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**Executive Summary**

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The nature and extent of consumer involvement in Medicaid managed care have been neither systematically studied nor studied from the perspective of the consumer. As a result, key stakeholders—government purchasers, managed care organizations, providers, consumers, and consumer representatives—lack vital information on the range of mechanisms that consumers will use and perceive as beneficial in making their views and needs known beyond the consultation room. Nor is there much information on mechanisms which states and contracting health plans will accept as adding value to program operation.

The need for consumer involvement in managed care is by no means limited to the Medicaid program. The involvement of Medicaid beneficiaries, however, needs special emphasis and consideration. Medicaid beneficiaries experience unique barriers in accessing health care and obtaining on-going and meaningful consumer involvement. Limited literacy, limited English proficiency, lack of transportation and child care, and lack of telephone services detract from the ability of some low-income consumers to participate actively. Moreover, the implications of these barriers are far greater for Medicaid consumers than for most privately-insured consumers. Accessing quality health care from managed care organizations, for example, is of universal concern. Yet, accessing quality health care from managed care organizations is even more critical for Medicaid beneficiaries who lack the resources to obtain out-of-network care. Furthermore, Medicaid recipients frequently have unique and overwhelming health care needs. Heightened consumer understanding and ongoing input are required to meet the greater health care needs of Medicaid consumers. Finally, the public responsibility and funding for the program demand an open process with maximum sharing of information. In recognition of both the specific needs of Medicaid consumers and of the significant changes in the structure of managed care, this report addresses the involvement of Medicaid consumers mandatorily enrolled in risk-based managed care organizations. Nonetheless, the mechanisms and strategies discussed herein can be adapted to meet the needs of most consumers in managed care organizations.

In this report, the National Health Law Program provides an in-depth look at how consumers are being involved in Medicaid managed care programs and offers numerous typologies for clarifying and comparing consumer involvement strategies both locally and at the state level. The report is designed to capture legally-required and voluntarily-initiated consumer involvement mechanisms and to obtain impressions of how these mechanisms operate in the interest of Medicaid consumers.

**Part I** of the report provides background information regarding Medicaid managed care and consumer involvement in the development and operation of Medicaid and managed care. We discuss the changes in the Medicaid managed care environment that make it unwise for Medicaid beneficiaries to rely solely on their doctors and government regulators to ensure consumer protections and needed care—as they often have done in the past. Our key findings and study methods also are described.

**Part II** examines the various federal and state provisions which mandate consumer involvement in Medicaid managed care programs. We describe the trends in government positions with respect to consumer involvement and point the reader to innovative legal requirements.

**Part III** looks at the extent to which Medicaid recipients, in practice, are finding a voice in the development and operation of managed care. Based on our review of the literature and over 150 interviews with state-based key informants, we explore how legally-required and voluntarily-implemented mechanisms are working for consumers. Notably, we provide the key informants' impressions on the mechanisms and strategies that are being used to obtain input from consumers and how that input is being incorporated into Medicaid managed care programs.

**Part IV** describes consumer education and empowerment strategies to improve consumer involvement. The need for improved consumer education was repeatedly noted during our key informant interviews, and this section of the report highlights some of the ongoing and innovative consumer education strategies now underway.

**Part V** concludes the report with our directions for future work. Through an in-depth study of consumer involvement in five states and the comments of our interdisciplinary technical advisory panel, we will draft best practice guidelines for consumer involvement. The best practice guidelines will be implemented and refined in selected states. A final set of best practice guidelines will then be widely distributed to the key stakeholders—government regulators, health plans, consumers, and consumer representatives.

### **Summary of the Report Methodology**

The National Health Law Program analyzes consumer involvement provisions contained in the federal Medicaid laws and cases. Section 1115 Medicaid demonstration waivers also are reviewed and reported. State-level consumer involvement provisions from Medicaid managed care laws and cases are analyzed, along with provisions contained in model Medicaid managed care contracts and requests for proposals (RFPs) from states with mandatory risk-based managed care.

Analysis of legal requirements does not provide a full picture of the activities underway to involve consumers in Medicaid managed care. Therefore, the report rounds out this "lay-of-the-land" analysis by discussing how consumer involvement works in practice. The published and unpublished literature on the subject is summarized, and an annotated bibliography is included.

Impressions of consumer involvement from over 150 key informants are incorporated throughout the report. The key informants include representatives from consumer organizations and consumer advocates; Medicaid recipients and parents of children enrolled in Medicaid managed care; state and local Medicaid agency staff and state Maternal and Child Health agency staff; and key personnel from managed care organizations participating in Medicaid managed care. The report, thus, reflects a wide range of qualitative information about existing

consumer involvement mechanisms, including impressions of how these mechanisms operate, how they were developed, future plans for involving consumers, and innovative activities to give voice to Medicaid consumers in the managed care system.

### Key Findings

#### *General*

**1. Medicaid recipients traditionally have not been directly involved in design and implementation issues with respect to either the Medicaid or Medicaid managed care programs.**

Recipients have tended to take a back seat when it comes to consumer involvement with the Medicaid program and its services. There are a number of reasons for this. Medicaid eligibility is, in most cases, not guaranteed for time periods long enough to allow consumer involvement to occur. Rather, Medicaid eligibility is frequently interrupted, making continuity of involvement difficult to maintain. The lack of financial resources or the consumer equivalent of a trade association makes it hard for consumers to obtain information, voice their opinions, and protect their interests. Consumer interests are diffused among individuals or groups who do not know one another and whose interests typically are focused on health care only when they need it. To the extent consumers have been involved, the process has tended to be sporadic, without the opportunity for ongoing, meaningful participation.

**2. Poor women and children, in particular, have found little voice in ongoing program design.**

Families with children (formerly known as AFDC and AFDC-related recipients) are particularly affected by the barriers to meaningful consumer involvement. By contrast, the chronically ill and disabled, as ongoing users of the health care system, have tended to be more involved in Medicaid program design and ongoing implementation issues. Policy makers traditionally have been more responsive to this consumer group.

**3. Consumers and their advocates need to be involved in the design, development, and implementation of Medicaid managed care. The public responsibility and funding for this program demand an open process with maximum sharing of information that may not be a hallmark of the private market.**

Based on the observations of key stakeholders, it is abundantly clear that states and plans need

consumer input to design feasible and acceptable models. State Medicaid agencies, managed care organizations, consumers, and consumer representatives view consumer involvement as important to the success of Medicaid managed care. Most state regulators and health plan administrators interviewed view consumer involvement as vital to their cost saving efforts, given their inability to affect care-seeking behavior using cost sharing incentives.

To date, however, only a few exceptional states and plans have made concerted efforts to involve consumers in the design and implementation of their Medicaid managed care programs. A few state agencies are resistant to the notion of including consumers because they see these activities as conflicting with the agency's emerging role as an insurance purchaser, as opposed to program administrator and system regulator.

#### **4. Efforts to involve consumers in Medicaid managed care have been slowed by recurrent questions about whose voice is appropriate.**

There is a tension over who should be included within consumer involvement efforts: consumers, representatives from consumer-based organizations, and/or consumer advocates. Concerns are raised, particularly at the state level, that the interests of consumers and consumer organizations/advocates may not always be identical. In practice, there is room for everyone: consumers, consumer organizations, and consumer advocates. There are a variety of strategies that some states, localities, and plans are using to involve each of these types of consumer representatives to improve consumer protection and plan/program accountability.

#### **5. The lack of information about effective mechanisms and strategies for consumer involvement has both limited the success of efforts to involve consumers and has inhibited efforts altogether.**

The nature and extent of consumer involvement in Medicaid managed care have been neither studied systematically nor studied from the perspective of the consumer. Key stakeholders—governments, managed care organizations, providers, consumers, and consumer representatives—lack vital information on the range of mechanisms and types of strategies consumers, purchasers, and plans will use and perceive as beneficial. These stakeholders need information that provides not only the range of mechanisms, but also specific design and implementation details integral to the success of the mechanism. As a result of the lack of detailed information, key stakeholders are faced with the daunting task of initiating and improving consumer involvement mechanisms without the benefit of learning from the

successes and failures of previous efforts.

### ***Legal Requirements***

**6. There are a limited number of instances where consumer involvement in Medicaid managed care is mandated by law. However, the existence of a legal requirement does not guarantee that the mechanism will be successfully implemented, used, or monitored.**

The federal Medicaid Act requires three methods of consumer involvement: consumer representation on medical care advisory committees, the employment of low-income consumers as community-service aides or in the administration of the state plan, and fair hearings before the state Medicaid agency. These mechanisms, developed for a Medicaid program dominated by fee-for-service reimbursement and free choice of provider, are falling into (greater) disuse as states move their programs to mandatory, risk-based managed care.

The federal government has stated that it wants the public to be involved in the development of section 1115 Medicaid demonstration waivers, but to date, there has been little federal oversight of the extent to which states actually are conducting effective public processes. The federal government has conditioned its approval of a number of section 1115 Medicaid waivers on states' agreements to include consumer involvement. Recent approvals, for example, condition the award on development of useful consumer satisfaction surveys and grievance processes. Few states have enacted statutes or regulations specifically mandating consumer involvement in Medicaid managed care. The majority of provisions that have been enacted address grievance procedures and ombudsprograms. States have included consumer involvement provisions in their model Medicaid contracts with health plans. For the most part, these provisions focus on in-plan grievance processes and consumer satisfaction surveying. The mere existence of a legal mandate does not guarantee that the provision will be implemented. There are, in fact, numerous examples of limited or no implementation of the various provisions.

### ***Use of Specific Mechanisms***

**7. Regardless of whether consumer involvement mechanisms are legally required or voluntarily initiated, a fairly uniform set of mechanisms are being used to involve Medicaid recipients in managed care. Each state reports that it uses at least one consumer involvement mechanism.**

Nine basic mechanisms are being used to involve consumers in Medicaid managed care. Advisory boards, hotlines, and grievance procedures are most frequently used. To a lesser extent Medicaid managed care also is making use of ombudsprograms, plan-level member advocates, focus groups, consumer surveys, hiring of recipient employees, and public hearings. Three of the mechanisms—ombudsprograms, member advocates, and focus groups—were noted repeatedly by interested parties to be helpful in improving consumer protection and program/plan accountability.

The majority of the mechanisms, however, are generally not perceived by consumers or consumer advocates as offering “real” opportunities for ongoing involvement. Consumers and consumer advocates often feel left out of the process or forced to insert themselves into the process to obtain needed consumer protections.

There are examples of how each of the involvement mechanisms operates effectively. The mechanisms themselves, thus, are not inherently flawed. Instead, the reasons for their limited success vary depending on the mechanism but generally can be attributed to: lack of consumer knowledge regarding the mechanism; inadequate funding or commitment to the mechanism; and haphazard design and implementation, often without the participation of key stakeholders.

**8. The grievance process is the most commonly used method for including consumer input. However, while these processes exist on paper, in practice they are “nonfunctional.”**

Grievance processes are uniformly acknowledged as crucial to ensure quality in Medicaid managed care settings. Provision for an in-plan grievance process is one of the most common legal provisions for including and protecting consumers. However, these processes usually are not described in any detail, and they tend to differ from plan to plan. Moreover, consumers, health plan administrators, and state administrators all express frustration with the grievance process—both the in-plan process and the process for state-level fair hearings. The most common complaints are that consumers do not know how or where to complain; grievance processes are complex to use and change too often; members are merely sent back to their health plans when they complain to the state agency; and grievance information is not uniformly collected, reported, validated, or monitored.

**9. Telephone hotlines and consumer surveys are used in most states and by some health plans.**

Although mandated by statute in only a few states, hotlines are operating in most states. It is not unusual for hotlines to operate at both state and plan levels. However, many hotlines frequently are criticized as being busy, staffed by untrained workers, inaccessible to non-English speakers, and unresponsive to the consumer’s concern (for example, simply referring the consumer back to the health plan). By contrast, some hotlines are functioning to resolve problems and obtain

and disseminate systemic information, thereby assisting the state in its monitoring and enforcement functions.

Interest in consumer surveys and report cards as tools for consumer plan selection is rapidly expanding. In particular, the need for consumer involvement in the development of the survey instrument is achieving wide-spread recognition.

### **10. Medicaid managed care advisory boards also have been established. Those boards that are perceived to be successful typically have strong local organization and orientation.**

Even though only a few states have passed legislation to mandate Medicaid managed care advisory boards, and consumer participation on those boards, a number of state Medicaid agencies voluntarily have created them. While there are criticisms that the mechanism is merely □ window dressing,□ advisory bodies appear to work when they have a strong community orientation and organization. The notable aspects of successful boards include: (1) operation at the local level; (2) targeting to specific population groups, such as children with special needs or the disabled; (3) frequent use of task-oriented subcommittees; (4) membership composition that includes both consumers and consumer advocates, with membership reflective of the ethnic, racial, and cultural diversity of the Medicaid population served by the managed care program; (5) compensation of consumer members for travel, child care, and attendance; (6) resources available to the consumers and consumer advocates to keep them informed and able to participate in often complex Medicaid discussions; (7) frequent meetings at sites other than the state capitol, such as county offices, community centers, and public housing sites; (8) board-set agendas, rather than agendas dictated by the state Medicaid agency; and (9) consistent state agency attendance at board meetings, including reporting to the board on state activities in response to consumer issues.

### **11. Ombudsprograms are a new and promising method for involving consumers in Medicaid managed care.**

Medicaid managed care ombudsprograms are used in a few states and interest in them is growing. They are almost uniformly perceived by states, consumers, consumer representatives, and health plans as positive additions to the Medicaid managed care system.



## **12. Consumer organizations and advocates are taking their own actions to make their voices heard.**

Consumer organizations are developing their own strategies to optimize consumer involvement. These strategies include: educating consumers about managed care, informing them of their options, helping consumers complain when problems arise, and providing detailed suggestions and comments to obtain consumer-oriented protections in managed care regulations and contracts. Consumer organizations view these activities as essential to attaining an optimal Medicaid managed care program.

### **Next Steps**

The National Health Law Program will next explore consumer involvement in-depth in five state sites: California, Kentucky, New York, Ohio, and Washington. Site visits, to include focus group meetings with consumers, will occur. A set of best practice standards will be tested in selected states, refined, and then circulated in final form in a future report. For more information, please contact:

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