

Advocating for Quality in Medicaid Managed Care:

Ideas for Families and Youth
Affected by HIV and AIDS

AIDS Policy Center for
Children, Youth & Families
Washington, D.C.



Introduction

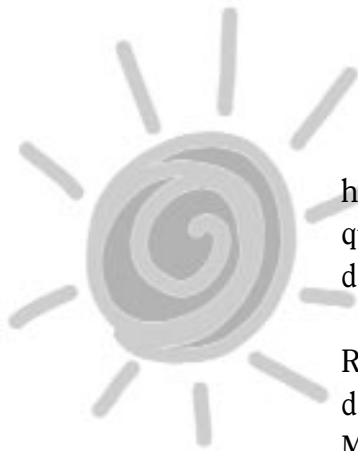
The Medicaid program is one of the most important government programs for children, young people, and families affected by HIV and AIDS. More than half of all Americans living with AIDS have their health care paid for through Medicaid. For children who are HIV infected, this number jumps to over 90 percent. If you or your family receive care paid for by Medicaid, you will need to know about a new trend in health care—managed care.

AIDS Policy Center for Children, Youth & Families created this guide as a companion to *Meeting the Needs of Children, Youth, and Families Affected by HIV and AIDS Through Medicaid Managed Care*. That document explains Medicaid and managed care in much more detail. It has been developed for youth, families, Title IV projects, and other health care providers who want to work with Medicaid officials and managed care organizations so that Medicaid managed care plans meet the needs of young people and families like yours.

Advocating for Quality in Medicaid Managed Care: Ideas for Families and Youth Affected by HIV and AIDS summarizes the information in the other book and includes some advocacy tips just for youth and families. We hope you find the two documents helpful.

About Medicaid

Medicaid helps pay for health care for 37 million Americans. One out of every four American children receives health care paid for by Medicaid. Medicaid is an entitlement program. This means that people who are eligible for Medicaid get the care they need, no matter how many people are in the program already. The cost of Medicaid is split between the federal government and each state. The federal government pays between 50 to 80 percent of the cost, and the state pays the rest. Therefore, both the federal government and the state have a stake in



how much the Medicaid program costs. For this reason, and also to improve quality, both are experimenting with different ways to run Medicaid and to deliver care through the program.

Right now, almost all states are experimenting with a model for financing and delivering health care called "managed care." You may already be enrolled in a Medicaid managed care program and be perfectly happy with the care you and your family are receiving. You may be in a managed care plan and not be so happy. Or, you may be in a traditional "fee-for-service" system in which you get to choose any doctor you like and Medicaid pays him or her for the care you receive. If you are in this traditional system, it is likely that your state is considering a move toward managed care. Whatever your circumstance, we hope you will find the following information about managed care helpful.

About Managed Care

More and more states are turning to managed care as a way to control Medicaid costs. Nationally, 40 percent of all Medicaid beneficiaries are enrolled in managed care programs, a big change from 1993. That year, only 14 percent of people covered by Medicaid were in managed care.

Managed care is a system for financing, delivering, and evaluating health care. Families enrolled in managed care are directed to use only certain doctors and health care providers who are part of a managed care plan. Care is coordinated by a primary care provider, usually a physician, who determines what care is needed, including making decisions about when it is necessary to see a specialist. A managed care organization typically receives a set amount per person enrolled in the managed care plan. This amount does not go up or down depending on how much care they provide.

A set fee or "capitation rate" per person means that when people in the plan use a lot of care, the managed care company does not make as much money. This is a concern for families and young people living with HIV and AIDS, who tend to need much more health care than others. Some worry that managed care companies will not want to serve children, youth, and families affected by HIV or will not want to provide all the care that is needed.

Some aspects of managed care hold out great promise for children, young people, and families affected by HIV and AIDS. Care coordination is one important advantage of managed care. Families living with HIV often say that having all the care they and their children receive coordinated by one person is a huge benefit. Care coordination is at the heart of managed care, so this may be a great help to you and your family.

If your state is moving toward Medicaid managed care, or if you are already enrolled, there are a number of ways you can help ensure that children, young people, and families with HIV get good quality care when they need it. If your state is thinking about Medicaid managed care, you should know about the "waiver" process.

The Medicaid Waiver Process

Part of the shift toward managed care in the Medicaid program has been taking place through special waiver programs. Through these waiver programs, the federal government allows states to experiment with different ways of providing Medicaid care. States must get permission from an agency in Washington called the Health Care Financing Administration (HCFA) to make certain kinds of changes in their Medicaid programs. This permission, when granted, is called a "waiver," because it allows states to waive or put aside certain parts of federal Medicaid law. State Medicaid waiver applications are public documents. That means you can get a copy, if you keep asking!

The federal government requires that states applying for a Medicaid waiver get advice and input from the public. So far, people living with HIV and AIDS have done a great job making their voices heard and their needs known by participating in the waiver process. They have identified some of the problems with proposed waivers and argued for the needs of people with HIV/AIDS under managed care. This advocacy has helped the federal government learn more about what these needs are. As a result, HCFA has required several states to revise their waiver applications to show that their managed care programs will be able to meet the health care needs of people living with HIV/AIDS.

There are a number of ways that you can get involved in the Medicaid waiver process, if your state is asking for a waiver. The following suggestions offer a starting point:

- ✓ Get involved with community organizations, including AIDS organizations, health or disability advocacy groups, and local or state medical or nursing associations.
- ✓ Call your state legislative representative and ask if your state has plans to submit a Medicaid waiver.
- ✓ Take part in public hearings or other opportunities to comment on proposed Medicaid waivers.
- ✓ Ask AIDS advocacy organizations for information on Medicaid and managed care issues.

Updated information about state Medicaid waivers is also available directly from HCFA's site on the World Wide Web. If you or your care provider has access to a computer linked to the Web, you can "visit" HCFA's Web site to find out about your state's Medicaid waiver. The address, or URL, for HCFA's web site is: <http://www.hcfa.gov>. When you reach HCFA's Web page, first click on "Medicaid," then click on "Professional/Technical Information," then click on "Comprehensive State Health Reform Demonstrations." The HCFA Web page also offers general information about Medicaid especially for consumers. To find it, just click on "Consumer Information" instead of "Professional Technical Information."

This all sounds a lot more complicated than it really is, so don't be intimidated if you haven't used the World Wide Web before. The hardest part is usually finding a computer you can use to get access to the Web. If your care provider cannot help you, your local library may be able to.

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Key Questions to Consider for Serving Children, Youth, and Families Affected by HIV/AIDS in Managed Care Plans

AIDS Policy Center for Children, Youth & Families developed some guidelines that we hope will help you if you decide to get involved in your state's waiver process. You can also use them as a checklist for other kinds of Medicaid managed care advocacy. We call them "key questions to consider" for serving children, young people, and families in Medicaid managed care. They are divided into five categories: quality, choice, access, cultural competence, and non-discrimination. We hope you find them useful.

Quality

- Does the managed care plan provide the highest quality care to all enrollees, with special consideration to the needs of children, youth, and families affected by HIV/AIDS?
- Are care and benefit packages based on clinical standards set by independent professional organizations or government bodies?
- Are clinical standards continually updated to include new and evolving HIV/AIDS treatment knowledge and technology?
- Does the managed care plan track the care needs of children, youth, and families affected by HIV/AIDS as a way to ensure that all needed care and services are offered by the plan?
- Do grievance and appeals procedures enable enrollees to challenge decisions to deny care, including experimental treatment?

Choice

- Does the managed care plan ensure that youth and families have a choice of qualified health care professionals with expertise in HIV/AIDS treatment?
- Are youth and families living with HIV/AIDS able to choose a primary care provider with HIV/AIDS expertise?
- Are youth and families living with HIV/AIDS able to choose a specialist as their primary care provider?
- Does the managed care plan's network of providers include physicians and other health care providers with expertise in HIV/AIDS treatment? If not, does the plan permit unlimited out-of-plan use of such providers?
- Does the managed care plan provide affordable options for youth and families to seek out-of-network health care when necessary?

Access

- Do youth and families have convenient and timely access to the care they need?





- Does the managed care plan contract with essential community providers who care for youth and families affected by HIV/AIDS, including Ryan White Title IV community providers?

- Do youth and families have access within a reasonable travel time to a full range of primary care providers, specialists, and specialty care centers?

- Are non-emergency services available evenings and weekends?

Cultural Competence

- Does the managed care plan provide enrollees with a full choice of culturally appropriate benefits and providers, including community-based facilities?

- Does the managed care plan ensure that its provider network reflects the cultural, religious, and demographic makeup of the communities the plan serves?

- Does the managed care plan ensure that culturally competent care is available to enrollees?

Non-Discrimination

- Does the managed care plan ensure non-discrimination against every consumer or provider in enrollment, access to care, and quality of care?

- Is the managed care plan—in marketing, enrollment, and the provision of services—free of discrimination based on current or anticipated mental or physical health status, race, gender, income, age, geography, or other factors?

- Is the managed care plan free of discrimination against providers based on their—or their patients’—mental or physical health status, race, gender, sexual orientation, religious beliefs, income, age, or other factors?

Medicaid Managed Care Advocacy Tips for Youth and Families and Affected by HIV and AIDS

A Washington advocacy group called the Bazelon Center for Mental Health Law developed some tips for families who want to get very involved with Medicaid managed care advocacy. We have adapted them slightly to fit the concerns of youth and families living with HIV and AIDS. Don't feel bad if you are not interested in this level of advocacy. Many youth and families have enough to do just taking care of their own or their families' health. For those of you who want to go all the way, here they are!

Analyze!

- 1.** Gather information—about both the potential and the pitfalls of managed care. Become familiar with the language of managed care, its terminology, acronyms, and definitions.
- 2.** Seek out individuals—those who are making the decisions about managed care for children and families with HIV/AIDS in your state. Keep asking questions until you find someone who can bring you up to date on the status of Medicaid managed care in your state.
- 3.** Find out what efforts are being made to include families, young people, and advocates in the planning process. Ask if planning groups or task forces have been or will be set up to study managed care. Ask how you or other advocates can become a member. Get the dates and times of public meetings, legislative hearings, and other public forums where citizens can speak out on the state's plans for Medicaid managed care.
- 4.** Request copies of any Medicaid managed care planning documents that exist. These could include planning outlines produced by state agencies and documents produced by managed care companies in response to state Requests for Proposals. Study these documents and see how well they address the needs of children, youth, and families living with HIV and AIDS.
- 5.** Develop a brief position paper (one sheet/two sides) on principles for good managed care for children, youth, and families affected by HIV/AIDS. In it, address the weaknesses you see in your state's planning documents.

Organize!!

- 1.** Build a coalition of youth, families, and care providers to strengthen your ability to influence state policy makers. Reach out to others who are already advocating on Medicaid managed care or who you think should be involved. Potential allies include: Ryan White Title IV projects and providers, child health and welfare advocates, family-to-family support networks, youth-serving organizations, special education teachers and organizations, children's care providers (from physicians to child care providers), social action committees of faith communities, labor unions, and many others.
- 2.** Get to know key staff in the state agencies that are involved in Medicaid managed care planning and implementation. You can become an important resource to these people as they seek to make managed care more responsive to the needs of children, youth, and families living with HIV and AIDS.

Advocate!!!

- 1.** Educate the public to gain support for quality Medicaid managed care. Use the media—TV, radio, and local newspapers—community meetings, clubs, and churches, synagogues, and other places of worship to spread the word and gain understanding.

Circulate your position paper far and wide. Make sure it has been delivered to all key state agency staff and that it is available at all public forums. Send it to your local newspapers and radio and TV stations, and urge them to publicize your efforts to rally support for children, young people, and families living with HIV and AIDS.

- 2.** Testify or get on the agenda at public meetings, hearings, and other public forums. Pack the audience with other families, neighbors, and supporters. It is important for policy makers to see that the community backs up your position.
- 3.** Meet with key state agency staff individually. Participating at public forums is important, but it is not a substitute for one-on-one meetings at which you can explain your position in great detail and staff can ask questions.



4. Ask the right questions! These can get you started:

- Does the managed care plan provide care and services specifically designed to address the special needs of children, youth, and families affected by HIV and AIDS?
- Does the managed care plan operate in a youth-friendly and family-friendly manner?
- Does the managed care plan provide home- and community-based services and supports as part of a comprehensive set of services?
- Are services and supports adapted to the different cultures present in the communities the managed care plan serves?
- Does the managed care plan have sufficient financial resources to stay in business and do the things it promises to do?
- Does the managed care plan include grievance procedures and other consumer protections for times when a problem occurs?
- Are there arrangements for youth and families to find help in negotiating the managed care system if they need it? Are youth and family groups funded for this purpose? Are advocacy programs available?

5. Follow up and monitor the contents of all managed care plans and contracts with private managed care companies to be sure they address the needs of children, young people, and families affected by HIV and AIDS. **REMEMBER:** If it is not in the plan/contract, it won't be in the service delivery system.