

Give People a Chance to Speak Up on Changes to Medicaid

This paper provides a short summary of the AARP research paper – *Let the Sunshine In: Ensuring Public Involvement in State Medicaid Policymaking*—by Barbara Coulter Edwards, MPP, Susan P. Garcia, and Aimee E. Lashbrook, JD, MHSA, of Health Management Associates and Lynda Flowers, JD, MSN, RN of the AARP Public Policy Institute.

In recent years, states have gained increased discretion to change Medicaid policies, benefits, and beneficiary cost-sharing. While many reforms may have a positive impact on consumers – such as expansion of home and community-based service options – other reforms, such as imposing new costs and cutting benefits, may harm consumers and restrict their access to Medicaid services. It is important that consumers – whose lives can be dramatically affected by policy changes --and their advocates have opportunities to comment at each stage of the Medicaid policy process.

Medicaid is a joint federal/state program that buys basic health and long-term care services for 51 million Americans: families of limited financial means, people with disabilities and the elderly. States can gain federal approval for major Medicaid reforms through a waiver request – a cumbersome process -- or a state plan amendment (SPA), which gives states more leeway in making changes.

The authors found that opportunities for public participation are not always present. They examined public comment policies in eight states – California, Connecticut, Florida, Illinois, Indiana, Michigan, Nevada and Texas – and also interviewed advocacy groups and AARP representatives in these states.

The report concludes that the best way to involve the public is to make all proceedings transparent; create opportunities that are predictable and meaningful; and make available accurate, objective and timely information.

Reaction from AARP State Offices and Advocacy Groups

Some AARP officials objected to the methods their states use to announce proposed Medicaid changes. Often the changes are announced in administrative rule publications or legislative publications that consumers normally cannot easily access. Another common complaint was states' failure to respond to comments made during public hearings, making those hearings seem irrelevant.

Other advocacy groups and AARP offices noted a total lack of transparency during waiver negotiations between state and federal officials. Many AARP chapters believed this stage was a closed-door process and that changes could be made without any input from stakeholders. On the state level, they felt that by the time the public had a chance to comment, the administration was already committed to a particular policy direction. Advocacy groups expressed concern over the quality of opportunities for public involvement - - for example, Medicaid agency hearings that didn't include decision-makers or failed to include people with disabilities, or placed time limits on testimony, reduced the effectiveness of opportunities for meaningful public participation.

Both AARP offices and advocacy groups support easy access to program notices, public comments, waiver documents and final approvals. They recommended all these documents and notices be placed on state-sponsored web sites.

What can the federal government do to create opportunities for meaningful public participation?

- Congress should establish minimum standards for public participation in the Medicaid policy making process.
- The Centers for Medicare and Medicaid Services (CMS) should require each state to document a public comment process – including what comments were made and how the state responded to them.
- If there are changes made in waiver requests during negotiations with the federal government, CMS should required states to seek additional public comment and document it.
- CMS should require Medicaid agencies to actively involve Medical Care Advisory Committees (MCAC) in all policy changes that directly affect consumers. Each state must have such an advisory committee to advise the state Medicaid agency on matters of health and medical care services.
- CMS should post all applications for change on the Internet, with a dedicated web page.

What can state governments do?

- Tell the public that the state intends to develop a waiver or SPA that affects Medicaid benefits.
- Create opportunities for public comment at three critical times: before the waiver or state plan amendment is filed; during federal negotiations, if the reform is substantial; and before implementing the changes.
- Give the public enough detail on the waiver to help consumers and advocacy groups decide if they will comment. People should never have to use a Freedom of Information Act request to get information.
- State Medicaid agencies should post all documents on a dedicated web page, use listservs, web-based information sessions and chat rooms to encourage participation.
- Increase opportunities for public input through statewide hearings and workshops that involve state and Medicaid officials. Also, states should provide transportation and child-care assistance to encourage participation.

Methodology

The authors of this policy paper are Barbara Coulter Edwards, MPP, Susan P. Garcia, and Aimee E. Lashbrook, JD, MHSA, of Health Management Associates and Lynda Flowers, JD, MSN, RN of the AARP Public Policy Institute. They collected information through interviews with Medicaid directors and counsels, consumer advocacy groups and provider associations and the Centers for Medicare and Medicaid Services (CMS).