treatment.
- Performance measures review. The Committee will review the criteria and recommendations for performance measures.
- Issues and complaints. The Committee will discuss and recommend for resolution any complaints or issues brought to it by the Department, consumers, providers, HMOs, or the community.



## **Boards and Committees: California's Local Authority Contract**

CALIFORNIA DEPARTMENT OF HEALTH SERVICES, BOILERPLATE AGREEMENT BETWEEN DEPARTMENT OF HEALTH SERVICES AND CONTRACTOR (entered into under the provisions of Section 14087.3, Welfare and Institutions Code) (November 7, 1995) [Eff. date: Ends 3/31/2002].

### **§ 6.10.5 (p. 107) Community Advisory Committee**

Contractor will implement and maintain community linkages through the formation of a Community Advisory Committee (CAC) with demonstrated participation of consumers, community advocates, and Traditional and Safety-Net providers. The Contractor will ensure that the committee responsibilities include advisement on educational and operational issues affecting groups who speak a primary language other than English and cultural competency.

## Recipient Employees: The Medicaid Act and Regulations

### 42 U.S.C. § 1396a(a)(4) (1998 Supp.)

A State plan for medical assistance must —

(4) provide . . . (B) for the training and effective use of paid subprofessional staff, with particular emphasis on the full-time or part-time employment of recipients and other persons of low income, as community service aides, in the administration of the plan and for the use of nonpaid or partially paid volunteers in a social service volunteer program in providing services to applicants and recipients and in assisting any advisory committees established by the State agency . . . .

### 42 C.F.R. § 432.31 Training and use of subprofessional staff

- (a) *State plan requirement.* A State plan must provide for the training and effective use of subprofessional staff as community service aides, in accordance with the requirements of this section.
- (b) *Recruitment and selection.* The Medicaid agency must have methods of recruitment and selection that afford opportunity for full-time or part-time employment of persons of low income, including:
  - (1) Young, middle-aged, and older persons;
  - (2) Physically and mentally disabled; and
  - (3) Recipients.
- (c) *Merit system.* Subprofessional positions must be subject to merit system requirements except where special exemption is approved on the basis of a State alternative plan for employment of disadvantaged persons.
- (d) *Staffing plan.* The agency staffing plan must include the kinds of jobs that subprofessional staff can perform.
- (e) *Career services.* The agency must have a career service program that allows persons:
  - (1) To enter employment at the subprofessional level; and
  - (2) To progress to positions of increasing responsibility and reward:
    - (i) In accordance with their abilities; and
    - (ii) Through work experiences and pre-service and in-service training.
- (f) *Training, supervision, and supportive services.* The agency must have an organized training program, supervision, and supportive services for subprofessional staff.

- (g) *Progressive expansion.* The agency must provide for annual increase in the number of subprofessional staff until:
  - (1) An appropriate ratio of subprofessional and professional staff has been achieved; and
  - (2) There is maximum use of subprofessional staff as community aides in the operation of the program.

**42 C.F.R. § 432.32 Training and use of volunteers.**

- (a) *State plan requirement.* A State plan must provide for the training and use of non-paid or partially paid volunteers in accordance with the requirements of this section.
- (b) *Functions of volunteers.* The Medicaid agency must make use of volunteers in:
  - (1) Providing services to applicants and recipients; and
  - (2) Assisting any advisory committees established by the agency.

As used in this paragraph, “partially paid volunteers” means volunteers who are reimbursed only for actual expenses incurred in giving service, without regard to the value of the service or the time required to provide it.

- (c) *Staffing.* The agency must designate a position whose incumbent is responsible for:
  - (1) The development, organization, and administration of the volunteer program; and
  - (2) Coordination of the program with related functions.
- (d) *Recruitment, selection, training, and supervision.* The agency must have:
  - (1) Methods of recruitment and selection that assure participation of volunteers at all income levels in planning capacities and service provision; and
  - (2) A program of organized training and supervision of volunteers.
- (e) *Reimbursement of expenses.* The agency must —
  - (1) Reimburse volunteers for actual expenses incurred in providing services; and
  - (2) Assure that no volunteer is deprived of the opportunity to serve because of the expenses involved.
- (f) *Progressive expansion.* The agency must provide for annual increase in the number of volunteers used until the volunteer program is adequate for the achievement of the agency’s service goals.

## **Recipient Employees: Pennsylvania's Request For Proposals**

OFFICE OF MEDICAL ASSISTANCE PROGRAMS, DEPARTMENT OF PUBLIC WELFARE, COMMONWEALTH OF PENNSYLVANIA REQUEST FOR PROPOSAL FOR A MANDATORY MEDICAL ASSISTANCE PROGRAM FOR BUCKS, CHESTER, DELAWARE, MONTGOMERY, AND PHILADELPHIA COUNTIES (April 22, 1996) [Eff. date: 11/1/96 - 10/31/99]

### **Part III § A.6 (p. 107) HMO Responsibility to Employ Welfare Recipients**

The HMO shall make a good faith effort to outreach, train, and employ welfare recipients in accordance with the provisions of Appendix Z.

### **Appendix Z Contractor Responsibility to Employ Welfare Recipients**

The successful contractor, within 10 days of receiving the unsigned contract, shall contact the Employment Unit Coordinator in the County Assistance Office in the county where the contractor delivers the service to present, for review and approval, contractor's plan for recruiting and hiring of public assistance recipients for employment under this contract. Contractors which provide services through the contract to more than one county, shall present their plan for review and approval to the central Office of Employment [and sic] Training, such plan shall be submitted o[n sic] Form PA 778. A copy of the contractor's approved plan shall be returned with the signed contract to the initiating office/facility for processing.

\* Pursuant to the approved plan, the contractor shall make a good faith effort to fill at least 25% of the new or vacant jobs created under this contract with qualified recipients referred by the County Assistance Office Employment Unit Coordinator.

\* Hiring under the approved plan shall be verified by Quarterly Contract Reports on Form PA 1540 to the Employment Unit Coordinator or to the Central Office of Employment and Training for plans covering more than one county. Such reports shall be made in the format approved by the Department.

\* The Department may cancel this agreement upon 30 days written notice in the event of contractor's failure to implement or abide by an approved plan.

\* Form PA 778 is required to be filled out by successful contractor and will be enclosed with the contract at the time it is presented for the contractor's signature.



## **Member Advocates: West Virginia's Request for Applications**

### **BUREAU FOR MEDICAL SERVICES, WEST VIRGINIA DEPARTMENT OF HEALTH AND HUMAN RESOURCES, REQUEST FOR APPLICATION (January 19, 1996).**

#### **Part 3 § 4.3.2 (p. 30) Medicaid Member Advocate**

The Member Services Department must employ a Medicaid Member Advocate. The Medicaid Member Advocate must be responsible for making recommendations to management on any changes needed to improve either the actual care provided or the manner in which the care is delivered. The person must be in a position within the MCP [Managed Care Plan] which provides the authority needed to carry out these tasks. This person must demonstrate substantial experience in health care, experience working with low-income populations and cultural sensitivity. . . . This advocate will:

- a) Investigate and resolve access and cultural sensitivity issues identified by MCP staff, State staff, providers, advocate organizations and recipients;
- b) Monitor MCP formal and informal grievances with the grievance personnel to look at trends or major areas of concern and discuss these reports with community advocates, if requested;
- c) Coordinate with schools, community agencies, local health departments, state health laboratories and state agencies providing complementary services to Medicaid enrollees;
- d) Recommend policy and procedural changes to MCP management including those needed to ensure and improve enrollee access to care and quality of care; changes can be recommended for both internal administrative policies and providers;
- e) Function as a primary contact for recipient advocacy groups and work with these groups to identify and correct recipient access barriers;
- f) Participate in local community organizations to acquire knowledge and insight regarding the special health care needs of recipients;
- g) Analyze systems functions through meetings with staff;
- h) Organize and provide training and educational materials for MCP staff and providers to enhance their understanding of the values and practices of all cultures with which the MCPs interact;
- i) Provide input to MCP management on how provider changes will affect enrollee access and quality/continuity of care; develop/coordinate plans to minimize any potential problems;

- j) Review all informing materials to be distributed to enrollees; and
- k) Assist enrollees and authorized representatives to obtain medical records.

## Hotlines: TennCare Consumer Advocacy Program

The Tennessee Department of Finance and Administration has contracted with the Crisis Intervention Center, a nonprofit organization “specializing in addressing the needs of Tennessee’s ‘special populations,’” to provide hotline assistance services to enrollees and applicants. These services have been nationally recognized as exceptional.

### Scope of Services: 1996/97

The Crisis Intervention Center agrees to provide assistance services to enrollees and applicants of the TennCare program. Such assistance services will include:

- A. Providing five 1-800 phone lines (Advocacy Lines), to be staffed by trained personnel, for the purpose of answering and addressing concerns of TennCare enrollees who request assistance in receiving necessary medical care. The Advocacy Lines will be available Monday through Friday from 8:00 am until 6:00 pm (Central Time).
- B. Serving as advocates for enrollees of the TennCare program who request assistance. This advocacy shall include assistance on behalf of the enrollee in his or her dealings with MCOs, providers, and the TennCare Bureau. Advocates assist the enrollees in accessing needed TennCare covered services and advocate on behalf of the enrollee on matters that cannot be resolved.
- C. Establishing a TennCare Consumer Advocacy Program Advisory Committee to create guidelines and standards as well as to oversee the operation of the services provided under this contract.
- D. Installing one 1-800 phone line, to be staffed by an Hispanic Coordinator, to reach the Hispanic population statewide. This phone line will be available Monday through Friday from 8:00 am until 4:30 pm, Central Time. Upon request, the coordinator shall assist the TennCare Bureau in translating TennCare enrollment forms and other printed materials. The coordinator shall establish and work with an Hispanic Advisory Committee.
- E. Providing two 1-800 phone lines (Denial Lines), to be staffed by trained personnel for the purpose of answering and addressing concerns of TennCare applicants who have been notified by the TennCare Bureau that they are not eligible for TennCare, and advising the applicant of other methods to obtain health insurance or where to go to receive medical care. These phone lines will be available Monday through Friday from 8:00 am until 6:00 pm (Central Time).
- F. Distributing (via mail and presentations) appropriate TennCare educational information to TennCare enrollees. Participate in and coordinate meetings state-wide for the purpose of informing case workers, enrollees, and others about TennCare and about the services of the Advocacy Program.



- G. Recording, sorting, and analyzing the nature of the difficulties that TennCare enrollees are having in obtaining medical care, as well as information obtained from those filing appeals with the TennCare Bureau. This research data shall be reported to the TennCare Bureau on a regular basis. Quarterly reports of the work of the Advocacy Line shall be written and distributed to the TennCare Bureau. An annual report shall be written and made available to the TennCare Bureau and the general public.
- H. Additional 1-800 phone lines may be authorized by written letter of approval from the TennCare Bureau.

## Consumer Assistance Programs: National Health Law Program Model

### Model Ombudsprogram Provision

#### *Purpose of the ombudsprogram*

Consumers are facing increasing frustration with the lack of resources available to them to address problems with access and quality in managed care plans. Consumers often lack objective information about the quality of specific plans and have few resources for learning about their rights with respect to obtaining timely and quality care.

Because purchasers and managed care plans operate with incentives to hold down costs, there needs to be independent oversight to ensure that there are not inappropriate trade-offs between controlling cost and providing care. This provision establishes an ombudsprogram that would operate at the state and local levels to monitor Medicaid managed care access, service delivery, and quality; to serve as a clearinghouse for objective consumer information; and to work locally and at the state level with consumers, consumer organizations and advocates, managed care plans, and government administrators to help consumers understand managed care and make appropriate use of it. The ombudsprogram will help consumers address their individual concerns and address patterns of problems where necessary. It is the intention of this provision that the ombudsprogram be funded adequately over the long-term so that staff can meet their prescribed responsibilities, as set forth herein.

#### *Description of the ombudsprogram*

1. A statewide [county-based] managed care ombudsprogram shall be established to protect Medicaid beneficiaries who are enrolled in managed care plans, mental health managed care plans, and any other kind of prepaid health plan.
2. The ombudsprogram will operate independently of any state or local agency or health plan.
3. The ombudsprogram will operate one state-level office and at least \_\_ local offices to serve metropolitan, county, and rural areas.
4. The offices of the ombudsprogram will be physically accessible and operate consistent with the Americans with Disabilities Act and Title VI of the Civil Rights Act.
5. The ombudsprogram will be culturally and linguistically accessible.

*Responsibilities of the state-level office*

6. The state office will be responsible for the following:
  - a. Creation and distribution of easy-to-understand consumer educational materials addressing consumer rights in Medicaid managed care. The ombudsprogram shall watch for changes in policy and inform the public of these changes. This responsibility is not a substitute for the educational activities performed by the state Medicaid agency, its enrollment entity, or the health plans. The state ombudsprogram office shall create new materials only where there are no existing materials or where existing materials are inadequate.
  - b. Collection and analysis of data regarding health plan performance in areas related to access and quality of care. The state office will issue annual “report cards” comparing plans within the same service area. The state office will hold discussions with consumers, consumer organizations, and consumer advocates to make sure that these reports contain information that consumers want and that consumers know about the availability of this information.
  - c. Acting as a clearinghouse for managed care data relevant to consumers. To this end, the state office of the ombudsprogram will have access to all data, audits, surveys, complaints, investigations, findings and corrective actions collected and/or conducted by any state agency responsible for monitoring managed care plans, including but not limited to the Department of Insurance and the Division of Medical Assistance.
  - d. Providing training and support to the local ombudsprogram offices and other consumer advocacy and provider groups, including legal services and protection and advocacy offices.
  - e. Working with the state or entities contracting with the state to survey consumers regarding their satisfaction with managed care plans.
  - f. Reporting annually to the Legislature and the public on the ombudsprogram's activities and managed care issues of concern to consumers.
  - g. Maintaining a toll-free number for consumers to call to obtain information about their local ombudsprogram office. The number shall be accessible to the hearing impaired and to non-English proficient individuals.
  - h. Ensuring that consumers in all parts of the state have readily available access to the services of at least one local office of the ombudsprogram.
  - i. Develop a centralized database for the collection of uniform data. The state office shall ensure that local ombudsprogram offices collect data uniformly. The state office will analyze and report on trends and areas of concern.

### *Responsibilities of the local offices of the ombudsprogram*

7. The local offices of the ombudsprogram will be responsible for the following activities:
  - a. Maintaining a toll-free number for beneficiaries to call. This number should be well-advertised. Multiple lines should be used, depending on the volume of calls. The number of lines should be periodically evaluated to assure that they are adequate to handle the number of incoming calls.
  - b. Assisting individual enrollees who are experiencing problems. Such activities include, but are not limited to: informing beneficiaries of their rights, including the right to a plan-level grievance proceeding and a state-level fair hearing; solving problems on an informal basis; representing individuals in plan-level grievance proceedings; and referring individuals to outside legal assistance.
  - c. Providing beneficiaries with educational materials and training regarding their rights. The local offices also will disseminate report cards and other information concerning the performance of specific plans. Materials shall be translated for individuals in language groups meeting the thresholds specified by the state ombudsprogram office.
  - d. Providing support and coordination to other local patient advocates, including local legal services and protection and advocacy programs.

### *Miscellaneous provisions*

8. The ombudsprogram shall have responsibility for hiring, training, and maintaining sufficient staff and for setting program priorities.

9. The ombudsprogram shall be funded through general state revenues and, in part, by state-licensed and Medicaid-participating managed care plans which must contribute \$\_\_ per enrollee per month in the first year, and in subsequent years, an amount which can be adjusted by the Legislature. Other sources of supplementary funding, such as foundation support, should be pursued as well.

10. The office of the ombudsprogram shall be administered by one or more non-profit organizations that obtain a state contract on a bid basis. The bidders must demonstrate that they have ongoing involvement and expertise in providing direct assistance to consumers with respect to their concerns and problems with managed care plans and the capacity to carry out the activities of the ombudsprogram. The ombudsprogram must include consumers and consumer advocates on its board of directors, including at least three consumer advocates. At least one board member must have expertise in assessing the quality of care provided by managed care plans. No board member may have an ownership interest in or otherwise be affiliated with a managed care plan.

11. The ombudsprogram shall have access to and copies of the full medical and other records of an individual enrollee upon his or her written authorization. The enrollee's full records include, but are not limited to the following: all medical records; all records of individual appointments, meetings, telephone conversations or other contacts with the plan; all internal investigations and their findings; all incident reports; and all quality assurance and utilization review records that relate to the individual enrollee's problem or complaint. Any records that contain names or identifying or confidential information about other enrollees must be redacted from the records. The ombudsprogram will comply with the requirements of 42 U.S.C. § 1396a(a)(7) and 42 C.F.R. §§ 431.300 - 431.307 (Safeguarding Information on Applicants and Recipients).

12. All managed care plans operating in the state and subcontractors thereof shall include in their membership materials information on the availability of the ombudsprogram and the services of the ombudsprogram. The information shall include, but is not limited to, the toll-free telephone number(s) for both the state-wide and local ombudsprograms and notice to enrollees that they can call the ombudsprogram for information or assistance at any time. This information also shall be provided in writing to any enrollee filing a grievance or requesting a fair hearing. Managed care plans and their subcontractors shall post this information at all primary care sites and shall provide translated written materials containing this information in languages other than English to individuals in groups meeting population thresholds as specified by the statewide ombudsprogram office.

## Complaint Process: The Medicaid Act and Regulations

### 42 U.S.C. § 1396a(a)(3) (1998 Supp.)

“A State plan for medical assistance must —

(3) provide for granting an opportunity for a fair hearing before the State agency to any individual whose claim for medical assistance under the plan is denied or is not acted upon with reasonable promptness.”

### 42 U.S.C. § 1396u-2(b)(4) (1998 Supp.)

“Each medicaid managed care organization shall establish an internal grievance procedure under which an enrollee who is eligible for medical assistance under the State plan under this subchapter, or a provider on behalf of such an enrollee, may challenge the denial of coverage of or payment for such assistance.”

## CODE OF FEDERAL REGULATIONS (C.F.R.)

### PART 431 — STATE ORGANIZATION AND GENERAL ADMINISTRATION Subpart E — Fair Hearings for Applicants and Recipients

#### GENERAL PROVISIONS

### 42 C.F.R. § 431.200 Basis and purpose.

This subpart implements section 1902(a)(3) of the Act [42 U.S.C. § 1396a(a)(3)], which requires that a State plan provide an opportunity for a fair hearing to any person whose claim for assistance is denied or not acted upon promptly. This subpart also prescribes procedures for an opportunity for hearing if the Medicaid agency takes action to suspend, terminate, or reduce services. This subpart also implements sections 1819(f)(3), 1919(f)(3), and 1919(e)(7)(F) of the Act by providing an appeals process for individuals proposed to be transferred or discharged from skilled nursing facilities and nursing facilities and those adversely affected by the preadmission screening and annual resident review requirements of section 1919(e)(7) of the Act.

### 42 C.F.R. § 431.201 Definitions.

For purposes of this subpart:

*Action* means a termination, suspension, or reduction of Medicaid eligibility or covered services. It also means determinations by skilled nursing facilities and nursing facilities to transfer or discharge residents and adverse determinations made by a State with regard to the preadmission screening and annual resident review requirements of section 1919(e)(7) of the Act.

*Adverse determination* means a determination made in accordance with sections 1919(b)(3)(F) or 1919(e)(7)(B) of the Act that the individual does not require the level of services provided by a nursing facility or that the individual does or does not require specialized services.

*Date of action* means the intended date on which a termination, suspension, reduction, transfer or discharge becomes effective. It also means the date of the determination made by a State with regard to the preadmission screening and annual resident review requirements of section 1919(e)(7) of the Act.

*De novo hearing* means a hearing that starts over from the beginning.

*Evidentiary hearing* means a hearing conducted so that evidence may be presented.

*Notice* means a written statement that meets the requirements of § 431.210.

*Request for a hearing* means a clear expression by the applicant or recipient, or his authorized representative, that he wants the opportunity to present his case to a reviewing authority.

#### **42 C.F.R. § 431.202 State plan requirements.**

A State plan must provide that the requirements of §§ 431.205 through 431.246 of this subpart are met.

#### **42 C.F.R. § 431.205 Provision of hearing system.**

(a) The Medicaid agency must be responsible for maintaining a hearing system that meets the requirements of this subpart.

(b) The State's hearing system must provide for —

- (1) A hearing before the agency; or
- (2) An evidentiary hearing at the local level, with a right of appeal to a State agency hearing.

(c) The agency may offer local hearings in some political subdivisions and not in others.

(d) The hearing system must meet the due process standards set forth in *Goldberg v. Kelly*, 397 U.S. 254 (1970), and any additional standards specified in this subpart.

#### **42 C.F.R. § 431.206 Informing applicants and recipients.**

(a) The agency must issue and publicize its hearing procedures.

(b) The agency must, at the time specified in paragraph (c) of this section, inform every applicant or recipient in writing —

- (1) Of his right to a hearing;
- (2) Of the method by which he may obtain a hearing; and
- (3) That he may represent himself or use legal counsel, a relative, a friend, or other spokesman.

(c) The agency must provide the information required in paragraph (b) of this section —

- (1) At the time that the individual applies for Medicaid;
- (2) At the time of any action affecting his or her claim;
- (3) At the time a skilled nursing facility or nursing facility notifies a resident in accordance with § 483.12 of this chapter that he or she is to be transferred or discharged; and
- (4) At the time an individual receives an adverse determination by the State with regard to the preadmission screening and annual resident review requirements of section 1919(e)(7) of the Act.

*NOTICE*

**42 C.F.R. § 431.210 Content of notice.**

A notice required under § 431.206(c)(2), (c)(3), or (c)(4) of this subpart must contain —

- (a) A statement of what action the State, skilled nursing facility, or nursing facility intends to take;
- (b) The reasons for the intended action;
- (c) The specific regulations that support, or the change in Federal or State law that requires, the action;
- (d) An explanation of —
  - (1) The individual's right to request an evidentiary hearing if one is available, or a State agency hearing; or
  - (2) In cases of an action based on a change in law, the circumstances under which a hearing will be granted; and
- (e) An explanation of the circumstances under which Medicaid is continued if a hearing is requested.

**42 C.F.R. § 431.211 Advance notice.**

The State or local agency must mail a notice at least 10 days before the date of action, except as permitted under §§ 431.213 and 431.214 of this subpart.

**42 C.F.R. § 431.213 Exceptions from advance notice.**

The agency may mail a notice not later than the date of action if —

- (a) The agency has factual information confirming the death of a recipient;
- (b) The agency receives a clear written statement signed by a recipient that —
  - (1) He no longer wishes services; or
  - (2) Gives information that requires termination or reduction of services and indicates that he understands that this must be the result of supplying that information;
- (c) The recipient has been admitted to an institution where he is ineligible under the plan for further services;
- (d) The recipient's whereabouts are unknown and the post office returns agency mail directed to him indicating no forwarding address (See § 431.231(d) of this subpart for procedure if the recipient's whereabouts become known);
- (e) The agency establishes the fact that the recipient has been accepted for Medicaid services by another local jurisdiction, State, territory, or commonwealth;
- (f) A change in the level of medical care is prescribed by the recipient's physician;
- (g) The notice involves an adverse determination made with regard to the preadmission screening requirements of section 1919(e)(7) of the Act; or
- (h) The date of action will occur in less than 10 days, in accordance with § 483.12(a)(5)(ii), which provides exceptions to the 30 days notice requirements of § 483.12(a)(5)(i).



#### **42 C.F.R. § 431.214 Notice in cases of probable fraud.**

The agency may shorten the period of advance notice to 5 days before the date of action if —

- (a) The agency has facts indicating that action should be taken because of probable fraud by the recipient; and
- (b) The facts have been verified, if possible, through secondary sources.

#### RIGHT TO HEARING

#### **42 C.F.R. § 431.220 When a hearing is required.**

(a) The agency must grant an opportunity for a hearing to:

- (1) Any applicant who request it because his claim for services is denied or is not acted upon with reasonable promptness;
- (2) Any recipient who requests it because he or she believes the agency has taken an action erroneously;
- (3) Any resident who requests it because he or she believes a skilled nursing facility or nursing facility has erroneously determined that he or she must be transferred or discharged; and
- (4) Any individual who requests it because he or she believes the State has made an erroneous determination with regard to the preadmission and annual resident review requirements of section 1919(e)(7) of the Act.

(b) The agency need not grant a hearing if the sole issue is a Federal or State law requiring an automatic change adversely affecting some or all recipients.

#### **42 C.F.R. § 431.221 Request for hearing.**

(a) The agency may require that a request for a hearing be in writing.

(b) The agency may not limit or interfere with the applicant's or recipient's freedom to make a request for a hearing.

(c) The agency may assist the applicant or recipient in submitting and processing his request.

(d) The agency must allow the applicant or recipient a reasonable time, not to exceed 90 days from the date that notice of action is mailed, to request a hearing.

#### **42 C.F.R. § 431.222 Group hearings.**

The agency —

(a) May respond to a series of individual requests for hearing by conducting a single group hearing;

(b) May consolidate hearings only in cases in which the sole issue involved is one of Federal or State law or policy;

(c) Must follow the policies of this subpart and its own policies governing hearings in all group hearings; and

(d) Must permit each person to present his own case or be represented by his authorized representative.

**42 C.F.R. § 431.223 Denial or dismissal of request for a hearing.**

The agency may deny or dismiss a request for a hearing if —

- (a) The applicant or recipient withdraws the request in writing; or
- (b) The applicant or recipient fails to appear at a scheduled hearing without good cause.

PROCEDURES

**42 C.F.R. § 431.230 Maintaining services.**

(a) If the agency mails the 10-day or 5-day notice as required under § 431.211 or § 431.214 of this subpart, and the recipient requests a hearing before the date of action, the agency may not terminate or reduce services until a decision is rendered after the hearing unless —

- (1) It is determined at the hearing that the sole issue is one of Federal or State law or policy; and
- (2) The agency promptly informs the recipient in writing that services are to be terminated or reduced pending the hearing decision.

(b) If the agency's action is sustained by the hearing decision, the agency may institute recovery procedures against the applicant or recipient to recoup the cost of any services furnished the recipient, to the extent they were furnished solely by reason of this section.

**42 C.F.R. § 431.231 Reinstatement of services.**

(a) The agency may reinstate services if a recipient requests a hearing not more than 10 days after the date of action.

(b) The reinstated services must continue until a hearing decision unless, at the hearing, it is determined that the sole issue is one of Federal or State law or policy.

(c) The agency must reinstate and continue services until a decision is rendered after a hearing if —

- (1) Action is taken without the advance notice required under § 431.211 or § 431.214 of this subpart;
- (2) The recipient requests a hearing within 10 days of the mailing of the notice of action; and
- (3) The agency determines that the action resulted from other than the application of Federal or State law or policy.

(d) If a recipient's whereabouts are unknown, as indicated by the return of unforwardable agency mail directed to him, any discontinued services must be reinstated if his whereabouts become known during the time he is eligible for services.

**42 C.F.R. § 431.232 Adverse decision of local evidentiary hearing.**

If the decision of a local evidentiary hearing is adverse to the applicant or recipient, the agency must —

- (a) Inform the applicant or recipient of the decision;
- (b) Inform the applicant or recipient that he has the right to appeal the decision to the State

agency, in writing, within 15 days of the mailing of the notice of the adverse decision;

(c) Inform the applicant or recipient of his right to request that his appeal be a *de novo* hearing; and

(d) Discontinue services after the adverse decision.

#### **42 C.F.R. § 431.233 State agency hearing after adverse decision of local evidentiary hearing.**

(a) Unless the applicant or recipient specifically requests a *de novo* hearing, the State agency hearing may consist of a review by the agency hearing officer of the record of the local evidentiary hearing to determine whether the decision of the local hearing officer was supported by substantial evidence in the record.

(b) A person who participates in the local decision being appealed may not participate in the State agency hearing decision.

#### **42 C.F.R. § 431.240 Conducting the hearing.**

(a) All hearings must be conducted —

(1) At a reasonable time, date, and place;

(2) Only after adequate written notice of the hearing; and

(3) By one or more impartial officials or other individuals who have not been directly involved in the initial determination of the action in question.

(b) If the hearing involves medical issues such as those concerning a diagnosis, an examining physician's report, or a medical review team's decision, and if the hearing officer considers it necessary to have a medical assessment other than that of the individual involved in making the original decision, such a medical assessment must be obtained at agency expense and made part of the record.

#### **42 C.F.R. § 431.241 Matters to be considered at the hearing.**

The hearing must cover —

(a) Agency action or failure to act with reasonable promptness on a claim for services, including both initial and subsequent decisions regarding eligibility;

(b) Agency decisions regarding changes in the type or amount of services;

(c) A decision by a skilled nursing facility or nursing facility to transfer or discharge a resident; and

(d) A State determination with regard to the preadmission screening and annual resident review requirements of section 1919(e)(7) of the Act.

#### **42 C.F.R. § 431.242 Procedural rights of the applicant or recipient.**

The applicant or recipient, or his representative, must be given an opportunity to —

(a) Examine at a reasonable time before the date of the hearing and during the hearing:

(1) The content of the applicant's or recipient's case file; and

(2) All documents and records to be used by the State or local agency or the skilled nursing facility or nursing facility at the hearing;

- (b) Bring witnesses;
- (c) Establish all pertinent facts and circumstances;
- (d) Present an argument without undue interference; and
- (e) Question or refute any testimony or evidence, including opportunity to confront and cross-examine adverse witnesses.

**42 C.F.R. § 431.243 Parties in cases involving an eligibility determination.**

If the hearing involves an issue of eligibility and the Medicaid agency is not responsible for eligibility determinations, the agency that is responsible for determining eligibility must participate in the hearing.

**42 C.F.R. § 431.244 Hearing decisions.**

- (a) Hearing recommendations or decisions must be based exclusively on evidence introduced at the hearing.
- (b) The record must consist only of —
  - (1) The transcript or recording of testimony and exhibits, or an official report containing the substance of what happened at the hearing;
  - (2) All papers and requests filed in the proceeding; and
  - (3) The recommendation or decision of the hearing officer.
- (c) The applicant or recipient must have access to the record at a convenient place and time.
- (d) In any evidentiary hearing, the decision must be a written one that —
  - (1) Summarizes the facts; and
  - (2) Identifies the regulations supporting the decision.
- (e) In a *de novo* hearing, the decision must —
  - (1) Specify the reasons for the decision; and
  - (2) Identify the supporting evidence and regulations.
- (f) The agency must take final administrative action within 90 days from the date of the request for a hearing.
- (g) The public must have access to all agency hearing decisions, subject to the requirements of subpart F of this part for safeguarding of information.

**42 C.F.R. § 431.245 Notifying the applicant or recipient of a State agency decision.**

The agency must notify the applicant or recipient in writing of —

- (a) The decision; and
- (b) His right to request a State agency hearing or seek judicial review, to the extent that either is available to him.

#### **42 C.F.R. § 431.246 Corrective action.**

The agency must promptly make corrective payments, retroactive to the date an incorrect action was taken, and, if appropriate, provide for admission or readmission of an individual to a facility if —

- (a) The hearing decision is favorable to the applicant or recipient; or
- (b) The agency decides in the applicant's or recipient's favor before the hearing.

### FEDERAL FINANCIAL PARTICIPATION

#### **42 C.F.R. § 431.250 Federal financial participation.**

FFP is available in expenditures for —

- (a) Payments for services continued pending a hearing decision;
- (b) Payments made —
  - (1) To carry out hearing decisions; and
  - (2) For services provided within the scope of the Federal Medicaid program and made under a court order.
- (c) Payments made to take corrective action prior to a hearing;
- (d) Payments made to extend the benefit of a hearing decision or court order to individuals in the same situation as those directly affected by the decision or order;
- (e) Retroactive payments under paragraphs (b), (c), and (d) of this section in accordance with applicable Federal policies on corrective payments; and
- (f) Administrative costs incurred by the agency for —
  - (1) Transportation for the applicant or recipient, his representative, and witnesses to and from the hearing;
  - (2) Meeting other expenses of the applicant or recipient in connection with the hearing;
  - (3) Carrying out the hearing procedures, including expenses of obtaining the additional medical assessment specified in § 431.240 of this subpart; and
  - (4) Hearing procedures for Medicaid and non-Medicaid individuals appealing transfers, discharges and determinations of preadmission screening and annual resident reviews under part 483, subparts C and E of this chapter.

### **PART 434 — CONTRACTS**

#### **Subpart C — Contracts with HMOs and PHPs: Contract Requirements**

#### *ADDITIONAL REQUIREMENTS*

#### **42 C.F.R. § 434.32 Grievance procedure.**

The contract must provide for an internal grievance procedure that —

- (a) Is approved in writing by the agency;
- (b) Provides for prompt resolution; and
- (c) Assures the participation of individuals with authority to require corrective action.

## Complaint Process: National Health Law Program Model

### Model Managed Care Complaint Process

Prepared by: Jane Perkins and Kristi Olson (revised January 1999)

*This model complaint procedure supercedes earlier versions. This process is intended for use in state-based managed care programs, particularly Medicaid and child health insurance programs. But, it can be adapted to other managed care situations as well. Many of the provisions are taken from existing state managed care rules and contracts or were developed out of our work with advocates and individual clients.*

*We encourage your feedback and would appreciate receiving copies of any provisions that you consider to be models.*

\*\*\*\*\*

#### Definitions

##### A. Definitions:

1. Complaint — Any clear expression by an applicant or recipient, or his authorized representative, that he wants the opportunity to present his case to a reviewing authority. A complaint may be brought at the Plan level, through the grievance process, or at the state level, through a State fair hearing.
2. Grievance — a complaint at the Plan level.
3. State fair hearing — a complaint to the State Medicaid agency to be heard by an impartial hearing officer.

[Note: States are using a number of terms to label complaint processes, such as: informal in-plan grievance, formal in-plan grievance, internal grievance, reconsideration, complaint, fair hearing. Clients, advocates, plans, and states have remarked to us that there is, in fact, a confusion of terms that hampers dispute resolution. See National Health Law Program, *Making the Consumers' Voice Heard in Medicaid Managed Care: Increasing Participation, Protection and Satisfaction -- Report on Legal and Voluntary Mechanisms* (Dec. 1996).]

#### Consumer relations office

- B. Each Plan will maintain an adequately staffed consumer relations office which can receive telephone calls and meet personally with members and which members can use to ask questions and get problems resolved informally. Although these consumer relations

activities will operate through verbal, as well as written, communications, consumer relations staff will document all communications. Consumer relations staff will receive regular training on the complaint process and appropriate referral procedures. The consumer relations office will maintain records that include the name of the member (or member identification number), a short summary of each question or problem, date of contact, the resolution, and date of resolution. If the Plan does not have a separate log for Medicaid recipients, the log shall distinguish Medicaid recipients from other Plan members. This information will be available to the State Medicaid agency.

### **The in-plan grievance process**

C. The Plan shall have a timely and organized grievance system.

[Note: This process is required for Medicaid recipients by 42 C.F.R. § 434.32].

1. The grievance process will be available for disputes between the Plan and the member concerning, among other things, denial, reduction, delay, suspension, or termination of services; requests for services that are not acted upon in a timely manner; dissatisfaction with providers; appropriateness of services rendered; availability of services; the inability to obtain culturally and linguistically appropriate care; or disputes concerning disenrollment. A denial includes any instance in which a request for a medical service has been made in which a member has been told “no” for all or part of the service.
2. The Plan's grievance procedures are neither a substitute for nor a prerequisite of a fair hearing before an impartial hearing officer. The recipient may request a fair hearing before, during, or after a Plan grievance procedure. The agency will provide a hearing and a final written decision within 90 days of the initial request unless the matter is resolved in favor of the recipient or involves urgent matters. Urgent matters will be resolved on an expedited basis described in section K, below.

[Note: This provision can also note other state-based hearing processes that are available, by law, to the member, including hearing procedures set forth in the state's Administrative Procedures Act or state Insurance Code. These procedures may supplement, but cannot substitute for, federally required grievance and fair hearing procedures.]

3. The Plan will develop written policies and procedures for its grievance process, which at minimum must comply with the following:
  - a. The procedure will be approved by the Plan's governing body and be the direct responsibility of the governing body, and it will be approved in writing by the State Medicaid agency prior to implementation.

[Note: Optimally, the Plan's governing body will include consumer representatives.]

- b. The procedure will name specific individuals in the Plan who have responsibility for the proper functioning of the grievance process and authority to require corrective action.
- c. The procedure will allow members to complain to the Plan's governing body. The governing body may delegate this authority to a grievance committee, but the delegation must be in writing.

[Additional suggestion: The grievance committee will include at least one Plan administrator with authority to require corrective action; at least two Medicaid consumers; at least two providers with expertise in the area in dispute; and at least one State Medicaid agency representative. The Plan must demonstrate that the Plan administrator has education and experience in necessary specialized areas such as mental health, substance abuse, and pediatric care.]

- d. Grievances will be filed by the member or member's representative, on a form to be developed by the State Medicaid agency. All grievances will be mailed to a single address within the State Medicaid agency. Unless the dispute involves a request for expedited review (described in section K below), the State Medicaid agency will log in the request and return it to the Plan within 72 hours of receipt.

[Note: By filing all grievances, first, with the state Medicaid agency, the process is simplified for recipients. In many cases, recipients do not know where in their plan to complain — or even know the name of their plan. Central logging also makes the process more accountable to consumers. Once the request is logged in, the time frame for a final decision will begin to run. The state will have a record of the grievance and can hold the plans accountable for resolving it. Finally, central logging enhances the program's ability to use complaint information in quality monitoring. Tennessee's Medicaid program is using a central log-in system.]

4. Benefits must be continued pending final resolution, in accordance with section L.

- D. The Plan will provide information about its grievance process to members and applicants, to all subcontractors at time of subcontracting, and to non-contracting providers within ten (10) days of the date of receipt of a claim.
  - 1. Members will be informed of the grievance process orally and in writing, through a state-developed [or state-approved] description of the grievance process, posted at no less than one conspicuous location of each reception area of each provider within the Plan; and provided to the member at:
    - a. the time of initial enrollment;
    - b. each time a service is denied, reduced, suspended, delayed, or terminated, and/or



whenever a Plan or provider does not take a course of action or treatment normally taken for the member's medical problem;

- c. when the member initially contacts the Plan regarding a problem or complaint;
  - d. at every eligibility recertification;
  - e. each time the recipient enrolls in a Plan;
  - f. at completion of the grievance procedure;
  - g. at the request of the member or member's representative; and
  - h. in the member handbook.
2. The oral information and written notice will explain:
- a. how to file both grievance and state fair hearing requests;
  - b. time frames for filing and resolving grievances and state fair hearing, including expedited time frames;
  - c. availability of free assistance with a grievance and/or state fair hearing; and
  - d. a statement that filing a grievance or state fair hearing request will not affect eligibility, benefits, or the way the member is treated by the provider/Plan or the state Medicaid agency.
3. If service or eligibility is denied, reduced, suspended, terminated or delayed, a written notice will be hand-delivered or mailed to the member (or the member's authorized representative) explaining:
- a. what action the Plan intends to take;
  - b. the reasons for the intended action;
  - c. the specific laws and rules that support the action;
  - d. an explanation of the individual's right to file a grievance with the Plan or to request a fair hearing before the state Medicaid agency;
  - e. an explanation of the circumstances under which benefits will continue pending resolution of the problem (described below);

- f. that the member has a right to a second opinion, at the Plan's expense and how to exercise that right;
  - g. that if the member decides to file a grievance, that the member has the option of an in-person hearing before the Plan personnel who will decide the grievance;
  - h. how to contact the consumer relations office;
  - i. how to request a grievance and/or fair hearing;
  - j. that filing or resolving a complaint through the Plan's grievance mechanism is not a prerequisite to obtaining a fair hearing with the state Medicaid agency;
  - k. that a state fair hearing will be held before an impartial decision-maker;
  - l. the circumstances that will cause an expedited review and how to request an expedited review;
  - m. an explanation of how members can obtain copies of their managed care Plan records, not to be limited to medical records. Members are entitled to receive copies of their records at no cost to the member.
  - n. the right to be advised or represented by a lay advocate or attorney and of the potential availability of free legal services. The notice will provide the phone number and address of legal services organizations.
4. The Plan will maintain copies of all notices sent for a one year period and will make these available to the State Medicaid agency.
  5. At each visit to a participating provider, the patient should receive an explanation that if they feel that they did not receive the services they need, they have the right to request an in-plan grievance or a state fair hearing. This explanation may be included as part of the information provided to the patient upon check-out.
- E. A trained Plan investigator will send a letter of notification to the member within two days of receipt of the grievance form from the state. The letter will either: (1) immediately resolve the grievance in the member's favor or (2) indicate that the matter will be further investigated and set a date for the hearing. The letter will summarize the investigator's understanding of the grievance. The investigator will investigate the claim by questioning concerned parties and conducting on-site visits, if necessary.
  - F. Upon completion of the investigation, the entire record of the grievance will be forwarded to the grievance committee. The decision on the grievance will be based upon the record of the case, including the hearing, if any, and relevant program laws and policies and will be

made in writing. The decision will be sent to the member by certified mail. The decision will include:

1. the name and address of the member;
  2. the name of staff investigator;
  3. the date the investigation was completed;
  4. the results of the investigation;
  5. a summary of the steps taken on behalf of the member to resolve the issue;
  6. the action taken; and
  7. a clear explanation of the right to a state fair hearing.
- G. Except in cases involving expedited review (described in section K), the grievance must be resolved and the member notified in writing of the decision as soon as possible but, in any event, no later than 30 days from the date the form was filed with the state Medicaid agency.
- H. The Plan will retain grievance documents for five (5) years following a final decision or close of a grievance. If any litigation, claim negotiation, audit, or other action involving the documents or records has been started before the expiration of the five (5) year period, the records shall be retained until completion of the action and resolution of issues which arise from it or until the end of the regular five-year period, whichever is later.

### **State Fair Hearings**

- I. If the member requests a state fair hearing, all documents supporting the Plan's actions must be received by the state Medicaid agency no later than five (5) working days from the date the Plan receives notice from the state that a fair hearing request has been filed.
- J. The State Medicaid agency will provide members with a fair hearing process that has the following characteristics:
1. The state fair hearing process shall adhere to 42 C.F.R. § 431.200 et seq., which is incorporated herein by reference;
  2. When an ongoing course of treatment is at issue, services must continue pending a final decision on the complaint;

3. Any Plan policy or procedure that impedes a member from obtaining supporting evidence, including medical records and affidavits from health care providers, is prohibited;
4. Before the hearing, the member has the right to review the case file and all records that will be used at the hearing in support of the adverse decision;
5. The individual has the right to an in-person hearing. At the hearing, the individual can present and cross-examine witnesses. The person can represent himself or herself at the hearing or be assisted by a representative. An in-person hearing can be waived at the request of the individual;
6. The hearing officer must be impartial and cannot engage in *ex parte* communications with either side;
7. The hearing decision must be based solely on the evidence produced at the hearing and the record of the case, which shall include the official transcript or report of the testimony at the hearing and all papers filed in the proceeding;
8. In cases other than expedited reviews (described in section K), a final written decision must be issued by the hearing officer within 90 days from the date the complaint was initially filed with the Plan, or if the member appeals directly to the state Medicaid agency, within 90 days of the date the fair hearing request was filed. If the individual is dissatisfied with the final decision of the hearing officer, he or she can appeal to a court of law as set forth in state law.

K. The State Medicaid agency will make an expedited review process available.

1. An expedited review will occur when the member attests that services are urgently needed and the failure to provide them promptly or to continue them may cause deterioration or impair improvement in condition, including but not limited to termination or denial of: inpatient services, home health care, pharmaceuticals, therapy services, or surgery;

[Alternative: An expedited review will occur when the member attests that the concern is urgent. An urgent concern is one in which a reasonable lay person could believe that delay could prevent a consumer from realizing the full benefit of a decision in her or his favor.]

2. Requests for expedited review will be filed with the State Medicaid agency. The agency will notify the Plan of the request. The Plan will forward case records and documentation supporting its decision immediately to the state. An expedited decision by the state Medicaid agency must be issued within 2 days of the request, unless the member requests additional time to obtain evidence;
3. The member's Plan can reverse its decision at any time prior to decision on expedited review by the state Medicaid agency;

4. Benefits will be continued pending final resolution, in accordance with section L.
5. The decision by the state Medicaid agency on expedited review will include the information contained in section F, above.

### **Continued benefits**

- L. The Plan and State Medicaid agency must provide for benefits to continue pending resolution of the complaint, as follows:
  1. If a member files a grievance, a request for expedited review, or a state fair hearing on or before the tenth day after a decision is communicated in writing to the member to reduce, suspend, or terminate services that the member has been receiving, or before the date of the proposed action, whichever is later, the Plan will continue to provide services at a level equal to the level ordered by the Plan physician until a final decision is made by the Plan and, if a state fair hearing is requested, by the state Medicaid agency.
  2. If the resolution by the Plan is adverse, in whole or part, to the member, the member must be notified again of his or her rights to a state fair hearing and to continued benefits pending the final decision. If the member appeals a Plan's written resolution within ten days after it is issued, or before the date of the proposed action, whichever is later, services must be continued pending a final state fair hearing decision. A resolution is made or issued on the date it is postmarked.
  3. Members will be notified that, if the final decision is adverse to them, they may be required to repay the costs of services provided to them during the pendency of the dispute, as allowed by 42 C.F.R. § 431.230(b).

### **Accessibility of the complaint process**

- M. All written and oral materials regarding the complaint process, including posted notices, descriptions of the complaint processes, complaint forms, and decisions, must be made available orally and in writing in the recipient's primary language and in alternative formats, including TTY and telecommunication devices for the hearing impaired, braille, large print, and cassette.
- N. In-person hearings must be held at locations that meet the requirements of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act of 1974. Trained interpreters must be used at hearings when the member's primary language is not English.
- O. The Plan and/or State must provide transportation to and from the grievance or state fair hearing for the recipient, his or her representative, and witnesses.

- P. The Plan and the state Medicaid agency will include toll-free numbers for a member to use to communicate a complaint and/or complete a grievance form by telephone. These toll-free services will have adequate TTY and language interpreter capabilities.
- Q. Members will be informed of these accessibility provisions in the written and oral materials describing the complaint processes and on posted notices.

### **Monitoring and Quality Assurance**

- R. Failure of a plan to comply with the complaint process requirements of state and federal Medicaid law and these provisions with respect to a particular service or payment for a member will result in an automatic ruling in favor of the member.
- S. The State Medicaid agency must monitor and investigate the compliance of plans with the foregoing hearing requirements. If it learns that a contracting entity has failed to meet these requirements, the State Medicaid agency is prohibited from renewing or entering into a subsequent contract with the entity.
- T. Information regarding the nature of grievances and their resolution must be publicly disclosed by the state Medicaid agency. Such disclosure will maintain member confidentiality.
- U. The state Medicaid agency will collect and analyze data, including data on complaints. This information will be collected quarterly and as part of annual reports made by the Plan to the state Medicaid agency. This information is to be used as an ongoing indicator of plan performance which may identify the need for targeted monitoring and special investigations. The data to be reported will be broken out by plan, to include:
  - 1. number and nature of complaints reported orally and in writing;
  - 2. time frame for resolution and outcome of resolution of complaints;
  - 3. listing of all grievances which have not been resolved to the satisfaction of the provider or subscriber who filed the grievance;
  - 4. number, nature, and resolution of expedited proceedings.
- V. When repeated grievances are filed against a Plan or provider, an in-depth review, including on-site visits, will be conducted by the state Medicaid agency. When a provider or a member files repeated complaints, a review will also be conducted by the state Medicaid agency.
- W. The information described in this subsection will be used for quality improvement, credentialing, and will be provided to the Consumer Advisory Board on a quarterly basis.

X. This complaint procedure should incorporate the following definition of medical necessity:

The health plan must provide all medically necessary care, including services, equipment, and pharmaceutical supplies. Medically necessary care is the care which, in the opinion of the treating physician, is reasonably needed to do one or more of the following:

- prevent or delay the onset or worsening of an illness, condition, or disability;
- assess or screen for an illness, condition, or disability;
- establish a diagnosis;
- provide palliative, curative or restorative treatment for physical and/or mental health conditions;
- prolong life;
- promote physical and mental health and efficiency;
- assist the individual to achieve or maintain maximum functional capacity.

Each service must be performed in accordance with national standards of medical practice generally accepted at the time the services are rendered. Each service must be sufficient in amount, duration, and scope to reasonably achieve its purpose; and the amount, duration and scope may not arbitrarily be denied or reduced solely because of the diagnosis, type of illness or condition (42 CFR 440.230). Children's medical necessity decisions will be governed by the EPSDT coverage rules (42 USC § 1396(r)(5) and 42 USC § 1396d(a)). The health plan should affirmatively ensure access to care. The definition will be applied and interpreted consistent with the best interests of the enrollee.

## **S**ection IV: The Consumer Involvement Action Plans

---

Kentucky .....	IV-3
New Mexico .....	IV-65
New York City .....	IV-87
Ohio .....	IV-93
Washington .....	IV-121

NOTE: Section IV is not included in the online version. To obtain the plans you must order the full report, which is available from our Los Angeles office for \$35.00. (310) 204-6010.