
Consumer Health Assistance Programs:

*Report on a
National Survey*

A REPORT BY
Families USA

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Report on a National Survey**

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INTRODUCTION

In recent years, the increasingly complex nature of our nation's health care system has given rise to an array of consumer health assistance programs (also called ombudsman programs) devoted to resolving disputes and otherwise helping consumers obtain quality health care. These programs not only provide crucial services to people who encounter problems with the health care system, they serve as the eyes and ears of policymakers, health care providers, and government agencies seeking to improve the management and delivery of health care services to diverse populations.

Consumer health assistance programs come in many shapes and sizes. Some are national in scope; others operate at the state or even the municipal level, sometimes under contract to nonprofit organizations. Some address the needs of health care consumers in specific settings, such as long-term care facilities; others target those with particular health challenges, such as those with mental or physical disabilities. Some focus on disputes involving health insurance coverage in general or with regard to particular insurers, such as Medicare, Medicaid, and other public programs. Still others deal with disagreements between consumers and private health insurers, or between health care providers and those with no coverage at all.

What characteristics do these programs share? How do they operate, and what services do they provide? How many people do they assist? How are they staffed and financed? What data do they collect? And how effective are they at representing consumers' interests and resolving disputes out of court?

In the summer of 2000, Families USA set out to answer these and other questions by conducting a nationwide survey of consumer health assistance programs. The findings of that survey, summarized in this report, describe the strengths of existing programs that other programs may wish to emulate, explore the untapped potential of consumer health assistance programs to address a variety of consumer concerns, and identify the types of support and resources staff need to enhance their programs.

Note: Unless otherwise noted, the word “program” throughout this report refers to consumer health assistance programs. Moreover, numbers and statistics cited in this report refer to the pool of programs surveyed by Families USA and not necessarily to all such programs in the U.S.

KEY FINDINGS

Consumer health assistance programs are quite successful in investigating and resolving individual complaints about health insurance and health care services, reporting that over two-thirds of the cases in which they intervene are resolved in consumers' favor. About two-thirds of the cases they handle require only brief advice, while one-third require direct representation. Almost all of the cases are resolved without litigation.

In addition to their primary function of investigating and resolving complaints, programs also educate individuals and community groups about consumers' health care rights. Staff speak at community events and develop and disseminate educational materials, and many programs use the media and websites to educate consumers as well.

Ombudsman programs provide valuable feedback to policymakers and other stakeholders about problems with the health care system through reports, meetings, and letters. Some regularly submit data about consumer complaints and recommend changes in the health care system to government agencies and policymakers—sometimes as mandated by law, as in the case of long-term care ombudsman programs. One-fourth to one-third of other types of consumer health assistance programs report data to policymakers and other health care stakeholders.

While some types of programs belong to networks through which they share information with similar programs and receive technical assistance, programs serving the privately insured and Medicaid beneficiaries work largely in isolation. All Medicaid programs, most programs serving the privately insured, and many programs of other types express the need for regular meetings and information exchange with their peers. Demand is also high for skills training; technical assistance in problem resolution and health care policy issues; and help with a variety of program design, management, and data-collection issues.

BACKGROUND

Federally Mandated Consumer Health Assistance Programs

By federal law, all states offer at least three specific types of consumer health assistance programs:

Long-Term Care Ombudsman Programs, which investigate and resolve complaints involving care in nursing homes (and, in some states, other residential settings¹), represent the interests of nursing home residents before government agencies, and work to protect residents' rights;

Protection and Advocacy (P&A) Programs, authorized under five federal laws to pursue legal, administrative, and other remedies to protect and advocate the rights of individuals with disabilities; and

State Health Insurance Assistance Programs (SHIPs), devoted specifically to helping those eligible for Medicare. SHIPs educate consumers about benefits and claims procedures for Medicare (and Medicaid as well, when necessary), provide information about other types of insurance to supplement Medicare (so-called “Medigap” policies), and refer consumers to government agencies that can help resolve problems related to health insurance.

The History and Structure of Federal Consumer Health Assistance Programs: Long-Term Care Ombudsman Programs

Long-Term Care Ombudsman Programs began in 1972 as a five-state demonstration project. With the passage of the Older Americans Act six years later, each state was required either to establish its own long-term care ombudsman program or contract with a public agency or nonprofit organization to provide ombudsman services.

These programs have specific duties and powers under federal law. They represent the interests of long-term care residents and seek administrative, legal, and other remedies. They comment—and facilitate public comment—on laws, regulations, and policies affecting residents; they analyze data on complaints filed by and on behalf of residents; they make recommendations for improving the nation’s system of long-term care; and they work with organizations of residents and their families. To facilitate their work, programs are guaranteed access to facilities and residents, to the medical and social records of long-term care residents (generally with the resident’s or guardian’s consent), and to the administrative, licensing, and certification records of long-term care facilities.

In FY 1998, long-term care ombudsman programs in 35 states and Puerto Rico operated within the state unit on aging. Programs in the other 15 states and the District of Columbia were either freestanding (independent) government programs, part of a larger government ombudsman program, or operated by private, nonprofit agencies under contract to the state.

In addition to statewide programs, some states also have local programs, run by paid staff or volunteers, serving nursing home residents in a particular region. Of the 587 local programs operating in FY 1998, 384 were run by area agencies on aging or other local government entities, 109 were operated by nonprofit legal service or social service agencies, 18 were freestanding programs, 46 were housed in regional offices of state ombudsman programs, and 30 had other arrangements.

Supporting these programs is the National Long Term Care Ombudsman Resource Center, a program funded by the U.S. Administration on Aging and operated by the National Citizens’ Coalition on Nursing Home Reform in cooperation with the National Association of State Units on Aging. The Center provides technical assistance and training; helps recruit volunteers; supports research on long-term care issues; publicizes ombudsman programs; and promotes cooperation among ombudsman programs, citizen advocacy groups, and other organizations working on behalf of long-term care residents.

Source: 42 US Code, Section 3058g; Administration on Aging, *Long Term Care Ombudsman Report: FY 1998* (U.S. Department of Health and Human Services, December 2000, www.aoa.gov/lombudsman); and information from www.ncchr.org/orcenter.html, 2001.

The History and Structure of Federal Consumer Health Assistance Programs: Protection and Advocacy Programs (P&As)

P&A programs originally were established by the Developmental Disabilities Assistance and Bill of Rights Act of 1975 to pursue legal, administrative, and other remedies to protect and advocate the rights of individuals with developmental disabilities.

Over the years, mandates for P&A programs have grown. Now, either through the state P&A agency or through additional networks, each state must provide advocacy for mentally ill individuals and investigate reports of abuse and neglect in facilities for the mentally ill; advocate the legal and human rights of persons with disabilities; protect those receiving or seeking rehabilitation services; and help people with disabilities obtain assistive-technology devices and services.

By federal law, each state governor designates an agency, independent of any service provider, to provide P&A services, and P&A programs have access to their clients' records. Unlike long-term care ombudsman programs, there is no defined advocacy role for P&A programs to effect change within the health care system, nor are they required to analyze data on consumer problems or recommend ways to address those problems.

The national Advocacy Training Technical Assistance Center (ATTAC), funded by a 2 percent set-aside in the federal P&A appropriation, provides support to the P&A network. Services include publications, training, conferences, model policies, and technical assistance.

Source: Information from www.protectionandadvocacy.com, 2001; 42 U.S. Code § 6042 and § 10801; and 29 U.S. Code § 794e.

The History and Structure of Federal Consumer Health Assistance Programs: State Health Insurance Assistance Programs (SHIPs)

SHIPs (also known by different names in different states—SHINE, SHIBA, HICAP, etc.) provide insurance counseling for Medicare beneficiaries. They were established nationally in 1990 when Congress instructed the Department of Health and Human Services (DHHS) to operate a "health insurance advisory service" for Medicare beneficiaries and authorized DHHS grants to states for this purpose. Originally, SHIPs primarily provided information and counseling about Medicare supplemental insurance, or Medigap, and long-term care insurance. Today they provide information and counseling on a wide range of Medigap, Medicaid, and Medicare matters, including managed care issues.

SHIPs in all 50 states and in the District of Columbia, Puerto Rico, and the Virgin Islands are funded by DHHS through the Centers for Medicare and Medicaid Services (CMS). Many state and local communities contribute additional resources to these programs. State units on aging administer these programs in 36 states, while state insurance departments or commissions run the SHIPs in the remaining states. SHIPs also provide outreach and individual Medicare counseling at the local level, either through volunteers or paid staff in a local sponsoring organization. Local sponsoring organizations include area agencies on aging, hospitals, and community organizations.

SHIPs are authorized by federal law to provide information and referrals to Medicare recipients and to make recommendations concerning consumer issues to appropriate state and federal agencies. Unlike other federal health ombudsman programs, SHIPs have no guaranteed access to their constituents' medical or insurance records. They also have no clear duty to represent consumers in disputes, and the extent to which they do so varies.

SHIPs at the state level receive training and technical support from the CMS-funded "SHIP Resource Center," currently operated by the National Association of State Units on Aging. Formal support for local Medicare counseling programs is provided by the state-level SHIPs rather than the national resource center.

Source: Information from www.nasua.org, "About State Units on Aging," 2001 and Centers for Medicare and Medicaid Services (formerly the Health Care Financing Administration), *The State Health Insurance Assistance Program (SHIP): Profiles of the 53 SHIP Grantees*, (Baltimore, MD: DHHS, 2000).

State-Initiated Consumer Health Assistance Programs

Additional consumer health assistance programs not required by federal law, such as those serving Medicaid beneficiaries and the privately insured, operate in many states as well. Some of these programs have been established by state (or in some cases, municipal) law and are either institutionalized within government agencies, such as within the state attorney general's office or insurance department, or operated by private, nonprofit organizations under contract to the state or municipality.

The rights and responsibilities of these programs differ by state. Some, but not all, states require insurers to make medical records available to consumer health assistance programs at the consumer's request. In some states, programs help consumers file complaints and even represent consumers in grievances and hearings, while programs in other states may be limited to referring consumers elsewhere for representation. Similarly, some states require programs to regularly assess their effectiveness, evaluate proposed and existing health care legislation from the consumer's perspective, and even recommend policy changes in the health care system, while other states define no such role for these programs.

State programs fall into two general categories:²

Medicaid ombudsman programs; and
general health care ombudsman programs.

Medicaid Ombudsman Programs

Many states have initiated consumer health assistance programs to educate Medicaid beneficiaries about managed care plans and help them resolve enrollment and access-to-care issues. States can claim federal matching funds for these programs because consumer education and counseling are considered Medicaid administrative expenses. Some states permit these programs to "advocate" for consumers and represent them throughout the grievance and appeals process, while others allow programs only to "mediate" and help beneficiaries file grievances and appeals, but not to actually represent consumers in proceedings.

The structure of these programs varies significantly by state. In New York City and in Colorado, Connecticut, Maine, Missouri, New Mexico, Tennessee, and Vermont,³ nonprofit organizations contract with the Medicaid program to provide consumer health assistance services to Medicaid beneficiaries. In Mississippi, a nonprofit organization receives private funds to help Medicaid and children's health beneficiaries; and in several other states, nonprofit organizations are privately funded to assist both Medicaid beneficiaries and those with private health insurance. In Kentucky, the government provides ombudsman services through the Cabinet of Health Services, which is independent of the Medicaid agency.

In Minnesota and Oregon, ombudsman offices operate within the Medicaid agency. In Maryland, the state Department of Health and Mental Hygiene works with ombudsman staff in local health departments to resolve complaints. In the District of Columbia and in California, North Carolina, Rhode Island, and Utah, the Medicaid agency designates staff to provide some consumer health assistance services. Finally, in a few states, such as Indiana and Louisiana, the “enrollment broker” (the private entity that helps the state enroll Medicaid beneficiaries in managed care) also has a role in investigating complaints and mediating or otherwise assisting with grievances.

General Health Care Ombudsman Programs

In some states these programs serve only those with private health insurance; in others, a single program may serve privately insured, publicly insured, and even uninsured consumers. Like consumer health assistance programs for Medicaid beneficiaries, these programs have emerged in recent years in response to the issues raised by managed care and the increasing complexities of health insurance in general.

Some states, including California, Connecticut, Florida, Georgia, Maryland, Maine, Nevada, Texas, and Vermont, have enacted laws establishing consumer health assistance programs. In Vermont, a nonprofit organization contracts with the government to provide ombudsman services; in other states, these programs are operated within the office of the state attorney general, the governor, or the insurance commissioner. Additionally, some major cities have established their own consumer health assistance programs. Two examples are Chicago, which provides services through a municipal agency, and New York City, which contracts with a nonprofit organization for services.

Lacking specific legislation establishing health ombudsman programs, some states, such as Illinois and Pennsylvania, have used their authority under state consumer protections or insurance laws to establish discrete health care assistance units, typically within the office of the attorney general or the state insurance commission.

SURVEY METHODS

In July 2000, Families USA surveyed all consumer health assistance programs identified in the U.S. meeting our definition of “a program independent of health facilities and/or health plans whose primary purposes are (1) to educate consumers about their health care rights and responsibilities and (2) to identify, investigate, and resolve consumers’ complaints about health care services.” The survey consisted of a questionnaire mailed to programs with a postage-paid reply envelope, as well as telephone interviews with a sample of programs throughout the U.S.

The written survey, reproduced in its entirety in Appendix I, consisted primarily of multiple-choice questions about the program's design, services, staffing, and needs for support and technical assistance. Our goal with this questionnaire was to obtain enough responses from each program category so we could consider the responses representative of all such programs.⁴

Written Survey Sample

Ultimately, we received 319 completed, written surveys, including: 22 statewide long-term care programs, representing a mix of large and small states throughout the U.S.; 20 statewide SHIPs, also spanning the country and including programs administered both by state insurance commissions or units on aging; 14 P&A programs; 15 Medicaid ombudsman programs, constituting more than half of all such programs nationwide (and including those operated by government agencies and enrollment brokers who reported performing some ombudsman functions); 28 programs operated either by government agencies or by nonprofit organizations that assist privately insured, or both privately and publicly insured, consumers; 128 local-level SHIPs, including programs in urban and rural areas throughout the country; 87 local long-term care ombudsman programs, also representing a cross section of urban and rural areas; and 5 specialized programs serving both privately and publicly insured persons (4 focusing on mental health care; the other geared to community living programs for persons with disabilities).

To supplement the questionnaire, we conducted in-depth telephone interviews with 69 programs (see box). Guaranteeing respondents' anonymity, our interviewer asked open-ended questions about programs' successes and challenges as well as their needs for support and technical assistance. The interviews were conducted from August to October 2000.

Telephone Survey Sample

In selecting programs to interview, we were aided by the Health Care Financing Administration (now the Centers for Medicare and Medicaid Services) and the National Citizens Coalition for Nursing Home Reform, which helped us identify programs in various agency and organizational settings, at different stages of development, and in geographically diverse locations. Ultimately, we interviewed by telephone 17 long-term care ombudsman programs (9 state-level programs, of which 5 were operated by state agencies and 4 were run by independent nonprofit organizations; and 8 local-level programs, 3 urban and 5 rural, in most of those same 9 states); 8 state-level SHIPs (3 operated by insurance commissions, 4 run by state units on aging, and 1 run by a state health department); 6 locally run SHIPs (2 rural and 4 urban); 15 Medicaid counseling programs; and 23 general consumer health assistance programs. We did not interview P&A programs.

SURVEY FINDINGS, PART I: CURRENT OPERATIONS OF CONSUMER HEALTH ASSISTANCE PROGRAMS

Whom Do Ombudsman Programs Serve?

Federally mandated consumer health assistance programs serve large numbers of consumers nationwide. In fiscal year 1998, long-term care ombudsman programs closed 121,686 cases involving 201,053 individual complaints.⁵ P&A programs represented 66,962 clients in 1999 and provided information and referral services to 274,542 people.⁶ SHIPs made 343,405 in-person contacts and 878,320 telephone contacts to Medicare-eligible consumers from the fall of 1999 to the fall of 2000.⁷

No national data are available on the number of people served by state-initiated consumer health assistance programs.

Because the number of people a program can serve depends on a variety of factors—among them the size of the program's budget and staff, the extent of services offered, the success of the program's outreach efforts, and the amount of resources devoted to direct services compared to other activities, such as community education—no patterns emerged from our survey about the number of people a given number of staff could serve. Indeed, one nonprofit general health care ombudsman program with 13 staff reportedly serves 2,800 people (or 215 people per staff member), while a similar program with a staff of 3 serves 246 people (82 people per staff member). Most programs provide direct assistance to between 800 and 2,000 consumers a year, but a few serve more than 10,000. Statewide SHIPs provide information and counseling to 33,500 people a year on average.

Consumer health assistance programs reach diverse cultural and linguistic populations. Programs report serving white, African-American, and Hispanic populations roughly in proportion to the racial mix of the U.S. About half of the statewide SHIPs, P&A programs, Medicaid, and general consumer health assistance programs surveyed have bilingual staff. Among long-term care programs and local SHIPs, bilingual staffing is less common. Other methods to reach multicultural and multilingual populations include the use of interpreters and assistance from community organizations.

Reaching vulnerable consumers in rural areas remains a challenge. Long-term care ombudsman staff in rural regions often travel great distances from one nursing facility to another and say they have inadequate funding and staff for this purpose. Some local SHIPs in rural areas lack the most basic resources, such as office space.

What Services Do They Provide?

Ombudsman services fall into three general categories:

- direct assistance to consumers;
- community outreach and education; and
- collection of data to provide feedback to policymakers and other health care stakeholders.

Programs differ in the types of services they provide, the extent to which they focus on one type of service over another, and how they define their roles in delivering those services. Some programs focus more on consumer education than problem solving, or vice versa. Some directly intervene on consumers' behalf and represent consumers in grievances and appeals; others see their primary role as that of neutral investigators or mediators.

Direct Assistance

Investigating and resolving individual consumer complaints about health care services—or “getting consumers what they need” and “getting consumers care,” as some respondents

Table 1

Program Activities of Consumer Health Assistance Programs

(Percent of programs, by program type, performing these activities)

	State SHIP	Local SHIP	State Long-Term Care	Local Long-Term Care	Protection & Advocacy	Medicaid	General
ASSIST INDIVIDUAL CONSUMERS	100.0%	98.4%	100.0%	98.9%	100.0%	100.0%	100.0%
Investigate complaint	85.0%	78.2%	95.5%	96.6%	92.9%	85.7%	89.3%
Empower consumers to resolve own issues by providing technical assistance	95.0%	84.7%	100.0%	93.1%	100.0%	78.6%	92.9%
Write letters/make calls on consumers' behalf	90.0%	90.3%	100.0%	88.5%	100.0%	78.6%	92.9%
Represent consumers in formal grievance reviews	50.0%	60.3%	66.7%	65.1%	100.0%	46.2%	40.7%
Follow case through to complaint resolution	70.0%	73.4%	95.5%	95.4%	92.9%	85.7%	82.1%
ASSIST GROUPS OF CONSUMERS	55.0%	37.1%	77.3%	79.3%	85.7%	35.7%	42.9%
OUTREACH AND EDUCATION	100.0%	96.0%	95.5%	100.0%	100.0%	93.3%	89.3%
Provide outreach	100.0%	96.0%	95.5%	97.7%	92.9%	92.9%	89.3%
Develop educational materials	100.0%	60.5%	90.9%	74.7%	92.9%	71.4%	85.7%
Train community org./providers	90.0%	52.4%	90.9%	87.4%	71.4%	57.1%	50.0%
OTHER ACTIVITIES (COLLECT DATA, PREPARE/DISTRIBUTE REPORTS, OTHER)	75.0%	64.1%	90.9%	96.6%	71.4%	86.7%	89.3%

put it—is the primary role of consumer health assistance programs. Ombudsman programs are quite successful in these efforts, reporting that over two-thirds of the cases in which they intervene are resolved in consumers’ favor.

Assistance takes many forms, including directly representing consumers in disputes over health plan coverage, both within the health plan appeals process and before government agencies authorized to intervene in disputes; referring consumers to other resources, such as other agencies or health plans; and providing immediate advice through telephone hotlines and other means.

Virtually all programs investigate complaints, provide technical assistance to help consumers resolve their own issues, and write letters or make calls on consumers’ behalf. Most programs follow cases through to resolution.

The extent to which a program perceives its primary role as a consumer advocate or as a neutral mediator or investigator in disputes depends in part on its statutory duties. The vast majority of P&A programs, and three-fourths of long-term care programs, see themselves as independent advocates who intervene in disputes on consumers’ behalf or advocate consumer interests in formal appeals.⁸ Over half of the general consumer health assistance programs and local SHIPs, and about two-fifths of Medicaid ombudsman programs and state-level SHIPs, perceive their primary role in this way.

Directly representing consumers in grievances and appeals is an important activity for some programs, and this representation need not be by an attorney. All P&A programs, most long-term care ombudsman programs, half of the state SHIPs and Medicaid ombudsman programs, and 41 percent of the general consumer health assistance programs provide this service.

Programs that provide *both* advice and direct representation report that approximately two-thirds of their cases require only brief (typically up to one-half hour) advice by phone or in person. The remaining third require direct representation, but only 12 percent of these require more than four hours of work to resolve the consumer’s problem.⁹

Among general consumer health assistance programs, there are marked differences between the services offered by programs within government agencies and those run by nonprofit organizations. Not one of the government agency programs responding to our survey says it represents consumers in grievances and appeals. By contrast, all but one private, nonprofit program surveyed say they directly represent consumers in grievances and appeals. Overall, 41 percent of the general consumer health assistance programs surveyed provide direct representation.

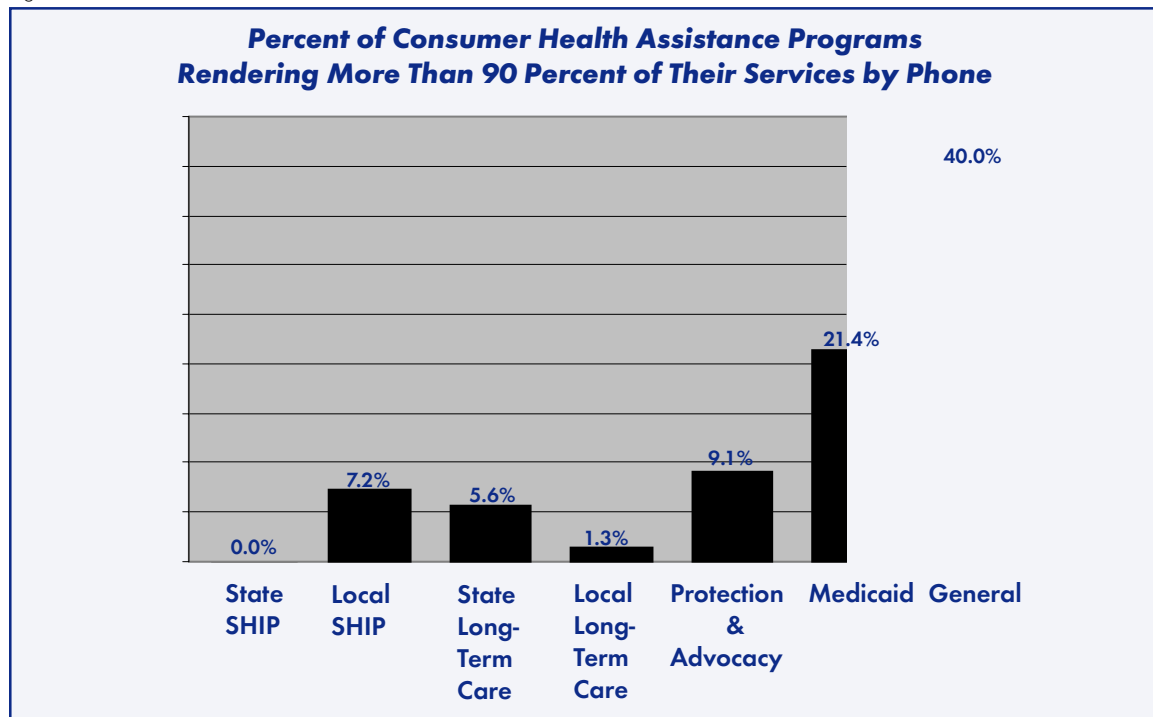
There is considerably less distinction between the services offered by nonprofit organizations and government-administered programs when it comes to ombudsman programs

serving Medicaid clients: Some government-run programs represent Medicaid beneficiaries in grievances, while some nonprofit programs do not.

All P&A programs provide some legal services. Long-term care ombudsman programs either provide some legal services themselves or have arrangements with programs to provide this assistance. Other types of consumer health assistance programs do not always include legal help. For example, many consist mainly of hotlines in social service agencies, or consumer health units in government agencies, that lack attorneys.

In addition to working with individuals, many programs also help groups of consumers resolve common problems. The proportion of programs that work with groups ranges from about one-third of the local SHIPs and Medicaid ombudsman programs to 86 percent of the P&A programs. Most programs devote only a small portion of their time and budgets to providing group assistance, however.

Figure 1



Most Problems Are Resolved Informally

Even among programs with the authority to pursue cases through the courts, most health ombudsman cases are resolved without formal action. Litigation is extremely rare.

Only 10 to 21 percent of all Medicare, Medicaid, and/or general consumer health assistance programs surveyed even have the authority to represent consumers in court. Of 42 ombudsman programs of all types with this authority, only six report they go to court more often than once or twice a year. Most programs say they "rarely," "occasionally" or "never" go to court.

Programs Have Established Working Relationships with Health Plans & Facilities

Many consumer health assistance program staff say they have established successful working relationships with health plans and facilities. How? By explaining their roles, focusing on their mutual goals of serving consumers, demonstrating their competency and reasonableness, and regularly meeting and communicating with key staff.

There are issues that can hinder such relationships, of course. Two common obstacles are staff turnover and turnover of health plans themselves, both of which hamper ongoing communications, several respondents point out. Good working relationships also may be thwarted if ombudsman staff are perceived as too aggressive, or if ombudsman staff feel there are major problems with the care provided by the facility or health plan.

Community Outreach and Education

Informing the public about the very existence of consumer health assistance programs—i.e., publicizing their own programs to potential constituents—and educating consumers about their health care rights are important tasks for all consumer health assistance programs.

Table 2

Methods of Publicizing Program

(Percent of programs, by type, using each method to publicize program)

Method	State SHIP	Local SHIP	State Long-Term Care	Local Long-Term Care	Protection & Advocacy	Medicaid	General
Through insurers/providers	85.0%	50.0%	45.5%	39.1%	21.4%	86.7%	53.6%
Adverse action notices	25.0%	19.5%	40.9%	19.5%	14.3%	53.3%	46.4%
Post in public agencies/providers	80.0%	73.4%	81.8%	74.7%	92.9%	73.3%	64.3%
Purchasers	5.0%	5.5%	0.0%	3.4%	0.0%	6.7%	3.6%
Government agencies	100.0%	75.8%	90.9%	78.2%	71.4%	60.0%	57.1%
Yellow pages listings	45.0%	32.0%	22.7%	25.3%	28.6%	46.7%	32.1%
Brochures/flyers	100.0%	90.6%	95.5%	92.0%	92.9%	73.3%	75.0%
Materials in languages other than English	75.0%	35.2%	59.1%	33.3%	64.3%	53.3%	28.6%
PSAs/media	55.0%	58.6%	40.9%	46.0%	21.4%	26.7%	42.9%
Web site	75.0%	31.3%	59.1%	42.5%	64.3%	40.0%	71.4%
Speak at community meetings/events	95.0%	86.7%	90.9%	86.2%	78.6%	60.0%	85.7%
Arrangements with neighborhood org's	25.0%	18.0%	0.0%	8.0%	21.4%	26.7%	14.3%
Ride circuit	20.0%	20.3%	31.8%	29.9%	42.9%	20.0%	3.6%
Other	10.0%	8.6%	13.6%	6.9%	14.3%	20.0%	14.3%

At the local level, virtually all programs publicize their services and activities through brochures, fliers, and speaking engagements at community meetings. Most also post notices in public agencies and/or in the offices of health care providers. Slightly more than half of all SHIPs, but fewer than half of the other types of ombudsman programs, advertise their services through the media. State-level SHIPs and Medicaid ombudsman programs commonly publicize their programs through health insurers and providers. However, only half of the Medicaid programs, and fewer than half of the SHIPs and general consumer health assistance programs, are listed as a source of help on insurers' "adverse action" notices. Moreover, despite their heavy reliance on telephone counseling to provide services (see Figure 1), fewer than half of the programs of all types advertise their services in the yellow pages of their local phone directories.

To ensure their services reach those who need them most, long-term care program staff make regular visits to nursing facilities, work with family and resident councils in these facilities, and communicate with volunteers who cultivate meaningful, lasting relationships with residents. Similarly, home visits are a common way for SHIPs and P&A programs to reach consumers with disabilities.

Table 3

Programs Serving People with Disabilities

(Percent of programs, by type, using each method to serve persons with disabilities)

	State SHIP	Local SHIP	State Long-Term Care	Local Long-Term Care	Protection & Advocacy	Medicaid	General
Conduct home visits	70.0%	80.5%	50.0%*	47.1%*	69.2%	26.7%	25.0%
Offer TDD services	50.0%	25.8%	59.1%	24.1%	100.0%	60.0%	50.0%
Contract with disability groups	20.0%	18.8%	9.1%	17.2%	46.2%	13.3%	10.7%
Use sign language	10.0%	3.1%	9.1%	4.6%	84.6%	6.7%	7.1%
Other	15.0%	4.7%	13.6%	10.3%	53.8%	6.7%	25.0%

*Long-term care ombudsman staff visit nursing facilities, but not all visit homes in the community.

Some ombudsman programs contract with disability groups to provide outreach or services to persons with disabilities. TDD equipment is available in P&A programs and is common among Medicaid and statewide long-term care ombudsman programs as well. Approximately half of the statewide SHIPs also report using TDD equipment. TDD equipment is less common among programs at the local level and among general consumer health assistance programs, even though most general programs provide assistance primarily by phone. (See Table 3.)

Table 4

How Programs Inform the Public of Their Rights

(Percent of programs, by type, using each method to inform the public of their rights)

	State SHIP	Local SHIP	State Long-Term Care	Local Long-Term Care	Protection & Advocacy	Medicaid	General
Speaking engagements	95.0%	82.8%	95.5%	94.3%	85.7%	57.1%	85.7%
Media	70.0%	63.3%	77.3%	59.8%	42.9%	14.3%	67.9%
Written materials	90.0%	76.6%	77.3%	78.2%	92.9%	78.6%	71.4%
Materials in other languages	55.0%	22.7%	45.5%	27.6%	57.1%	57.1%	32.1%
Low-literacy materials	25.0%	23.4%	13.6%	11.5%	42.9%	85.7%	28.6%
Website	55.0%	21.1%	59.1%	37.9%	64.3%	57.1%	78.6%
Audiotapes/recorded messages	5.0%	6.3%	13.6%	12.6%	42.9%	7.1%	7.1%
Train community organizations' staff	50.0%	26.6%	22.7%	32.2%	35.7%	42.9%	32.1%
Other	0.0%	9.4%	9.1%	5.7%	7.1%	35.7%	10.7%

When it comes to educating constituents about their health care rights, most programs rely primarily on speaking engagements and written materials; some also employ the media, the Internet, and other community organizations to help spread their message. (See Table 4.)

Most consumer health assistance programs operating at the state level, and many operating at the local level, develop educational materials. Because many programs serve people of other cultures and languages, more than half of all statewide Medicare, Medicaid, and P&A programs responding to our survey produce materials in languages other than English, as do nearly half of statewide long-term care ombudsman programs and one-third of the general consumer health assistance programs.

Eighty-six percent of the Medicaid programs provide materials written at a low-literacy level. Among other types of programs, low-literacy materials are much less common, ranging from 12 percent of local long-term care programs to 43 percent of P&A programs.

Educating consumers about their health care rights through the media is a strategy used by most long-term care programs, SHIPs, and general consumer health assistance programs. Education through the media is less common among P&A programs, and rare among Medicaid programs.

About half of the state SHIPs and Medicaid ombudsman programs train staff from other community organizations in consumer health insurance issues, thereby enabling these organizations to educate their constituents on these issues. Fewer programs of other types work with community organizations in this manner.

Data Collection and Feedback to Health Care Stakeholders

Through their daily work, consumer health assistance programs compile a wealth of information on the problems people encounter with the health care system and how those problems are resolved. Some programs use this information to issue general reports (such as on the number of complaints filed against a particular health plan, which consumers may find helpful when choosing a plan) or simply to let their funding sources know how many cases they handle and how those cases are resolved. Other programs use the information they gather to formulate recommendations on how health plans, nursing facilities, and the health care system in general could be improved.

Under federal law, long-term care ombudsman programs are required to collect data on consumer complaints and recommend changes based on their findings. The U.S. Department of Health and Human Services issues an annual “Long-Term Ombudsman Report” based on this national data that is shared with Congress and available to the public. In addition to identifying the number of cases nationwide and the resources available to help, the report summarizes the types of complaints (e.g., resident care, facility administration, and quality of life) received by state and nationwide.¹⁰

Virtually all other programs also collect data on their services and on consumer complaints. However, many provide this information only to their funding source; just one-fourth to one-third actually report this data to policymakers. About one-fourth of the general consumer health assistance programs report their data to the public, but few programs serving only Medicaid beneficiaries make their data publicly available. Many other programs gather data but do little or nothing to categorize their findings or share their information.

Through reports, meetings, letters, and phone calls, many consumer health assistance programs keep health care stakeholders informed about consumer health care problems and potential solutions. Different types of programs appear to target this information to different audiences. For example, P&A programs typically provide information to public agencies, legislators, and consumer organizations. Most Medicaid programs keep health plans, health regulators, public agencies, and consumer organizations informed, while about half make a point to educate legislators. State-level SHIPs typically provide feedback to other public agencies and health plans (but generally not to health care regulators), and about half share their information with legislators and other consumer organizations. Meanwhile, most long-term care programs provide feedback to health care providers, health regulators, other public agencies, legislators, and consumer organizations.

Among those we interviewed, many ombudsman staff who work in nonprofit organizations believe their independence from government gives them more credibility as consumer

advocates and the freedom to work toward improving the health care system. On the other hand, a number of nonprofit organizations contracting with states to provide ombudsman services are cautious about advocating policy changes because of their funding source; of these, some recommend changes to state agencies, but not to legislators.

Programs located within state government report a range of abilities to advocate policy change. Some have a role in drafting legislation; some can make recommendations to other state agencies and officials but not directly to legislators; some say that formal procedures are in place that make it difficult, but not impossible, to bring issues to the attention of policymakers; and a few say they cannot work on policy issues at all.

Program staff of government-run ombudsman programs who *do or can* engage in policy work say it is easier to effect policy change if they:

- work in a department charged with drafting legislation and commenting on its impact on consumers;

- work in the office of an elected insurance commissioner who has no restrictions on lobbying;

- work in the office of an attorney general who does not have a role in regulating health insurance;

- work in the office of the governor and thereby report directly to the governor rather than health agencies;

- if appointed, have term appointments that temporarily shield them from political changes in the administration;

- work for supportive supervisors, departments, or elected officials;

- have ready access to resources, such as regulators, that help in analyzing a problem; and/or

- have ready access to policymakers.

Factors identified as hindering the advocacy efforts of staff in government-run ombudsman programs include:

- political and other connections between health industry and government officials;

- employment within insurance commissions that are required to maintain impartiality in carrying out their regulatory role;

- requirements to go through formal procedures in order to propose policy changes;

- unsupportive supervisors; and/or

- restrictions on communicating with community groups and/or legislators.

Staff of long-term care ombudsman programs and SHIPs at the local level report having mixed feelings about their roles in influencing policy. Many staff say they do not advocate change themselves, but instead rely on their counterparts at the state level to do this. Most say they are satisfied with the state office in this regard, but a few feel the state office does not hear their concerns or do enough to correct problems within the system.

Policy Changes Program Staff Have Helped Bring About

Consumer health assistance programs are responsible for a number of important consumer safeguards in the health care arena. Programs with the ability to recommend improvements and advocate policy change have paved the way for numerous changes in health care policies and regulations that benefit consumers. Program staff we interviewed offered these and other examples of changes they helped bring about through their advocacy efforts:

Long-term care ombudsman programs have fostered stricter regulations governing assisted-living facilities, legislation protecting residents' rights, family participation in the development of care plans for residents, improvements in the appeals process, and increased staffing in nursing homes.

Medicare ombudsman programs have helped achieve Medigap protections, including open enrollment of persons with disabilities in Medigap and the establishment of a Medigap helpline; clearer notices to beneficiaries; and state drug-assistance programs with eased application and eligibility standards.

Nonprofit general consumer health assistance programs have helped to change the practices of health plans that refused payment for emergency care, to reduce the amount consumers co-pay for brand-name drugs, and to establish external appeals processes.

Programs operated within state offices of attorneys general have helped change the policies of health maintenance organizations (HMOs) so that procedures once considered experimental in nature are now covered as standard treatments. They also have been instrumental in enacting "hold harmless" legislation protecting patients from charges when HMOs have not paid health care providers.

Ombudsman programs run by state insurance commissions have helped shape "patient bills of rights"; developed laws allowing for external appeals of health plan decisions; and ensured that health insurers were fined and/or required to pay claims when they were consistently late or remiss in paying claims.

Programs serving Medicaid consumers have helped improve state enrollment and retention policies; increase reimbursement rates for providers, thereby enlarging the pool of those accepting patients on Medicaid; improve access to prescription drugs on weekends and holidays; improve transportation to medical care; ease authorization procedures for mental health care; and ensure that Medicaid agency and other health plan materials are provided in languages other than English.

Program Resources: Budgets and Staffing

Just as there are enormous variations in the structure and services of consumer health assistance programs, so too are there significant differences in program budgets and staffs. Thus, no patterns emerge from our survey concerning the resources required to serve a given population. Some programs emphasize managed care education and devote substantial resources to producing consumer guides. Others focus primarily on telephone consultation, while others directly represent consumers in disputes and follow cases to resolution. The cost of these activities per consumer served differs dramatically.

Program expenditures also vary depending on the program's stage of development. Several programs we surveyed had started only within the past year, so their caseloads were smaller, and their expenditures on planning and program design larger, than what would be expected in subsequent years.

Rather than attempting to identify patterns and themes, this section discusses some of the resources available to different types of ombudsman programs and how those resources are used.

Volunteer Help Is Common

Many consumer health assistance programs make extensive use of volunteers. Volunteers provide direct services to consumers, make presentations before community groups, and help compile data. Perhaps most important, they allow ombudsman programs to provide intensive, one-on-one services at the local level.

Our survey reveals that volunteer help is particularly common among long-term care programs and statewide SHIPs, and particularly *uncommon* among programs serving Medicaid beneficiaries and the privately insured.

The use of volunteers appears to be a mixed blessing for most programs. On the one hand, volunteers provide critical staffing to programs with limited resources. On the other, volunteers may not consistently complete paperwork or maintain data; they may lack the skills needed to understand complex information; and it may be difficult for programs with workloads that ebb and flow to retain volunteers.

Managing volunteers appears to be a particular problem for SHIPs and long-term care programs. Although some of these programs now receive support with volunteer training and retention (and staff describe this support as "valuable")—staff at about half of the long-term care programs and one-fourth of the SHIPs want more help in this area. To a lesser extent, Medicaid and general consumer health assistance programs also want help with volunteers.

Program staff cite several areas where additional support would be helpful, including setting standards for volunteers' work, providing ongoing volunteer training and enrichment, retaining and recruiting volunteers, and determining appropriate work assignments and supervision systems.

Resources of Long-Term Care Ombudsman Programs

In FY 1999, long-term care ombudsman programs nationally received \$51.3 million in funding, with \$31.4 million distributed to programs at the federal level, \$13.6 million going to state programs, and \$6.3 million allotted to local programs. Paid program staff consisted of 974 full-time equivalents (FTEs) in 587 local programs. In addition, the programs used 8,451 certified volunteers. Nationally, long-term care ombudsman programs handled 215,650 complaints in 1999, and closed 130,255 complainants' cases.¹¹

Among the state programs we surveyed, budgets in 2000 ranged from \$99,400 to \$3.95 million, with an average staffing of 5.1 FTEs. Two-fifths of the programs had at least one attorney on staff,¹² and one-seventh had at least one registered nurse on staff.

At the local level, program budgets ranged from \$4,000 to \$425,000,¹³ with a median budget of \$57,500 (which funded services to more than 100 consumers). Overall, the median number of consumers served by local long-term care ombudsman programs of all budget levels in 2000 was 141.¹⁴ Budgets per eligible population ranged from 76 cents to \$62.50. Average local staffing was 2.1 FTEs, with one of seven programs having a nurse on staff. Very few local-level programs have staff attorneys.

Among the obstacles to success listed by program staff are inadequate funding and a shortage of volunteers. Funding is particularly a problem for rural programs, where staffs have to travel long distances to visit facilities.

Resources of Protection and Advocacy Programs

Budgets of state-level P&A programs responding to our survey ranged from \$275,000 to \$3.9 million. The median budget of \$1,083,000 enabled programs to serve 581 consumers. We did not receive sufficient data about the number of consumers served or the size of the eligible population to draw any conclusions about typical caseloads for programs of various budget sizes.

On average, P&A respondents in 2000 had 18 FTEs, and virtually all programs had at least one attorney on staff.

Resources of SHIPs

Consumer health assistance programs serving Medicare beneficiaries had a total federal funding base of about \$18 million in calendar year 2000. Of this amount \$11 million was distributed to states based on a formula: 75 percent was distributed according to the state's population, 15 percent was based on the proportion of Medicare beneficiaries living in rural

areas, and 10 percent was based on the proportion of Medicare beneficiaries relative to the overall state population. Additionally, some funds were distributed based on a state's proportion of "Medicare Plus Choice" enrollees (enrollees in Medicare managed care or Medicare private fee-for-service plans), and some outreach grants were awarded competitively. In addition, some SHIPs received state and local funding. According to data kept by the federal government, the SHIPs with the most funding, those in Florida and California, each received about \$1 million in federal funds; in addition, California received about \$300,000 in state funds. Most other SHIPs received far less funding. At the state level, average SHIP staffing was 3.45 FTEs.¹⁵

At the local level, some SHIPs we surveyed had no budgets at all, as they were run entirely by volunteers. Although a number of local programs provided a range of services and could not provide their budgets for Medicare counseling alone, the median budget among local Medicare programs surveyed was \$26,500. In a service area of 4,000 eligible persons, a program with a budget of this size typically provides direct assistance to 200 to 250 consumers. There was no clear pattern to these figures, however: The eligible population for many programs with budgets under \$10,000 was more than 20,000, while one program budgeted at \$6,500 served nearly 1,200 people.

While very few SHIPs had attorneys or medical professionals on staff, about 10,900 counselors—the vast majority of them volunteers—were part of the SHIP network in 2000.¹⁶ When last studied in 1997, volunteers accounted for more than 93 percent of the staff at the local level and 96 percent of the staff at the state level.¹⁷

In telephone interviews, some SHIP staff at the state level report that the pay scale is too low, it is hard to recruit and retain volunteers, there is insufficient funding to advertise their programs or provide in-depth services, and they lack sufficient phone lines to meet demand. At the local level, many SHIP programs cite a lack of funds from the state. In one locality, a part-time SHIP counselor, frustrated at her inability to provide comprehensive assistance with limited resources, obtained private funding to start a Medicare managed care ombudsman program to supplement her SHIP's services.

Resources of Medicaid Ombudsman Programs

Budgets of Medicaid ombudsman programs ranged from \$19,300 for a program serving a special-needs Medicaid population to \$2.4 million for a program that both helped consumers and tracked statewide data on Medicaid services. Excluding this latter program, budgets of the programs we surveyed generally ranged from about 30 cents to \$2 per eligible person.

On average, ombudsman programs for Medicaid beneficiaries were staffed by 3 FTEs. About one-fourth of Medicaid program respondents have attorneys on staff; one of 15 programs responding had a nurse, and one had a doctor.

One-third of the Medicaid programs cite budget and staffing constraints as major obstacles to their success. In addition to concerns about the amount of funding, some staff at programs funded solely by the state voice concerns about the *source* of their funding, indicating a need for a separate revenue stream in order to be truly independent advocates.

Resources of General Health Care Ombudsman Programs

Among programs serving at least some privately insured consumers, budgets ranged from \$60,000 for a managed care ombudsman program run by a state government and whose staff described it as “under-funded” to \$1.5 million for a managed care training, information, and assistance program serving a large city. Among programs providing both their budgets and the number of people eligible for their services, budgets ranged from 1 cent to \$1.57 per eligible person.

Staff sizes ranged from 1 to 15 full-time staff, with an average FTE of 6.2. Three of 24 programs surveyed provided direct assistance to more than 2,000 consumers a year; among these, staff sizes ranged from 7 to 15 FTEs. About half of the programs had an attorney on staff, two had a nurse, and one had a doctor.

Commonly cited as obstacles to success are limited financial resources and insufficient staff to keep pace with consumer problems—a complaint voiced whether the program is run by a government agency or a nonprofit organization. Staff in several programs, particularly those run by private, nonprofit organizations, mention unmet needs for counseling.

SURVEY FINDINGS, PART II: HOW CONSUMER HEALTH ASSISTANCE PROGRAMS COULD BE STRENGTHENED

Responses to many questions in our survey indicate a significant need among consumer health assistance programs for additional resources and networking with their peers. The need is particularly acute among Medicaid and general consumer health assistance programs (and to a lesser extent, local-level SHIPs), for which no national support networks are in place.

This section summarizes the needs program staff expressed in written surveys and telephone interviews for additional training and support.

Programs Need Support Networks

While some consumer health assistance programs share information and technical support, other programs—particularly Medicaid and general consumer health assistance programs—work in relative isolation from each other. In order to address specific consumer issues, ombudsman staff would benefit from knowing how similar programs are handling these issues, how changes in health policies and practices are affecting consumers in other states, and what successes and failures similar programs have encountered. Program staff can learn all these things simply by networking with their peers.

Medicaid and general consumer health assistance programs overwhelmingly express the need for more support and less isolation, as do local-level SHIPs. By contrast, national support networks for federally mandated programs—long-term care programs, P&A programs, and state-level SHIPs—are well-established, and staff of these programs regularly participate in annual meetings, conference calls, and other forums conducive to networking.

In addition to exchanging information with other consumer health assistance programs, ombudsman programs would benefit by exchanging information with community organizations that work on a variety of health care issues.

Support Needs of Long-Term Care Ombudsman Programs

Long-term care ombudsman programs enjoy perhaps the most extensive peer network of all programs surveyed. Support is provided by the National Long-Term Care Ombudsman Resource Center, which is funded by the U.S. Administration on Aging. Virtually all long-term care programs at both the state and local levels participate in annual meetings—meetings staff rate as the most important type of support they receive—and most also benefit from regular

meetings and conference calls with their peers. A few respondents note that additional networking would be useful—for instance, through regional meetings, more information about activities in other states, and relationships with community organizations outside the long-term care network that share common interests.

Among the issues staff would like to discuss with their peers in other states: insurance coverage and Medicaid reimbursement for nursing home care, appeals, assisted living, staff shortages, improper discharges, behavior management, adult protective services, patient self-determination, and funding and staffing for ombudsman programs.

Support Needs of P&A Programs

The overwhelming majority of P&A programs also participate in regular meetings and conference calls. These programs receive extensive support from the National Association of Protection and Advocacy, Inc. (a national membership organization) and the Advocacy Training Technical Assistance Center (ATTAC), which is funded by a 2 percent set-aside in the federal P&A appropriation.

Support Needs of SHIPs

Nearly all state-level SHIPs participate in a network with other state-level SHIPs called the National SHIP Resource Center, which is funded by the Centers for Medicare and Medicaid Services, or CMS (formerly the Health Care Financing Administration), and operated by the National Association of State Units on Aging. Some programs also receive support from legal services or other nonprofit programs or the National Association of Insurance Commissioners.

Programs at the local level are far less likely to network with their peers. While the vast majority of state program staff participate in annual meetings, only two-thirds of their local counterparts do; and while most state programs benefit from regular meetings or conference calls, fewer than half of the local programs enjoy this luxury. Nearly half of local program respondents express a desire to attend an annual meeting with their peers, and more than one-third request regular meetings or conference calls. Most local program staff feel that statewide or regional meetings would best meet their needs.

Support Needs of Medicaid Ombudsman Programs

There is currently no designated support network in place for Medicaid ombudsman programs. Some programs tap into Families USA, the National Health Law Program, Community Catalyst, the National Legal Aid and Defender Association, Family Voices, and other national

advocacy organizations for support. Others design their own training programs independent of outside help, find organizations within their state to supplement their training, or rely on informal contacts with Medicaid ombudsman programs in other states.

Nearly half of all Medicaid ombudsman programs surveyed participate in annual meetings, and 40 percent participate in regular meetings or conference calls with other ombudsman programs. All respondents in this program category list annual meetings and “regular meetings or conference calls” among their unmet support needs.

Support Needs of General Health Care Ombudsman Programs

Most general consumer health assistance programs have no access to ombudsman support networks, instead hiring consultants when needed (for example, to help with computer issues and media relations), seeking expertise from other community-based organizations, obtaining general training on low-income issues and health law through legal services networks, and relying on medical advisors and associations for help with medical treatment issues.

Programs operated by state insurance departments or commissions may participate in programs sponsored by the National Association of Insurance Commissioners or receive training through such federal agencies as CMS and the Department of Labor, but other resources are few and far between.

Top on the list of support needs for programs in this category: annual meetings, other regular meetings, and conference calls.

Programs Need Training and Technical Assistance

Staff of all types of consumer health assistance programs use a common set of skills. They interview consumers, investigate cases, negotiate, gather evidence that sometimes involves medical records and medical facts, read documents such as rules and policies, and sometimes represent consumers in grievances. Programs must train new staff in these areas as well as improve the skills of existing staff.

Consumer health assistance programs of all types say they want more training on issues facing consumers and more technical assistance in resolving consumer problems. In addition, they want regular updates on health policy issues and information on trends in the health care industry. Although the mix of training and technical assistance desired varies by program type, in general between one-fourth and one-half of the programs of each type want more of such support.

Training Needs of Long-Term Care Ombudsman Programs

Three-fourths of statewide survey respondents in this category, and even more respondents at the local level, say they receive assistance on problem resolution and skills training. At the state level, 82 percent of these programs participate in training that deals with health industry and policy changes and in technical assistance that addresses policy advocacy and systemic issues. Technical assistance in these areas is ranked as the most important type of technical assistance staff receive, with two-thirds expressing a desire for more. Most programs at the local level also receive technical assistance in problem resolution and skills training, sometimes from their statewide offices.

In general, staff say they are satisfied with the training they receive, both through national conferences and within their states. Nonetheless, about two-fifths of local and state programs say they want more skills training. Specific needs include interviewing and negotiation skills, communicating with people with dementia and other special needs, recruiting and retaining volunteers, fundraising, and program operations and management.

Training Needs of P&A Programs

The overwhelming majority of P&A programs receive training on important consumer issues as well as technical assistance on policy and systemic issues. Two-thirds would like more technical assistance on policy advocacy and systemic issues and more skills training, and one-third desire more information about health industry and policy trends.

Training Needs of SHIPs

Most SHIPs at the state and local levels receive some training on consumer issues and technical assistance on problem resolution—state-level programs typically from CMS and the SHIP National Resource Center; local-level programs from the state (and in some cases, from state insurance commissions or other government agencies). About half say they receive technical assistance on policy advocacy or systemic issues; likewise, about half say they receive skills training.

Of the support they receive, respondents cite training on consumer issues as particularly valuable. About half of the programs at the state level express a desire for more training on consumer issues, health industry trends, and policy trends, as well as more technical assistance on policy and systemic issues.

In telephone interviews, state-level SHIP staff cite a need for more training and technical assistance on secondary payer issues, COBRA policies, appeals and grievances, and continu-

ing Medicare education in general. Although some local SHIP staff feel they receive adequate support through their state agencies, others complain that state agencies do not share information that would be helpful to their work.

Training Needs of Medicaid Ombudsman Programs

Medicaid ombudsman programs receive very little skills training. Only one of the 14 respondents says outside support for skills training has been provided, while half of those surveyed specifically cite it as a need. Fewer than half receive training in priority consumer issues or in health industry and policy trends.

Half of those responding want technical assistance in problem resolution, policy advocacy, and systemic issues. Specific needs identified by some respondents include regular updates on state and federal Medicaid policy, training on dual eligibility for Medicaid and Medicare, children's health, and Social Security disability determinations (which affect Medicaid eligibility). Staff also express an interest in talking with program staff in other states about Medicaid provider shortages, managed care enrollment and exemption issues, and Medicaid transportation issues.

Training Needs of General Health Care Ombudsman Programs

Among ombudsman programs serving the privately insured, the greatest needs—expressed by one-third of respondents—are for training and technical assistance on policy advocacy and systemic issues, and skills training. About one-fourth of the programs want both technical assistance on problem resolution and training on health industry and policy trends. Specific needs include training on such issues as medical necessity, behavioral health care, appeals processes, Medicare, ERISA and self-funded plans, and handling claims.

Programs Need Written Materials on Substantive Issues

With limited time for reading, ombudsman staff cite a high demand for regular updates on health policy and the health care industry that can be easily digested. Most SHIP, P&A, general, and long-term care ombudsman programs already receive written material on substantive issues, and SHIPs and long-term care ombudsman programs list such materials as one of the most important types of support they receive.

Written Materials Needs of Long-Term Care Ombudsman Programs

Almost all respondents at both the state and local levels use written materials to keep themselves informed, and most believe they have enough—or more than enough—of such resources, with only 18 percent requesting more. Regular updates on laws and regulations, as well as copies of information sent by state regulatory agencies to nursing homes and similar facilities, are among their needs.

Written Materials Needs of P&A Programs and SHIPs

The overwhelming majority of P&A programs receive written materials on substantive issues. One-third expressed a need for more, but no specific needs were identified.

Most SHIP programs say they receive enough written materials, but some cite the need for more timely updates on Medicare law and regulatory changes, as well as more information about COBRA, appeals and grievances, and state-specific Medigap plans. Because Medicare serves some people who are eligible for Medicaid as well, materials about state Medicaid rules are also desired.

Written Materials Needs of Medicaid Ombudsman Programs

Forty percent of the Medicaid program staff we surveyed express a need for more substantive written materials. They need resource manuals, brief explanations of consumer health issues, state-specific information about Medicaid eligibility as well as information about Medicaid eligibility in other states, materials on fair hearings and grievances, and advance copies of Medicaid materials distributed to consumers and health providers.

Written Materials Needs of General Health Care Ombudsman Programs

Over one-fourth of the respondents in this category not only want more materials, they rate this among their most important unmet needs. In telephone interviews, program staff specifically cite a need for simple materials on COBRA, ERISA, and the Department of Labor's process for responding to complaints; resource manuals of other organizations that help consumers; literature on the appeals process; "best practices" in mental health and substance abuse cases; materials explaining how advocates elsewhere have approached different issues; comparisons of states' performance on various health care issues; literature that could be adapted to educate consumers about their benefits and rights; and educational materials for new staff.

Programs Need Assistance with Community Education

Program staff of all types express a strong need for materials in different languages and at low literacy levels to inform the public of their health care rights. Many ombudsman programs serve consumers with limited English proficiency, and most have made some arrangements to serve multicultural/multilingual populations.

Nonetheless, survey results indicate that many programs—i.e., about half of the long-term care ombudsman programs and SHIPs, and two-thirds of the general consumer health assistance programs—do not provide community-education materials in languages other than English. Moreover, with the exception of Medicaid ombudsman programs, most programs do not provide such materials at low literacy levels; for example, only 29 percent of the general consumer health assistance programs do.

SHIPs note that standardized materials developed by CMS have been very helpful in their community-education efforts. Other programs express a need for brief materials on the appeals process and consumer issues in general, such as those developed by programs in other states, that could be adapted for their constituents.

In addition to producing educational materials, some programs use the media and host training sessions to educate people about their rights. The proportion of consumer health assistance programs employing the media ranges from three-fourths of statewide long-term care ombudsman programs to about one-seventh of Medicaid programs. In phone interviews, staff of all programs say they would benefit from training and technical assistance in the effective use of the media.

Training other community organizations about consumer rights can be an effective—albeit resource-intensive—community-education technique. One-third of general consumer health assistance programs, 43 percent of Medicaid ombudsman programs, and half of the SHIP programs undertake such activities. Some programs have invested extensive resources in developing training curricula and materials for this purpose.

Programs Need Help Collecting Data and Disseminating Feedback to Stakeholders

Ombudsman programs have the potential to be a tremendous source of information for policymakers, health care providers, and the general public about what is and is not working for health care consumers. Programs could provide this feedback informally through conversations and meetings, or more formally through reports and presentations. Our survey indicates that programs could use improvement in both areas: Many of them provide little if any feedback to relevant stakeholders, and many fail to report data in ways that paint meaningful pictures for those striving to improve the health care system.

The benefits of collecting and reporting reliable data to stakeholders are many. For example, in a system that could be replicated by other programs, long-term care ombudsman staff use standardized data-collection categories developed by the federal government to gather information on the types of problems they handle; this information in turn helps identify ways to improve nursing facilities and long-term care policy.

Most general consumer health assistance programs and those serving Medicaid consumers already compile data on the number of consumers they serve, the number of complaints they receive, the number they resolve, and types of problems reported. Far fewer compile or report data on the demographics of the populations they serve, the insurers involved in complaints, or how complaints are resolved. (See Table 5.)

Even though state long-term care ombudsman programs are more advanced than other types of consumer health assistance programs in categorizing and using data, more than half of them want more support with their data systems. Staff cite problems with computer systems plagued with “bugs” and not “user friendly,” and concerns about the reliability of data collection.

About 40 percent of the Medicaid ombudsman programs and 24 percent of the general programs say they need help with their data systems. For the most part, these programs currently receive no outside support in this area. A number of general programs—particularly those operated by independent, nonprofit organizations—want help collecting and presenting data in a way that would allow them to track complaint trends and evaluate their own programs.

Among other types of ombudsman programs, 21 to 27 percent desire support with their data systems. Like long-term care programs, SHIP staff cite problems with computer “bugs” and systems that are not “user friendly,” as well as the reliability of the data collected, because a number of people are responsible for data entry. Another concern among SHIPs is the fact that some offices still maintain data manually. Key needs include assistance in develop-

Table 5

Data Reported by Programs

(Percent of programs, by type, reporting this data)

	State SHIP	Local SHIP	State Long-Term Care	Local Long-Term Care	Protection & Advocacy	Medicaid	General
# of consumers served	88.9%	89.1%	81.0%	81.0%	100.0%	73.3%	73.1%
# of complaints received	50.0%	52.9%	90.5%	89.3%	76.9%	73.3%	69.2%
# of complaints resolved	27.8%	42.9%	90.5%	88.1%	69.2%	60.0%	61.5%
Type of problem	77.8%	75.6%	95.2%	85.7%	92.3%	66.7%	73.1%
Referral source	44.4%	47.9%	47.6%	72.6%	23.1%	46.7%	46.2%
Amount of time required to resolve	33.3%	28.6%	28.6%	54.8%	7.7%	26.7%	26.9%
How complaint resolved	38.9%	42.9%	47.6%	70.2%	76.9%	46.7%	34.6%
Source of complaint	16.7%	26.9%	38.1%	58.3%	7.7%	66.7%	50.0%
Type of service provided	44.4%	62.2%	71.4%	58.3%	100.0%	60.0%	46.2%
Whether formal grievances filed	11.1%	31.1%	19.0%	34.5%	30.8%	53.3%	26.9%
Consumer's insurance source	16.7%	36.1%	14.3%	16.7%	7.7%	33.3%	38.5%
Consumer's age	27.8%	58.0%	38.1%	38.1%	100.0%	26.7%	26.9%
Consumer's ethnicity	27.8%	54.6%	33.3%	38.1%	100.0%	6.7%	23.1%
Consumer's gender	27.8%	58.0%	47.6%	36.9%	100.0%	20.0%	26.9%

ing data-collection categories, locating appropriate computer software, and determining how to present the data they gather.

Programs Need Help with Community Outreach and Publicity

Program staff express a strong desire for assistance with community outreach, publicizing their programs, educating consumers about their rights, and reaching special populations.

Medicaid ombudsman staff note a need to constantly promote their programs so consumers will remember them when problems arise. SHIP staff list the high cost of advertising and “a lack of focus for their activities and outreach” among the obstacles to their programs’ success. General consumer health assistance program staff also cite the cost of advertising and say it is difficult for small programs to achieve public visibility. They also note the difficulty getting consumers interested in understanding their health insurance before problems arise. A number of programs want help with publicity and say they would benefit from market-tested messages and strategies for publicizing their programs.

Many ombudsman programs do not collect data on the source of their referrals, even

though that data could help them evaluate the effectiveness of various outreach methods. Similarly, many programs do not advertise in telephone directory yellow pages or use public service announcements or other media to publicize their programs—methods one study¹⁸ suggests would be helpful.

Programs providing services mainly through telephone hotlines note gaps in their services to frail, disabled, and otherwise vulnerable consumers; many programs even lack TDD equipment. Face-to-face contacts and home visits would be a more effective means of outreach, of course, but that requires a network of reliable volunteers or more resources for staff. (As discussed on page 18, training, retaining, and supervising volunteers presents its own challenges, and programs need support in these areas as well.)

Meanwhile, long-term care programs, P&A programs, and SHIPs have years of experience working with vulnerable populations, and programs that have developed more recently could learn from them. To ensure their services reach those who need them most, for example, long-term care ombudsman staff make regular visits to nursing facilities, work with family and resident councils in these facilities, and communicate with volunteers who cultivate meaningful, lasting relationships with residents.

Peer outreach is another method some consumer health assistance programs use to reach vulnerable consumers. While many long-term care programs, P&A programs, and SHIPs include consumers on their advisory boards or as peer counselors or volunteers, only half of the general ombudsman programs and even fewer Medicaid programs involve consumers in their work. In a few states, Medicaid agencies have contracted with parents of children with special needs or with mental health ombudsman programs that employ consumers to provide ombudsman services—a model that may be useful to other programs.

Programs Need Help with Program Management and Design

Directors and managers of consumer health assistance programs face many common challenges in the design and operation of their programs. They must identify outreach strategies, establish systems for maintaining files and data, decide on appropriate staffing patterns, recruit and train staff and volunteers, decide how and with whom to share information, and consider liability and client-confidentiality issues.

Very few general consumer health assistance programs currently receive support in program design and management; 24 percent specifically express a need for it. About one-third of Medicaid programs have received some help with management and program design, and almost an equal number want more help in this area. Two-thirds of long-term care ombudsman programs currently receive such help, and about one-third want even more.

Many staff indicate a desire to discuss a number of topics with staff of similar pro-

grams, including program startup and outreach, data and telephone systems, and how to prevent “burnout” and handle a variety of problems in general. Additionally, they want the ability to draw on outside trainers or consultants with legal and mediation skills, knowledge of consumer health issues, expertise in federal and state health laws, experience in community outreach (including reaching culturally diverse populations), and media skills. They say they would use this help to improve their collection and use of data, develop program-evaluation tools, write policies and procedures for their programs, train caseworkers and volunteers, and “get out their clients’ stories.”

Programs Need Help with Fundraising

Few programs receive support with fundraising.¹⁹ Meanwhile, nearly half of the SHIPs and about one-third of the Medicaid, long-term care and general consumer health assistance programs want fundraising assistance. Some want information about resources available to programs in other states so they can make a better case for adequate funding to their own states, while others want help identifying private funding sources. Many programs also cite a desire to diversify their funding source(s).

CONCLUSION

Consumer health assistance programs provide a valuable service to the public. Some programs have existed for years, while others—notably those focusing on Medicaid beneficiaries and the privately insured—have emerged only recently, and only in a number of states. These “new arrivals” are not part of a formal network, nor do they receive the support and technical assistance available to many other types of programs.

In some cases, a program’s ability to assist individual consumers and address systemic issues largely depends on whether it has the legal authority to do so. Although most consumer complaints are resolved informally, the ability to represent consumers in grievances and hearings is an important one. Similarly, laws can help programs reach consumers by requiring health plans and facilities to notify their constituents of available ombudsman services, and laws can help programs resolve complaints by requiring health plans and facilities to cooperate with investigations. In addition, a program’s organizational placement—whether in a government agency or a nonprofit organization—can help determine the extent to which it is protected from political pressure and help or hinder its efforts to bring consumer issues to policymakers’ attention.

There is a strong need among consumer health assistance programs for increased support and technical assistance. All programs would benefit both by sharing “lessons learned” with one another and by receiving outside help from experts with specialized skills, especially skills in developing educational materials for diverse health care consumers, training and retaining staff and volunteers, reaching their constituents, and creating data systems that can be used to analyze consumer health care problems.

Help with program design and management is another priority, as is networking—both with peers in similar programs and with the broader spectrum of community organizations involved in health care. Program staff want to know how other states, other advocates, and other health insurers and providers have addressed the issues they are facing.

Coordination among the diverse types of consumer health assistance programs, combined with additional support and technical assistance, would help these programs not only realize their potential to assist consumers, but provide valuable information on consumer health care problems and solutions to policymakers and other key stakeholders.

ENDNOTES

¹ In some states, long-term care ombudsman programs also investigate complaints by residents of group homes, assisted living facilities, and similar residences.

² Several states also have established programs specifically targeted to those receiving mental health services. These programs help consumers access mental health services and resolve disputes over insurance coverage. Programs may be housed within state government (as in California, Minnesota, and Montana), or operated by nonprofit organizations under contract to the state (as in Colorado, Pennsylvania, and Indiana). These programs are not discussed in this report.

³ The Medicaid ombudsman program in Vermont also serves privately insured consumers.

⁴ For categories with a large pool of programs (e.g., SHIPs and long-term care ombudsman programs), we needed relatively few responses, but we sought to obtain them from programs that were geographically and otherwise diverse. For Medicaid and general health consumer assistance programs, we received information from most existing programs.

⁵ U.S. Administration on Aging, *Long-Term Care Ombudsman Report, FY 1998* (Washington, DC: Department of Health and Human Services, 2000).

⁶ Advocacy Training and Technical Assistance Center, *Protection and Advocacy Systems Annual Report 2000*. Available at (www.protectionandadvocacy.com).

⁷ SHIP Resource Center, *One Voice, Many Faces: State Health Insurance Information, Counseling and Assistance Programs 1990-2000* (Washington, DC: SHIP Resource Center, National Association of State Units on Aging, 2001).

⁸ Some long-term care ombudsman programs perform additional functions, such as investigating cases of abuse and neglect. In this function, states may require programs to play a neutral role. Some do not represent consumers in appeals but instead arrange with legal counsel for representation. (Information from telephone interview with Alice Hedt, National Long-Term Care Ombudsman Resource Center, April 2001).

⁹ Not all programs maintain data in this fashion. The stated percentages are based on responses from 6 local and 1 statewide SHIP, 16 local and 5 statewide long-term care programs, 2 P&A programs, 1 Medicaid program, and 1 general consumer health assistance program.

¹⁰ 42 U.S. Code § 3058g and DHHS, FY 1998 Long-Term Care Ombudsman Report (Washington, DC: Administration on Aging, December 2000).

¹¹ U.S. Administration on Aging, *1999 National Ombudsman Reporting System Data Tables*. Available at (www.aoa.gov/ltombudsman/99nors/default.htm).

¹² The Older Americans Act requires states to make legal counsel available to long-term care ombudsman programs, but the legal counsel is not necessarily on the staff of the program.

¹³ This figure does not take into account amounts reported by two survey respondents who apparently misunderstood the question.

¹⁴ Median among survey respondents only. National statistics indicate that on average in FY 1999, local ombudsman programs closed 222 cases (involving complaint investigation) and provided 303 additional consultations to individuals.

¹⁵ Information from Michael Adelberg, Director, Division of Monitoring and Interventions, U.S. Centers for Medicare and Medicaid Services (formerly, Health Care Financing Administration), June 2001.

¹⁶ SHIP Resource Center, *New SHIP Directors Handbook* (Washington, DC: National Association of State Units on Aging, 2001).

¹⁷ Information Counseling and Assistance (ICA) Resource Center, 1997, as cited in *One Voice, Many Faces*.

¹⁸ The Lewin Group, *Evaluation of the First 18 Months of Operation of the Health Rights Hotline: A Pilot Independent Assistance Program of the Center for Health Care Rights*, January 2000. Available at (www.hrh.org).

¹⁹ Among survey respondents, only 17 percent of P&A programs, 14 percent of long-term care ombudsman programs, and 10 percent of all other programs report receiving help with fundraising.

APPENDIX:
SURVEY FORM

For Office Use Only:

ICAS _____ ICAL _____ LTCS _____
LTCL _____ P&A _____ MED _____
INS _____ (O) _____

Health Care Consumer Assistance/Ombuds Program Survey

Name of program: _____

Agency: _____

Address: _____

Person completing survey: _____ Title/Role: _____

Phone: _____ Fax: _____

e-mail: _____

Organization's web site, if any: _____

Program Design

1. Which of the following best describes the scope of issues addressed by your program?
(Circle all that apply)

- a. Long term care issues
- b. Health insurance issues, including managed care issues
- c. Health issues affecting people with disabilities
- d. Mental health care issues
- e. Other _____

2. Does the population you serve include the following? (Circle all that apply)

- a. Medicaid beneficiaries
- b. Medicare beneficiaries
- c. Other publicly insured consumers
- d. Privately insured consumers
- e. Uninsured

3. Is the population you serve limited by any of the following:

<u>Factor</u>	<u>Yes/No</u>	<u>Describe limit</u>
Age	_____	_____
Income	_____	_____
Geographical area	_____	_____
Other	_____	_____

4. Which statement *best* describes your program's role (please circle one)?

- a. Our program acts as a neutral investigator of consumer problems.
- b. Our program acts as a mediator, seeking to forge agreements between health care providers or insurers and consumers.
- c. Our program acts as an independent advocate for the consumer. We represent the consumer's interests by mediating disputes on the consumer's behalf or advocating for the consumer in a formal appeal.
- d. Other/comments _____

**Please return survey to: Families USA, 1334 G Street, NW, Washington, DC 20005
(202) 628-3030, FAX (202) 347-2417**

5. Following is a list of services that ombuds programs may provide. Please check the services that are provided by your program, and indicate the approximate percentage of your program's time and financial resources that are devoted to each activity.

Activity	Check if your program does this	% staff time	% budget
Assist Individual Consumers			
Investigate complaint			
Empower consumers to resolve own issues by providing technical assistance			
Write letters, make calls on consumers' behalf			
Directly represent consumers in grievances or appeals			
Follow case through complaint resolution			
Assist Groups of Consumers			
Investigate complaint			
Empower group to resolve own issues by providing technical assistance			
Write letters, make calls on groups' behalf			
Directly represent group in grievances or appeals			
Follow case through complaint resolution			
Other Activities			
Provide outreach/public education to consumers			
Develop consumer educational materials			
Collect data on complaints &/or inquiries			
Prepare/distribute reports on complaints &/or inquiries received			
Train community organizations and/or health care providers on consumers' health care rights			
Other: Please list			

6. Please list any federal, state, or local laws, regulations, contract provisions, or public agency policies and procedures that authorize your program or define your program's operations and authority:

☐ Older American's Act
☐ Developmental Disabilities Assistance and Bill of Rights Act, Title V
☐ Protection and Advocacy for Mentally Ill Individuals Act
☐ OBRA 90 and Social Security Act, Health Insurance Information, Counseling and Assistance Grants
☐ Federal law and regulations governing nursing homes
☐ Other federal law/regulation (list): _____
☐ State law/regulation (please attach) _____
☐ Local law/regulation (please attach) _____
☐ Contract authority (please attach) _____
☐ Court order (please attach) _____
☐ Other policies (please attach): _____

7. Which of the following best describes the organizational placement of your ombuds program?
- State agency (what one)? _____
 - County agency (what one)? _____
 - City/municipal agency (what one)? _____
 - Nonprofit organization _____
 - For-profit organization _____
 - Other _____
8. If you are a nonprofit or for-profit funded in part by the government, what departments or agencies contract with you? _____
 Do any of those departments or agencies run or contract with any health plans or health care institutions that you may investigate as an ombudsman program? _____
We'd be interested in your comments on whether your placement or funding results in any potential conflicts of interest, or whether there are "firewalls" that protect you from conflicts of interest. Comment space is provided on the back page.
9. How much of your services (approximate %) are rendered by phone? ____ Face to face? ____

Statistical Information

10. What was your program's total operating budget for the past fiscal year? \$ _____
 Please list your program's revenue sources, and the approximate amount of the operating budget received from each source:

Revenue source	Amount

11. What is the size of the population in your service area that is potentially eligible for your services (that is, the number of insured consumers in your area if you handle insurance disputes, or the number of long term care residents if you are a long term care ombudsman, etc.) _____
12. What is the estimated ethnic make-up of the population potentially eligible for your services:
- | Ethnic group | Percent of target population |
|--------------|------------------------------|
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
| _____ | _____ |
13. Is the population that you serve primarily (circle one):
- Urban
 - Rural
 - Suburban
 - Mixture of urban and rural

Staffing

14. We are interested in the staffing of your program. In the following table, please describe the types of paid positions in your program, whether each is full-time or part-time, the training/educational background *required* of someone in this position (e.g., college, grad school, J.D., R.N., M.P.H., other formal training), and the training/educational background of the person *currently* holding this position.

Position	Full-time? (If not, approx.	Educational level or formal training required hrs/wk)	Educational level or formal training of person currently in this position

15. Does your program use volunteers? Yes _____ No _____ If so, how many? _____ What types of services do volunteers provide (circle all that apply):

- Presentations to consumers
- Outreach/education through the media
- Training community groups/providers in health care issues
- Developing consumer materials
- Providing information and advise to individual consumers
- Investigating and resolving complaints
- Directly representing individuals
- Organizing groups of consumer into self-help or advocacy programs
- Providing information and advise to groups of consumers about complaints
- Investigating and resolving complaints by groups of consumers
- Directly representing consumer groups
- Preparing and distributing reports on complaints &/or inquiries received
- Advocating for changes in public policy
- Collecting data on complaints &/or inquiries
- Support services
- Other (list) _____

Does your program provide formal training or certification for volunteers? _____

16. How are the consumers that you serve involved in the operation of your program (circle all that apply)

- Consumers serve on program advisory committee
- Consumers provide peer counseling as part of our program
- We employ some consumers
- Some consumers volunteer in our program
- Other (describe) _____
- Not involved

Outreach

17. Which of the following methods do you use to inform the public of the availability of your services (circle all that apply)
- a. Insurers and/or health care providers publicize our program through general informational materials
 - b. Insurers and/or health care providers inform consumers of our program in notices of adverse action.
 - c. Information about our program is posted in public agency and/or provider offices
 - d. Purchasers publicize our program
 - e. Federal/state/local government agencies publicize our program
 - f. We are listed in the yellow pages
 - g. We distribute brochures/flyers
 - h. We provide informational materials in languages other than English
 - i. We regularly publicize our program through public service announcements and other media
 - j. We maintain a web site
 - k. We regularly speak at community meetings, health fairs, and other events
 - l. We have formal arrangements with neighborhood organizations to provide outreach
 - m. We "ride circuit" to different health care facilities or neighborhood organizations to take cases
 - n. Other (list) _____
18. To serve a multi-cultural, multi-lingual population, does your program (circle all that apply):
- a. Have bilingual staff members
 - b. Have a multi-cultural staff
 - c. Contract with an interpreter service
 - d. Provide outreach and/or services through community organizations serving other linguistic groups
 - e. Other _____
 - f. No specific arrangement
 - g. Not applicable
- What languages and cultures are you serving? _____
19. To serve persons with disabilities, does your program use (circle all that apply):
- a. Home visiting
 - b. TDD equipment
 - c. Contract with disability groups to provide outreach and/or services
 - d. Provide presentations and/or individual services in sign language
 - e. Any other accommodation? _____
20. Which of the following methods does your program use to inform the public of their rights?
- a. Speaking engagements
 - b. Media
 - c. Publish written materials
 - d. Publish written materials in languages other than English
 - e. Publish written materials at low literacy levels
 - f. Put information on the web
 - g. Provide audio tapes/recorded phone messages about rights
 - h. Train key staff in community organizations, who then train the community
 - i. Other (describe) _____

Representation

21. Does your program represent consumers in formal grievance reviews? Yes _____ No _____
22. Does your program represent consumers in fair hearings (e.g., for Medicaid and Medicare beneficiaries), or in external appeals (e.g., for managed care consumers)? Yes _____ No _____
23. Can your program represent consumers in court? Yes _____ No _____
If yes, how often do you actually go to court: _____
24. Do you have formal arrangements with legal assistance programs to provide representation? Yes _____ No _____
25. Which of the following authorities does your program have, if any:
- a. Subpoena power
 - b. Access to health facilities
 - c. Access to medical record
 - d. Authority to act on behalf of an incompetent client
 - e. On-line access to eligibility files of public program
 - f. Other _____

Data

26. Does your organization compile and report the following types of data (check all that apply):

Data	We compile this data	We report this data
No. of consumers served		
No. of complaints received		
No. of complaints resolved		
Type of problem/inquiry		
Referral source		
Time to resolution		
How resolved		
Facility/health plan/medical group giving rise to complaint		
Type of service you provided (eg, brief advise, investigation, etc.)		
Formal grievances filed		
Consumer's insurance source		
Consumer's age		
Consumer's ethnicity		
Consumer's gender		

We do not compile any of the above data _____

27. Do you report the data
- a. To a public agency (what one?) _____
 - b. In a written report distributed to policymakers _____
 - c. In a written report shared with the general public _____
 - d. Other (describe) _____
 - e. We do not report data _____

28. How many people did your program serve during the last twelve months for which you have compiled statistics? How many issues or complaints did you handle? (One person may have multiple complaints.) If your program is new, please provide data for whatever period is available. (If possible, please provide information on the chart below. On the chart, "representation" includes not only cases where you acted as the legal representative of a consumer, but also any cases in which you wrote letters, made phone calls, or met with providers on the consumer's behalf.)

Total No. of Consumers Served (One consumer may present more than one issue)	
Total No. of Unduplicated Consumers Served	
No. of Brief Cases – Advice Only (up to ½ hour on phone or in person)	
No. of Brief Direct Representation (up to 4 hrs)	
No. of Extended Service Representation (anything above 4 hrs)	
Total No. of Issues Presented by Consumers (one specific problem)	
No. of Issues Resolved in Favor of Consumer	
No. of Issues Resolved but Consumer not Completely Happy	
No. of Issues Closed but No Satisfactory Resolution Possible, Consumer Got Something	
No. of Grievances Filed	
No. of Appeals or Fair Hearing Requests Filed	
No. Resolved in Favor of Consumer	

What year or period do these figures reflect?

If you keep data in a different format, please provide statistics as you maintain them and explain: _____

Informing Policy

29. Does the ombudsman program give the following groups feedback regarding the problems it has detected and its recommended solutions? If so, what method is used to provide feedback (please select)?

Group	Method of Feedback					
	None	Phone	Letter	Report	Meeting	Other (Specify)
Health Plans						
Health Care Providers						
Private Health Purchasers						
Health Regulators						
Insurance Agents						
Other Public Agencies						
Legislators						
Employers						
Consumer Organizations						
Other Consumer Assistance Programs (specify):						

Support and assistance

30. Which of the following types of support does your program now utilize (circle all that apply):
- a. Attend annual meeting or conference with similar ombuds programs
 - b. Meet regularly or participate in conference calls (more than once/year) with other ombuds-type programs
 - c. Receive technical assistance on how to resolve consumer problems
 - d. Receive training on priority issues faced by consumers
 - e. Receive training/information about health care industry and policy trends
 - f. Receive assistance with policy advocacy and developing strategies to resolve systemic problems
 - g. Receive substantive manuals or other materials on high-priority concerns of consumers
 - h. Receive skills training, such as on investigating complaints, gathering and interpreting evidence, representation
 - i. Receive help training volunteers
 - j. Receive help or advice on retaining volunteers
 - k. Receive technical assistance on designing/managing ombuds programs
 - l. Get help developing data systems comparable to those used by other ombuds programs
 - m. Receive assistance with fundraising
 - n. Other (describe) _____

From the above list, which are the most important kinds of support that you now utilize. (List in rank order, with the most important being #1)

1. _____

2. _____

3. _____

31. Do you use the internet for research or to obtain other support in your work? Yes __ No __

32. What organizations now provide you with that back-up assistance: _____

What national organizations do you turn to for help, if any: _____

33. In which of the following areas would you like more support (circle all that apply):
- a. Would like to attend annual meeting or conference with similar programs (If yes, would you prefer a meeting that is national ____; regional ____; statewide ____?)
 - b. Would like regular meetings (more than once/year) with other ombuds-type programs (If yes, should the meetings be national ____; regional ____; statewide ____; local ____?)
 - c. Need more technical assistance on resolving consumer problems
 - d. Need more training on priority issues faced by consumers
 - e. Need more training or technical assistance on health care industry and policy trends
 - f. Need assistance with policy advocacy/strategies to solve systemic problems
 - g. Need more substantive manuals or other materials on high-priority concerns of consumers
 - h. Need more skills training, such as on investigating complaints, gathering and interpreting evidence, representation
 - i. Need more training for new and existing volunteers
 - j. Need help retaining volunteers
 - k. Need more technical assistance on designing/managing ombuds programs

- l. Need help developing data systems
m. Need assistance with fundraising
n. Need other support (describe)

Of the needs you described, which three are most important to your program (list in rank order)

1. _____
2. _____
3. _____

Other comments regarding support: _____

Families USA will be interviewing a few ombuds programs by telephone to get more information about their key successes, challenges, ways that they have contributed to systemic changes for consumers, and their back-up needs. Would you be willing to be interviewed by phone?

If so, name and phone number _____

Please list any other privately funded health care ombudsman programs that you think we should survey in your state:

Do you want to receive a copy of the survey results? Yes_____ No_____

Notes/Additional comments on any of the preceding questions:

[illegible]

OPTIONAL

The next few questions are open-ended. If you have time, we would appreciate receiving your feedback. (However, if you don't have time to complete this section, we understand. Please go ahead and mail back the portion of the survey that you did have time to complete.)

1. What are the major successes of your program?

2. What are the key elements of your program design that led to success?

3. What are the major obstacles to your program's success?

4. What do you think are the major issues other groups should think through in designing an ombuds program?

5. Do you have comments/suggestions regarding our project?

Finally, if you have time to attach any of the following, we would be interested in samples of: your mission statement, if any; reports that your program furnishes to the public or policymakers; and/or state or local legislation that authorizes your program. Many thanks!

Credits

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Families USA

Families USA is a national, nonprofit organization dedicated to the achievement of high-quality, affordable health and long-term care for all Americans. You can help promote Families USA's goals by becoming a member of Families USA today.

Yes, I want to add my voice in support of affordable, high-quality health care for all.

_____ \$25 _____ \$50 _____ \$100 _____ \$250 _____ Other

Please send me information about the following Families USA's grassroots advocacy networks.

___ *asap!* ___ Medicaid Advocacy Network ___ Medicare Action Campaign ___ Children's Health Campaign

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