

## The Consumer Voice in Medicaid Managed Care: State Strategies

By John Barth, MSW

A growing number of states are developing or expanding Medicaid managed care programs to better meet the complex needs of people with disabilities. These models include traditional full-risk capitation, as well as alternative options, such as enhanced primary care case management and comprehensive care management. States recognize opportunities to use these managed care strategies to improve health outcomes, focus on quality improvement, and provide better coordination across systems of care, while providing budget predictability. Despite these benefits, many states that are planning new programs or expansions report concerns from the consumer and advocacy communities that managed care may potentially restrict service and access, disrupt continuity of care, and limit consumer choice.

A critical strategy for the success of any Medicaid managed care program, especially one serving people with disabilities, is building consumer support. States can get early buy-in by partnering with consumers and advocates and by continuing the partnership throughout the life cycle of the program — including consumer representatives in the development, implementation, and oversight of programs. States face challenges to developing strong partnerships for a number of reasons, including the complexity of state and federal managed-care regulations, misunderstandings about the aims of managed care programs, and the lack of trust among consumers, advocates, health plans, and states. Despite these challenges, several states and health plans have been successful in building sustainable long-term partnerships with the consumer and advocacy communities, resulting in stronger managed care programs that are more responsive to consumer needs.

This brief, developed through a series of interviews with state and health plan officials, consumers, and advocates, describes ways to engage and build strong, reciprocal relationships with consumers and advocates.

This issue brief reviews several states' successful efforts to engage the consumer and advocacy communities in the development, implementation, and oversight of Medicaid managed care programs for people with disabilities.

State Strategies to Engage Consumers and Advocates					
	Public Meetings	Focus Groups	Technology	Advisory Committees	Quality Committees
Program Development	X	X	X	X	
Program Implementation		X	X	X	
Program Oversight		X	X	X	X

# Medicaid Strategies to Involve Consumers and Advocates

## 1. Engage Early and Often

States, health plans, consumers, and advocates agree that when a managed care program for people with disabilities is being planned, misinformation can spread quickly, leading to confusion and resistance. The best way to prevent the spread of misinformation is for states to engage with the consumer and the advocacy communities as early as possible. By sharing information and providing meaningful opportunities for input, states demonstrate willingness to listen to the disability community's ideas and concerns and are better able to "make the case" for the benefits of managed care and to build trust with the key stakeholders.

States can use several strategies to identify leaders from the consumer and advocacy community, including:

- Networking with established community advocates and the nonprofit social service system for suggestions (e.g., Centers for Independent Living);
- Soliciting suggestions from state agencies that have a longer history of working with specific groups of consumers and advocates (e.g., the state mental health agency); and
- Coordinating with the state's enrollment brokers, which often maintain close relationships with consumer groups and nonprofit agencies.

## 2. Use a Multi-Pronged Engagement Strategy

Recognizing that people have limited time for in-person meetings, states can use multiple vehicles to engage with the consumer and advocacy communities during program development, implementation, and oversight.

- **Public Meetings.** Regional public meetings can be used to gather opinions from the broader consumer and advocacy communities. This venue can be particularly effective in engaging with the larger disability community during the design phase of new programs. For example, as part of designing its primary care case management program for aged, blind, and disabled (ABD) populations, Indiana held a series of public meetings prior to the release of its request for proposals. The public sessions gave consumers and advocates information about the proposed program's framework as well as the opportunity to provide feedback to the state.
- **Focus Groups.** Focus groups can help states pinpoint feedback regarding specific program design and operational questions. This strategy is often used during program development and to gauge member satisfaction and solicit input as managed care programs mature. New York held focus groups to ensure that member education materials for the state's new managed care program for people with disabilities were understandable and useful for consumers.
- **Advisory Committees.** Advisory committees, commissioned to help guide the design and oversight of managed care programs for people with disabilities, can be an effective vehicle. Advisory committees are most successful when they are designed to go beyond simple information sharing and provide clear opportunities for meaningful programmatic feedback. When developing its managed care program for Supplemental Security Income beneficiaries, Wisconsin established an advisory committee very early in the process and the state expanded the committee's role as the program matured.
- **Oversight Committees.** Transparency is particularly critical when health care may be the most important issue in a person's life, as it often is for people with disabilities. An oversight committee that includes consumer and advocacy group representatives can review program data and identify relevant quality measures and mechanisms to share information and build credibility with the broader community of people with disabilities. In Pennsylvania, a consumer subcommittee focusing on oversight issues regularly reviews managed care program quality data, assists with the development of consumer education and outreach materials, and suggests new quality measures. Consumers

and advocates can use these ongoing forums and their relationship with state officials to provide “ground-level” intelligence that will help states understand how the program is working for consumers and identify and resolve problems before they escalate.

- **Technology.** States can use web sites and listservs to share information with the broader consumer and advocacy communities and provide a conduit for feedback. To facilitate communication as it developed its new managed care program for the ABD population, Ohio created a web page that was updated regularly to provide current information for the public.

### 3. Support Consumer Participation

Participation in an advisory committee that is focused on a topic as complex as Medicaid managed care can be intimidating to those who are not familiar with state and federal Medicaid regulations, are not experienced in reviewing quality improvement reports (such as HEDIS), and are not acquainted with managed care jargon. As one advocate stated, “Education is the key; the state overestimated how much consumers knew about the program.”

To close this knowledge gap, and to ensure that consumers can participate fully, some states have provided education on the basics of Medicaid managed care. For example, Wisconsin used early advisory committee meetings as “Medicaid Managed Care 101” classes, providing clear and understandable descriptions regarding basic managed care information to help consumers and advocates be strong partners in providing feedback to the state.

States have also tried “pay for participation.” Consumers with disabilities who are interested in participating in an advisory committee may have limited resources for travel costs. Some states have paid for transportation to and from advisory committee meetings. Some advocates suggested that states should go further. One noted that, in her state, many advisory committee members were paid staff from managed care organizations participating as part of their jobs, while the consumers were unemployed and participating as volunteers. To address this disparity, it was suggested that consumers be paid a stipend to attend each meeting.

It is also important for states to be responsive to any accommodations consumers may need to attend and be actively involved in meetings. For example, states should ensure that meetings are held in accessible facilities, and also be prepared to provide meeting materials in alternative formats, ensure that sign interpreters are available for people with hearing impairments, and develop web sites that meet accessibility standards.

### 4. Set Ground Rules (and Follow Them)

States, consumers, and advocates all agree that, due to lack of trust and resistance to managed care, early exchanges among states, plans, and the consumer and advocacy communities can be tense. To reduce the tension and move toward forming strong, long-term partnerships, states have used several strategies:

- Committee membership should represent all the key stakeholders, including consumers, advocates, managed care organizations, providers, state agencies, and nonprofit organizations.
- Committee and public meetings should be facilitated by neutral parties who “don’t have a dog in the fight” and can help bring groups to consensus.
- All meetings should be promoted in multiple media to ensure that all interested parties are alerted. Participants with disabilities might need extra time to make arrangements for transportation and to ensure availability.
- All public meetings should allow a set amount of moderated time for audience comments, questions and suggestions, with structured opportunities for post meeting input as well.

All parties should “play by the rules” and come ready for open and honest discussion — the facilitator may have to remind consumers and state officials alike that the rules of engagement are there for the greater good.

## 5. Value Consumer Input

Consumers and advocates want to know that the time they spend working with and providing information to the state is taken seriously, whether or not their feedback results in a policy or program change. As one advocate stated: “We don’t want to be a rubber stamp; we want to give input that is valued.”

Accordingly, states need to ensure that consumer and advocacy community participation and feedback is a real opportunity, and not a “show.” Wisconsin made programmatic changes based on its commitment to consumer and advocate involvement. State officials note that the “all-in, opt-out” enrollment policy, continuity of care policies, and the addition of certain quality measures were developed in close consultation with consumers and advocates.

## Conclusion

States are moving forward with Medicaid managed care programs for people with disabilities. As they develop and implement programs, states must welcome feedback — both positive and negative — from the consumer and advocacy communities. If states plan ahead and implement a thorough program of engagement with consumers and advocates, the managed care program will be improved. When states take this input seriously and invest in education sessions, information, and interaction with consumers and advocates, the advocacy community gains a level of sophistication about Medicaid managed care, programs are more effective and responsive to consumer needs, and, as one state official noted, it is possible for “consumers to become the program’s best friend.”

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## About the Author

John Barth, MSW, is a senior program officer at the Center for Health Care Strategies.

## About the Center for Health Care Strategies

The Center for Health Care Strategies (CHCS) is a nonprofit organization dedicated to improving the quality and cost effectiveness of publicly financed care for people with chronic health needs, the elderly, and racially and ethnically diverse populations. CHCS works with state and federal agencies, health plans, providers, and consumers to design programs that better serve high-need and high-cost populations. To achieve its goals, CHCS focuses on three priorities: regional quality improvement, racial and ethnic disparities, and people with complex and special needs.

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**CHCS** Center for  
Health Care Strategies, Inc.

200 American Metro Blvd. Ste. 119  
Hamilton, NJ 08619-2311  
Phone: (609) 528-8400  
Fax: (609) 586-3679  
[www.chcs.org](http://www.chcs.org)