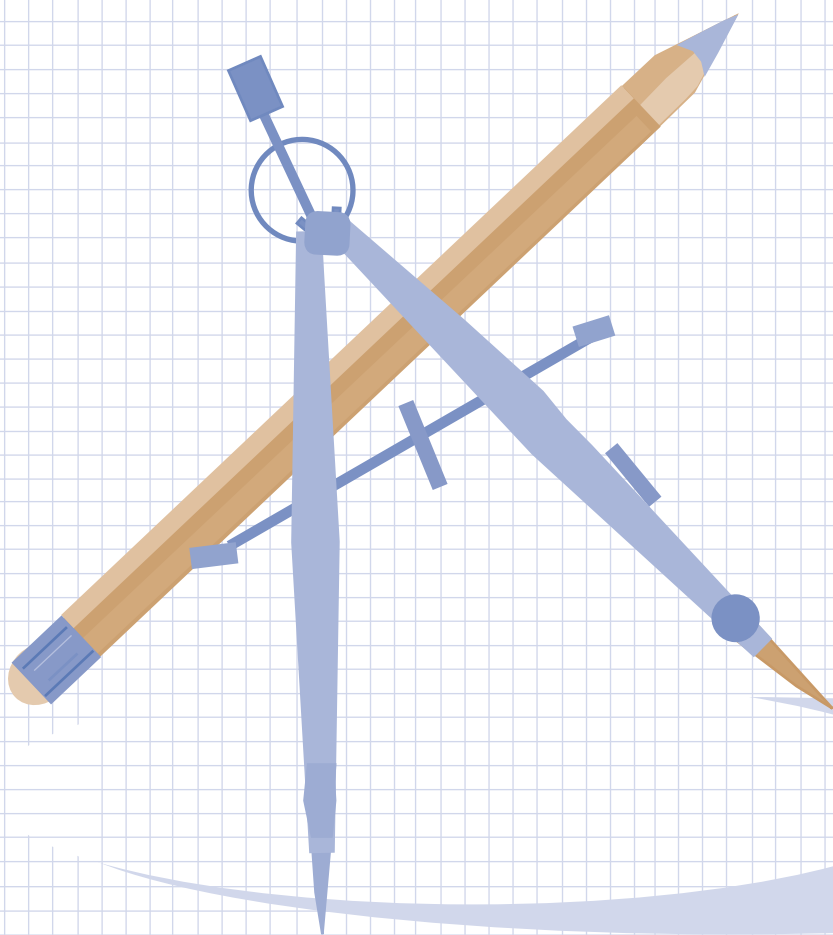


Designing a Consumer Health Assistance Program



Design

Grants

Functions

Scope

Location

Funding

Staff

Training

Outreach

... and more

Families USA

Designing a Consumer Health Assistance Program

© August 2010 by Families USA

Updated from the original guide published in June 2001 and supported by a grant from the Robert Wood Johnson Foundation.

Families USA

1201 New York Avenue NW, Suite 1100
Washington, DC 20005
Phone: 202-628-3030
Fax: 202-347-2417
Email: info@familiesusa.org

This publication is available online at www.familiesusa.org.

Cover Design by Nancy Magill

CONSUMER HEALTH ASSISTANCE PROGRAMS

Making a Difference

A 10-year-old boy with a serious knee injury was taken to the nearest emergency room. After the child received emergency surgery to repair a ligament, the family's health plan refused to pay. The family appealed the decision unsuccessfully. A consumer health assistance program helped the family gather information showing that the care was, in fact, immediately necessary and advised the family to proceed to the next level of appeal. At the second review, the plan's original decision was overturned, and the emergency room services were covered.

A 14-month-old boy with congestive heart failure and a pacemaker needed constant monitoring of his breathing and oxygen. His family's health plan, which originally covered private duty nursing, reversed itself and said that the nursing was not medically necessary. The mother appealed, but the appeal was denied. A consumer health assistance program helped the family gather more evidence from the child's medical team and seek a review external to the health plan. The external reviewer overturned the plan's decision, and the child got the private duty nursing he needed.

A family lost its Medicaid benefits when the household head was hospitalized and unable to turn in a required form. A consumer health assistance program representative attended a hearing with the consumer and was able to get the family's coverage reinstated.

When an HMO stopped serving Medicare patients, one elderly man had to join a new Medicare HMO. The man had partially paid his first HMO for a prosthetic leg and was unable to get either the leg or his money back. A consumer health assistance program helped resolve the problem, and a month later, the man received a prosthetic leg.

CONTENTS

Designing a Consumer Health Assistance Program	3
New Grants under Health Reform	5
Functions of Consumer Health Assistance Programs	7
Program Scope	9
Program Location	11
Funding	13
Staff and Volunteers	15
Training	17
Outreach	18
Methods of Complaint and Resolution	19
Access to Records	21
Collecting and Disseminating Information	22
Resources	24

DESIGNING A CONSUMER HEALTH ASSISTANCE PROGRAM

Health insurance and health coverage options can be confusing. Fortunately, there are programs to help people navigate the complexities of health insurance and, thanks to health reform, this kind of assistance will soon expand dramatically. When considering health reform legislation, the new Patient Protection and Affordable Care Act (Affordable Care Act), Congress added \$30 million dollars in the first year for states to establish or strengthen consumer health assistance programs, with more money authorized for following years. Consumer health assistance programs will help ensure that health care consumers have access to an unbiased, trustworthy source of information.

Consumer health assistance programs (sometimes called “health care ombudsman programs” or “health consumer advocates”) provide critically important services to today’s consumers in the states where they already exist. These programs, which are independent of health facilities and health plans, have traditionally had three primary purposes: (1) to educate consumers about their rights and responsibilities; (2) to identify, investigate, and help resolve consumers’ complaints about their health coverage and health care services; and (3) to collect, analyze, and report data and information to all stakeholders in the health care system about the types of problems that consumers encounter so that health plans and government agencies can improve their services. Health reform expands the role that consumer health assistance programs will play to help people understand their new options and rights.

The Affordable Care Act requires states to establish health insurance “exchanges” by 2014. The exchanges will help individuals and small businesses purchase and enroll in, health insurance. When states establish these exchanges, they must also make more kinds of consumer help available. The exchanges themselves must provide a toll-free hotline. The hotlines will likely deal primarily with enrollment questions. Many people will qualify for premium assistance and cost-sharing help if they purchase coverage through the exchanges, and states must also provide grants to “navigators”—entities that can reach out to uninsured consumers, small businesses, and others to provide public education and assist with enrollment. Consumer assistance programs that provide more intensive assistance with grievances and appeals will continue to have a role. Navigators, for example, will refer more complex problems to those consumer assistance programs.

Some states already have consumer health assistance programs and have years of experience assisting people. Families USA has worked with these programs to discover what types of models and practices are most effective. As more people obtain the health coverage they deserve, questions will arise, and the need for assistance will grow. Many states and localities are looking ahead at developing consumer health assistance programs to meet the needs of health care consumers within their jurisdictions. This guide reviews some key considerations to keep in mind when designing such programs.

NEW GRANTS FOR CONSUMER HEALTH ASSISTANCE UNDER HEALTH REFORM

Under health reform, states will be eligible for grants (beginning in 2010) to establish, expand, or support “offices of health insurance consumer assistance” or “health insurance ombudsman programs.” States that want a grant will have to do the following:

- Designate an independent office or ombudsman that will respond to inquiries and complaints about health coverage.
- Comply with any grant criteria that the Secretary of Health and Human Services establishes.
- Collect and report data to the Secretary of Health and Human Services on the types of problems and inquiries encountered.

Offices of health insurance consumer assistance or health insurance ombudsmen will be responsible for the following:

- Helping people file complaints and appeals, including filing appeals with the health plan or health insurer (internal appeals) and providing information about appeals processes that are external to the health plan or health insurer.
- Collecting data on problems and inquiries encountered by consumers and reporting that data to the federal government.
- Educating consumers about their rights and responsibilities.
- Assisting with enrollment in health plans by providing information, referrals, and assistance.
- Helping resolve any problems people encounter with receiving the new premium tax credits that will be available under health reform.

These programs will help consumers with their rights under both state and federal laws. Thus, for example, the office might help with an appeal in a job-based plan that is “self-funded” and thus subject only to federal law—as well as with appeals in health plans that are subject to state regulation.

The grant announcement and criteria for the first year were published online at www.grants.gov on July 22, 2010, CFDA No. 93.519. The announcement explains that the designated office or ombudsman must have the independence to advocate “freely and vigorously on behalf of consumers” and report objective information. Further, the announcement explains that states can provide consumer assistance

services directly or can partner with nonprofit organizations to provide the assistance. Designated consumer assistance programs must have the expertise to perform their duties and must make services accessible throughout the state and to vulnerable populations, including people with limited English proficiency.

Other Funding for Consumer Assistance

These new grants are not the only source of federal funding for consumer assistance programs. For example, programs called SHIPs (State Health Insurance Assistance Programs) receive federal grants to counsel Medicare beneficiaries. Long-term care ombudsmen receive federal grants to assist nursing home residents and sometimes to assist people who receive home care services. And some state Medicaid agencies, which receive federal matching funds for their administrative functions, have designated, or contracted with, programs to assist and counsel Medicaid beneficiaries.

The new grants will play an important role in enhancing assistance for privately insured consumers, and states will need to determine how to best coordinate and provide assistance for the entire population.

THE FUNCTIONS OF CONSUMER HEALTH ASSISTANCE PROGRAMS

Consumer health assistance programs typically perform three major functions:

- **They provide information to health care consumers.**

Through telephone hotlines, one-on-one meetings, community forums, written materials, the media, and other means, consumer health assistance programs educate consumers about their health care rights (e.g., their rights to second opinions, to out-of-network care, and to involvement in their own treatment decisions) and about formal procedures for resolving problems, such as grievances, external appeals, and administrative hearings. To help people choose a health plan, programs describe how managed care, preferred provider organizations, and indemnity insurance differ. They also identify available information about various plans, including the quality of care provided, the costs and benefits to consumers, and participating providers. To help uninsured consumers, programs explain eligibility guidelines and application procedures for public coverage (such as Medicare and Medicaid) and refer them to facilities that offer free or reduced-fee health care services.

- **They investigate and help resolve consumer complaints regarding health coverage and services.**

Consumer health assistance program staff know the laws, regulations, and other policies that apply to various health care issues. They develop contacts with health plans, insurance commissions, health departments, employers, legal services programs, and other community organizations, coordinating with existing resources. They are skilled in mediation and negotiation, and they know how to gather meaningful evidence and present grievance and appeal cases. In some cases, consumer health assistance programs explain how consumers can pursue problems on their own (e.g., whom to contact in a health plan or government agency and what that person is required to do). In other cases, they make calls and write letters on consumers' behalf. They can direct consumers to the appropriate entity to hear a complaint—for example, the administrative hearing office of a human services department in cases involving Medicaid, an external appeals unit of the health department or insurance commission in matters concerning privately insured consumers, an employer or the federal Department of Labor for complaints

involving self-funded plans, or a licensing body or medical board for quality-of-care complaints. Sometimes they even represent consumers in grievances and administrative appeals, but rarely (if ever) do they bring cases to court. Most cases are resolved with only limited intervention from program staff.

- **They collect, analyze, and report data and information to all stakeholders in the health care system.**

For example, they maintain information about the types of problems consumers encounter and how those problems are resolved. Information about recurring issues helps health plans and providers target areas for improvement and helps government agencies spot gaps in existing policies and procedures, while a high number of complaints against a particular plan or facility may alert regulators to substandard care.

PROGRAM SCOPE

A key consideration in establishing a consumer health assistance program is the scope of its responsibility. Will it focus on a particular segment of the health care system, such as mental health or long-term care, or will it assist consumers in a variety of health care settings? Will it target services to a particular population based on the payment source for health services, such as Medicaid or private insurance, or will it help consumers regardless of their insurer? Will it serve consumers in self-insured plans (plans in which the employer assumes all or some of the financial risk rather than simply purchasing coverage from an insurer)? In other words, is a broad or a narrow scope better? There are pros and cons to both approaches.

Advantages of Programs with a Broad Scope

- Consumers need not determine which of a myriad of consumer health assistance programs is appropriate to address their concern. One call to a single consumer health assistance program would connect them to a person with the expertise to resolve the problem.
- As consumers' health needs change and they move into various health care settings (e.g., hospitals, nursing homes, and home care), they would deal with the same consumer health assistance program.
- The consumer health assistance program would have a comprehensive view of problems in the health care system and similar insight into their resolution. For example, staff would know whether publicly and privately insured people encounter the same problems in a health plan and/or whether an insurer's payment policies affect the quality of care in a particular setting.

Advantages of Programs with a Narrower Scope

- The consumer health assistance program would establish expertise in particular health care issues and have in-depth knowledge of the laws, regulations, and policies relevant to that particular type of health care consumer.
- Populations with differing needs would not compete for program resources.
- Available funding or political considerations may make it more feasible to launch a program serving only a particular population.

Recommendation

When possible, develop a consumer health assistance program that is broad in scope but that has staff with distinct areas of expertise, including private insurance coverage, self-insured plans, Medicare, Medicaid, and coverage and service options for the uninsured. If it is not feasible to create a single program for financial or political reasons, ensure that programs regularly exchange information and referrals and otherwise coordinate with each other.

PROGRAM LOCATION

Depending on the state, existing consumer health assistance programs are operated by an independent, nonprofit agency, the state insurance commission or health department, the attorney general's office, another government agency, or any combination of these. Wherever a program is located, one consideration is paramount: The program must be able to work on consumers' behalf without conflicts of interest.

Advantages of Locating a Program in a Nonprofit Organization

- Nonprofit organizations can readily take a pro-consumer stand. They can help consumers articulate issues and gather evidence that will best present the consumer's side of a case. In appeals, they can directly represent consumers. They do not need to judge cases and enforce rules as regulators must do.
- Boards and staffs of nonprofit organizations can be structured so there is no conflict of interest involving health insurers or providers. By contrast, government agencies contract with health insurers and providers, and they may actually deliver some health care services.
- In general, consumers feel they can trust nonprofit organizations as independent sources of information.
- Nonprofit organizations typically have well-established relationships with their constituents, which in turn promotes program outreach.
- Nonprofit organizations are insulated from some (if not all) political pressures and can bring consumer issues to the attention of policy makers even if their positions on those issues differ.
- Many nonprofits face fewer bureaucratic hurdles than government agencies and thus can produce written materials and other communications more quickly.

Advantages of Locating a Program in a Government Agency

- Agencies have clout because they enforce licensure and other requirements, so insurers and providers are more likely to respond to government investigations or even inquiries.
- Agencies have access to records about health providers and insurers, and about consumers' eligibility for Medicaid and other public programs, which may facilitate investigation of a complaint.
- Some government agencies recommend legislation and public policies regarding health insurance as part of their work. Consumer health assistance programs located within such agencies may have the ear of executive-branch policy makers.

- Consumers may already be contacting another government agency (such as the local Medicaid office) about a problem, and that agency could readily provide information and refer cases to the consumer health assistance program.

Some states have taken steps to protect government-run consumer health assistance programs from conflicts of interest by distancing them from health service and regulatory agencies and spelling out their consumer-related duties by law. However, red tape, such as state chain-of-command rules, can still significantly constrain an ombudsman's independence.

Recommendation

If nonprofit organizations in your state or community have the capacity to take on this work, determine how your state can best use their expertise. Can the state locate the consumer assistance program in a nonprofit, perhaps through a contract that allows the nonprofit to receive federal funding as well as any state revenues dedicated to consumer assistance? Or can the state contract with the nonprofit for some aspects of consumer assistance, such as representing consumers in an appeal, while the state retains other functions? Locating programs in nonprofit organizations ensures that they can truly represent consumer interests. However, the state should still be in regular contact with the consumer assistance program about the problems consumers experience so that the state can help to remedy systemic problems and take action if health insurers are not following regulations. To protect nonprofit consumer assistance programs from political pressures, establish multi-year contracts that can be terminated only for malfeasance.

If the program must be located within a government department, make sure its functions are clearly defined and are distinct from that of a regulator. Separate it organizationally. A consumer assistance program should advocate on behalf of consumers and help them prepare their side of a case in an appeal. The regulatory agency that hears appeals and acts as a neutral judge plays a different role, so these two functions must be clearly separated. Also separate the consumer assistance program from agencies that provide health services to avoid conflicts of interest. Specify that the program is required to report data and policy recommendations to other government agencies and regulators, and appoint the program director for a term that shelters him or her from political pressure.

Regardless of where the program is located, ensure that it (1) has the legal authority to obtain consumer records (using a written authorization) when necessary to investigate complaints, and (2) can represent consumers in health plan appeals and administrative hearings. And, if your state is one that initially established its consumer assistance program in an agency where there are conflicts of interest, work to relocate or restructure it as quickly as possible so that it can serve as an independent advocate for consumers.

FUNDING

How much money does a consumer health assistance program need in order to serve its target population effectively, and what funding sources are available? Neither of these questions can be addressed until key decisions about program design are made.

Key Program Design Issues

- Will services be delivered solely through telephone hotlines, or will there be personal counseling as well? Will services include direct representation (e.g., writing letters on behalf of complainants or assisting consumers in grievances and appeals)?
- How will the program reach people with limited English proficiency, people with disabilities, and people in remote geographical regions?
- What role will the program play in community education? Will it prepare and distribute its own educational materials?
- How will the program analyze consumer complaint data? Are new computer systems needed? Is software available from the federal government, and does it need to be adapted to fulfill the state's needs?
- Will the program use volunteers? How will volunteers be trained, recruited, supervised, and reimbursed for expenses?
- Will the program have medical and legal expertise on staff, or will it need consultants to help with medical and legal issues?
- How will the program publicize its services?
- Is the program operated by a freestanding agency or organization—that is, must it pay all its own overhead expenses?
- How will the program be evaluated? A regular, formal evaluation is crucial to determine whether the program is effective in the first place, to ensure that services are continually improved, and to inform policy makers, consumers, and outside organizations of the program's value.

An earlier Families USA survey of programs throughout the United States revealed that the funding needs of consumer health assistance programs vary dramatically depending on how each of these questions is answered. Comparing the program budgets to the population potentially eligible for services, we found that existing program budgets ranged from a low of 1¢ per eligible consumer in a program described as “badly underfunded” in 2000 to \$1.57 per eligible consumer in a better-funded program.

Funding Sources

- State funding, such as general revenues, specially designated taxes or fees, tobacco settlement money, or other funds designated for health care.
- Federal funding, such as grants to establish or support offices of consumer health insurance assistance or ombudsman programs; grants for programs that counsel Medicare beneficiaries (SHIPS); funding for certain program activities, such as matching funds for services to Medicaid beneficiaries; and specialized grants from agencies of the Department of Health and Human Services, available in some years to facilitate access to substance abuse or mental health services.
- Private funding, including grants from foundations and other charitable contributions. (“Conversion foundations,” formed when a nonprofit health care entity is sold to a for-profit entity, are important sources of funding for some programs.)

Recommendation

Plan adequate resources both for program start-up and for long-range program needs based on the scope of services offered and the population served. Allocate funds for program outreach, direct services, training, professional and nonprofessional staff, data collection, and regular program evaluation. To determine an adequate budget, talk with staff of programs in other states that have a similar program design, being sure to allow for geographic differences in salaries and operating costs. Because the program will serve a public function and need a stable source of funding over time, public financing is the most desirable source of core support. Supplementing public funds with private sources of revenue will help ensure that the program has an independent voice on health care issues.

STAFF AND VOLUNTEERS

Like funding, the staffing needs of a consumer health assistance program depend on program design. Some issues to consider:

- Depending on the program's scope, staff may need expertise in Medicare, Medicaid, private insurance, long-term care, mental health, or other issues.
- An attorney on staff (or under contract) can help answer questions about insurance contract provisions, as well as laws and regulations pertaining to health care. In addition, the program may need legal advice on such matters as confidentiality, liability, and the rights and responsibilities of the consumer health assistance program itself.
- Some programs include nurses or doctors to help address quality-of-care issues.
- Programs may need to devote staff time for traveling to meet with consumers, facilities, and insurers. Programs serving consumers who are homeless or have other special needs may need to allocate extra staff time in order to unravel problems.
- Programs in multicultural, multilingual communities typically need a multicultural, multilingual staff.
- Programs may designate particular staff members (or allocate a certain amount of staff time) to such tasks as community education and outreach, data collection and analysis, and establishing and maintaining relationships with health care stakeholders.
- If the program uses volunteers, staff members must coordinate and supervise volunteers' work.

Advantages of Using Volunteers in Addition to Paid Staff

- Volunteers can supplement the resources of programs with limited staffing.
- Volunteers can extend a program's reach into communities, especially if the volunteers are from the community being targeted.
- Volunteers can help establish favorable relationships between the program and community leaders.

Disadvantages of Using Volunteers

- Volunteers who contribute limited hours or who stay with programs only a short time may be unable to stay current on complex health care policies and issues that affect consumers.
- Many programs that use volunteers report high rates of turnover.
- Recruiting, training, retaining, and supervising volunteers are major tasks. In the 1995 report *Real People, Real Problems: An Evaluation of the Long-Term Care Ombudsman Programs of the Older Americans Act*, the Institute of Medicine recommends staff-to-volunteer ratios of one staff to every 20 to 40 volunteers in long-term care ombudsman programs.
- Some programs report difficulties getting volunteers to consistently and reliably report data on the consumers they serve.

Recommendation

Ensure there is adequate professional expertise among program staff. If the program uses volunteers, clearly define the volunteers' roles, maintain appropriate staff-to-volunteer ratios, and make sure volunteer casework and other tasks are professionally supervised. Develop standards for volunteer performance, and release volunteers who are unable to meet these standards. Recruit and train new volunteers on an ongoing basis.

TRAINING

Regardless of the population they serve, staff of consumer health assistance programs need to develop specialized skills in certain areas, including interviewing, problem solving, conducting investigations, gathering evidence and building a case, negotiating, and maintaining case and data files.

In addition to skills training, program staff need continuing education and training in key program areas in order to stay abreast of health care and health coverage laws. Key program areas include eligibility for public coverage and for various tax credits that help individuals and businesses afford the cost of coverage; enrollee rights under both federal and state laws; health plan requirements; what to do if a plan has an inadequate network or is marketing inappropriately or seems not to be offering good service; enrollee rights; case-specific grievance and appeals procedures; who to contact in either the federal government or state governments about various problems; and ethical considerations, such as protecting a client's privacy.

Recommendation

Make sure a realistic portion of the program's budget is devoted to training. Consult similar programs in other states, as well as specialized health care ombudsman programs within your state, for examples of training materials and curricula. Also consult national organizations, including Families USA, associations concerned with specific health conditions, and other national consumer advocacy organizations.

OUTREACH

Consumer health assistance programs conduct two forms of outreach: They educate consumers about their health care rights, and they publicize their services to their target audience. Most consumer health assistance programs devote significant resources to outreach and community education.

Common Outreach Strategies

- Laws in some states require insurers to promote consumer health assistance programs through their member handbooks, on membership cards, on notices about denials of coverage, and in other communications. The Affordable Care Act will require new insurers and health plans to provide notice about the availability of consumer assistance programs beginning in 2011.
- Programs publicize their services on a continuing basis so people can remember the program when problems arise. Among the vehicles: public service announcements, talk show appearances and other media events, yellow page ads and listings, appearances at community events, refrigerator magnets, newsletters, websites, and regular communications with community organizations.
- Programs adopt outreach strategies to reach various populations within the community. They hire multicultural staff, contract with community organizations that work with diverse cultures or special populations, and hire peer outreach workers to reach vulnerable constituents.
- Programs distribute educational materials, including fact sheets about consumers' rights, sample letters and appeal forms, information about health insurance plans, and other consumer guides.

Recommendation

Develop a comprehensive outreach strategy and devote adequate program resources to these efforts. Require by law that health plans and/or facilities provide information about the consumer health assistance program, and establish working relationships with health plans, providers, and facilities. Track how people hear about the program so you can evaluate the effectiveness of outreach efforts.

METHODS OF COMPLAINT AND RESOLUTION

Another important decision to make in designing a consumer health assistance program is at what point the program will intervene in the complaint process. A program can help consumers at every stage of the process or limit its services to consumers at certain points along the way.

- **The program can explain consumer rights and responsibilities and make referrals (i.e., advise whom to contact and what to say) before the consumer contacts a health plan or public agency with a complaint.**

Advantages

- Problems are potentially resolved at the earliest possible moment.
- Consumers may be better able to articulate their problems within the context of the health plan's or public agency's guidelines, making it easier for the plan or agency to respond.

Disadvantage

- The program could be drawn into inquiries that otherwise might be handled by health plan customer service personnel or a Medicaid caseworker.

- **The program can make calls or write letters on the consumer's behalf and/ or give advice on how to appeal after a consumer has tried but failed to resolve the problem on his or her own.** Virtually all existing consumer health assistance programs provide this type of assistance, and we know of no disadvantages to this approach.

- **The program can represent consumers in internal grievances and administrative appeals if earlier efforts to resolve the problem do not succeed.**

Advantages

- Consumer health assistance program staff develop considerable expertise in presenting cases and translating the finer points of health insurance policies—expertise generally not available from other sources. Consumers are more likely to succeed in their appeals with such expert assistance.
- Many problems can be resolved through administrative appeals without the need for litigation.

Disadvantage

- Under certain circumstances, it may be easier to obtain support for a program that provides information to consumers, as opposed to one that represents consumer interests against insurers. Under other circumstances, the opposite may be true.

- **The program can represent consumers in litigation if authorized to do so (but most consumer health assistance programs do not have this authority).**

Programs authorized to pursue matters through the courts can file lawsuits on behalf of consumers and defend consumers who are being sued (for example, for nonpayment of medical bills). As the July 2000 Families USA nationwide survey of consumer health assistance programs makes clear, however, among the few programs with this authority, the vast majority seldom go to court.

Advantages

- The threat of litigation can make some health plans more willing to settle cases.
- Programs can follow cases from start to finish, using all possible means to resolve problems.

Disadvantages

- Litigation is expensive. Just a few cases can consume many program resources.
- Politically, it may be easier to get consensus for a program that avoids litigation.
- Attorneys may already be available to handle the few cases that warrant litigation, so there may be no need for the consumer health assistance program to play this role.

Recommendation

Consumer health assistance programs should offer information and referrals to consumers, make calls or write letters on behalf of consumers and/or give advice on how to appeal, and represent consumers in internal grievance and administrative appeals. Since most states will be less inclined to support litigation, it makes sense to refer consumers to other resources if they wish to pursue appeals through the courts.

ACCESS TO RECORDS

In some states, consumer health assistance programs have the right to review the health insurance and medical records of consumers who have provided written consent. (The consumer's legal representative or guardian also can provide written consent.) Similarly, some programs authorized by federal law, such as protection and advocacy (P&A) programs and long-term care ombudsman programs, are guaranteed access to the medical records of clients they represent. In some programs and in some states, other rights of access are mandated by law, including the following:

- access to health care facilities and residents of health care institutions;
- access to licensing and certification records; and
- access to government agency information concerning clients' coverage by public programs, as well as information about their enrollment in health plans serving Medicaid or Children's Health Insurance Program (CHIP) consumers.

Recommendation

Establish the rights of consumer health assistance programs to access relevant records of the consumers they serve upon written authorization of the consumers involved. Develop procedures to protect consumers' confidentiality—procedures that follow the privacy guidelines established by HIPAA—and require the program to obtain consumers' consent before disclosing information about them.

COLLECTING AND DISSEMINATING INFORMATION

Virtually all consumer health assistance programs collect some data on the consumers they serve and the services they provide. Some programs use this information primarily in reports to their funding source. Others use data in reports to health care stakeholders and the general public.

Coupled with data that is available from regulators, health plans, and accrediting organizations, information from consumer health assistance programs can keep stakeholders posted on the strengths and weaknesses of various health plans and the status of the health care system in general.

Data that stakeholders find useful includes the following:

- the number and types of consumer issues addressed (e.g., problems obtaining coverage, problems with customer service, delays in providing care, denials of care, inappropriate care, payment disputes, problems getting prescription drugs);
- the type of care involved (e.g., primary, specialty, acute, or long-term care);
- the origin of the complaint (e.g., whether the dispute was with a particular health plan, a facility, a medical group, an individual provider, or a public program);
- the specific insurance involved;
- how long it took to resolve the problem and whether the problem was resolved to the consumer's satisfaction;
- the amount of benefits recovered for the consumer;
- whether grievances or appeals were filed;
- demographic information about consumers served; and
- how the complainant heard about the consumer health assistance program.

Some programs are required by law to report data annually to government agencies and/or state legislators. Additionally, some programs are mandated to assess the effects of proposed and existing health care laws on consumers and provide their recommendations.

In addition to gathering and disseminating data, consumer health assistance programs can provide other information to stakeholders through regular meetings and communications, testimony at public hearings, and participation on advisory committees. Through their daily work, consumer health assistance program staff learn about barriers to care, and they can warn health care plans and other stakeholders when procedures and policies are not working for consumers.

Recommendation

Determine at the outset what information from the consumer health assistance program will be most useful to health plans and providers, the government, and consumers. Devote adequate resources to data collection and dissemination. Establish a regular dialogue among health plans and facilities, regulators, policy makers, and the consumer health assistance program about systemic problems consumers face and how those problems might be addressed. Make sure the laws establishing the program reflect its important role in providing information about consumers' experiences with the health care system.

RESOURCES

From Families USA

Websites of existing consumer health assistance programs provide information about the activities of existing programs. To find a list of these sites, go to www.familiesusa.org and search “program locator.”

Families USA, *Consumer Health Assistance Programs: Report on a National Survey* (Washington: Families USA, 2001). This report gives statistical information about the services now provided by ombudsman programs and discusses some of the challenges they face in their work.

Testimony of Ronald F. Pollack, Executive Director of Families USA, before the U.S. Senate Committee on Health, Education, Labor, and Pensions (Washington, March 28, 2001), available online at www.senate.gov/~labor/107hearings/mar2001/032801wt/032801wt.htm.

From Families USA’s Health Assistance Partnership

Resources on various management and case-handling issues, developed by the Health Assistance Partnership for Medicare counseling programs (SHIPs), can be found at www.hapnetwork.org.

Cheryl Fish-Parcham, *Assistance for Health Care Consumers: Key Provisions of State Laws* (Washington: Health Assistance Partnership, 2005), available online at http://www.familiesusa.org/assets/pdfs/pages-from-hap-State_lawsa966.pdf.

Health Assistance Partnership, *Consumer Health Assistance Programs: A Model Act for Legislators* (Washington: Health Assistance Partnership, 2005), available online at http://www.familiesusa.org/assets/pdfs/pages-from-hap/Model_law804d.pdf.

Lee Thompson, *Consumer Health Assistance Programs: Bridging Gaps in the Health Care System* (Washington: Health Assistance Partnership, 2005), available online at http://www.familiesusa.org/assets/pdfs/pages-from-hap/survey_report25c1.pdf.

From Other Organizations

Center for Health Care Rights, *Managed Care Ombudsman Programs* (Los Angeles: Center for Health Care Rights, 1996). This includes a compilation of sample materials (legislation, contracts, job descriptions, notices to consumers, etc.) from programs as of 1996.

Jesse Gately, *Mental Health Ombudsman Programs: Working to Improve Mental Health Delivery Systems for Consumers* (Alexandria, VA: National Mental Health Association, 1999).

Jo Harris-Wehling, Jill C. Feasley, and Carroll L. Estes, eds., *Real People, Real Problems: An Evaluation of the Long-Term Care Consumer Ombudsman Programs of the Older Americans Act* (Washington: Institute of Medicine, U.S. Department of Commerce, 1995). This provides lessons learned from this specialized type of consumer health assistance program.

Gina A. Livermore, David C. Stapleton, Peter V. Lee, and Larry Levitt, “The Health Rights Hotline: Role of a Model Independent-Assistance Program,” *Health Affairs* 19, no.1 (January/February, 2000): 239-241.

New York City Task Force on Medicaid Managed Care, *Ombudsprograms: How to Make Managed Care in New York Consumer Friendly* (New York: New York City Task Force on Medicaid Managed Care, c/o Elisabeth Benjamin, The Legal Aid Society, 1997).

Jane Perkins, Kristi Olson, and Lourdes Rivera, *Ombudsprograms and Member Advocates: Consumer-Oriented Approaches to Problem-Solving in Medicaid Managed Care* (Los Angeles: National Health Law Program, 1998).

CREDITS

Written by:

Cheryl Fish-Parcham
Deputy Director of Health Policy
Families USA

**The following Families USA staff assisted in the
production of this publication:**

Peggy Denker, Director of Publications

Ingrid VanTuinen, Senior Editor

Colleen Haller, Publications Assistant

Nancy Magill, Senior Graphic Designer



1201 New York Avenue NW, Suite 1100 • Washington, DC 20005
Phone: 202-628-3030 • Fax: 202-347-2417 • E-mail: info@familiesusa.org
www.familiesusa.org