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Setting Up a Hotline

ABOUT THIS BRIEF

Consumer assistance hotlines represent one important model for delivering health-care information to consumers. However, developing and managing such programs can be complicated. This issue brief presents some of the issues involved in setting up and maintaining a hotline. It also highlights the experiences of the Health Rights Hotline, an independent consumer assistance program in Sacramento, California.

Special thanks to our guest authors this month, Shelley Rouillard and J. Bridget Sheehan-Watanabe of the Health Rights Hotline.

In recent years, hotlines have become a very popular way of providing "live" answers to consumers' health-care questions. Within the field of Medicare education, hotlines have gained prominence through the 1 (800) MEDICARE (1 (800) 633-4227) line maintained by the Centers for Medicare and Medicaid Services (CMS) and the State Health Insurance Assistance Programs (SHIPs), some of which have their own helplines. In addition, other advocacy organizations have also created their own hotlines, designed to provide independent consumer assistance.

However, while the premise behind hotlines seems simple in nature, the reality is that the issues associated with the implementation and management of these lines are complex. In this brief, we will discuss some of the issues—including costs—you will need to think about as you develop and maintain a consumer assistance hotline at your organization, using real-life examples from experiences of the Health Rights Hotline (HRH), an independent consumer assistance program based in Sacramento, California.

Background

Designed as a source of free, independent assistance and information for health-care consumers, the HRH provides its services primarily through telephone counseling and community education and outreach. The hotline was intended to serve as a state and national model for independent assistance programs for consumers in managed health-care systems. Over time, the hotline's services have expanded to cover all health-care consumers, including persons who receive care on a fee-for-service basis or who are uninsured.

As a model, one of the goals of the HRH is to bring consumers' perspectives into the political dialogue around managed health care. The HRH encourages managed health-care systems to better meet consumers' needs by helping them understand consumers' experiences with the health-care system. The hotline's philosophy is to foster collaboration with the various health-care stakeholders in order to improve consumers' access to health-care.

Designing the Program and Scope of Services

Deciding who to serve and how to serve them is a preliminary step in any hotline venture. You can determine the need for a hotline in your community by consulting with advocates and policy-makers and/or by conducting surveys or focus groups of the people in your area whom you want to serve. It is important to identify existing resources so that the hotline can fill service gaps and work collaboratively with the resources that already are available.

CENTER FOR MEDICARE EDUCATION
2519 Connecticut Avenue, NW
Washington, DC 20008-1520
Phone: 202-508-1210
Fax: 202-783-4266
Email: info@MedicareEd.org
Web site: www.MedicareEd.org

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CENTER STAFF
Marisa A. Scala
Robyn I. Stone
Sharon R. Johnson
Rachel J. Bealle

During the development of the HRH, staff developed a list of key issues to consider.

- ***Independence:*** An overriding consideration was that the hotline must be independent from the health-care system. To gain consumer confidence, consumer assistance hotlines must be viewed as unbiased sources of information and assistance, capable of conducting effective advocacy on behalf of consumers.
- ***Service goals and strategies:*** As with all projects, it is important to have clear goals and objectives for your hotline at the outset. The HRH assists individual consumers with their health-care problems, conducts educational activities to help consumers understand how to navigate the health-care system, and keeps abreast of changing health plan and medical group policies, as well as legislative and regulatory changes affecting the health-care delivery system.
- ***Service delivery:*** Although the primary mechanism for providing services is through a telephone hotline, it also was important that the HRH have the capacity to provide face-to-face counseling in its offices and, when necessary, in clients' homes.
- ***Cultural/linguistic and disability access:*** Cultural diversity issues are critical for any organization wishing to provide consumer assistance. Consumers need to feel comfortable sharing their problems and issues, and that means being able to communicate in their language. The HRH hired counselors who spoke Spanish, Hmong, Russian and Japanese; installed a dedicated TTY/TDD phone line (for the hearing impaired); and ensured that its office was accessible to people with disabilities. The hotline also contracts with a telephone language line to provide interpretation for callers who speak languages not available through hotline staff.
- ***Scope of services:*** Once you've established your goals, you will need to lay out how you plan to achieve those goals, including the services that you are going to offer. HRH counselors clarify consumer rights and responsibilities; refer consumers to appropriate resources, including health plans, government agencies and community organizations; and represent consumers in health-related disputes. Hotline staff also conduct educational presentations and advocate for policy changes to improve the health-care system.
- ***Relationships with related organizations:*** It is important to acknowledge and involve other organizations in your area that may be providing similar services to yours. Recognizing the critical role that the local SHIP (in California, called HICAP—Health Insurance Counseling and Advocacy Program) plays for many seniors and Medicare beneficiaries, the HRH contracted with the local HICAP to base a counselor at their offices who had been extensively trained on managed health-care issues. She was available as an expert resource on consumers' rights in Medicare health maintenance organizations (HMOs) for HICAP clients and volunteers.

Establishing an Advisory Committee

Input from stakeholders (e.g., consumers, health plans, employers, etc.) is fundamental to the success of a hotline. One of the HRH's first activities was to establish an advisory committee that represented a broad range of managed health-care stakeholders. Among the issues to consider in deciding whom to invite to participate on the advisory committee are:

- ***Workable size:*** It is important that your advisory committee be broad enough to reflect stakeholder interests, but still be manageable.
- ***Local focus:*** It should be locally based to foster collaboration and provide a common frame of reference.
- ***Balance of participants:*** In selecting individual representatives, you may want to have a mix of perspectives. The hotline included representatives from health plans and providers, consumers who had knowledge of or experience with particular medical conditions (such as cancer or mental health) or types of payers (such as Medicare or Medicaid), large and small employer representatives, and state legislative and regulatory staff.

Advisory committees can provide significant input into development and management issues. For the HRH, the committee offered suggestions on program design and evaluation, service protocols, training,

educational materials, outreach and promotion, and data collection and reporting.

Involving Key Stakeholders

As mentioned earlier, it is important to develop good relationships with those people and organizations involved in and affected by your work. The HRH has developed and maintained constructive working relationships with the major stakeholders in its local health-care delivery system, particularly the managed health-care system. Some ways to develop these relationships include:

- ***Individual meetings with stakeholders:*** In-depth meetings with health plans, medical groups, health systems, regulators and purchasing groups were held prior to the HRH's launch. The hotline also holds ongoing meetings with various stakeholders to discuss findings from call data and any identified trends or issues arising from hotline calls.
- ***Soliciting input through mailings:*** Periodic letters have been sent to key stakeholders requesting feedback on programmatic issues, including program protocols and data collection, analysis and reporting.
- ***Sharing data on consumers' concerns:*** Each year, the HRH provides statistical data and case summaries to each health plan and medical group serving the Sacramento area. These reports identify the issues faced by health-care consumers but do not contain caller-specific information that could be used to identify a particular consumer.

Developing the Telephone System

Clearly one of the most important decisions that you will make with regard to your hotline is deciding on a telephone system. The HRH made an early decision to answer all calls live, understanding consumers' frustrations with phone trees that ask you to press one for this, two for that. With that in mind, the hotline purchased an automatic call distribution (ACD) system to answer hotline calls. (Many companies use an ACD system for their customer service departments.) The hotline's ACD system is basic but cost about $45,000.

Hotline counselors log onto the system, ready to answer calls as they come in. Calls are routed from person to person. If all the counselors are busy, then callers hear a message asking them to wait for the next available counselor. After about 30 seconds, callers hear a second message suggesting that they might want to call back at a later time. (Since the average length of time for a hotline intake call is about 24 minutes, someone could be on hold for a long time if all the counselors are assisting other callers.) The hotline found that most people will not remain on hold for more than about 1½ minutes.

Developing Your Management Information System

Another critical choice for your organization is deciding on the management information system (MIS) that you will use to track your calls and the services and advice provided to callers. The requirements for your system should be driven by your data collection and service goals. The MIS needs to be easy to use, and it should allow them to input caller information directly into the database while on the phone. Staff at the HRH identified four primary functions for their MIS:

- **Case management.**
- **Information and referral.**
- **Demographic and health-care system data collection.**
- **Time tracking.**

The hotline evaluated a number of software programs including those used by legal services organizations, information and referral agencies, and health plans. The cost and time to develop a wholly customized program were also considered. They ultimately decided to purchase a software program called CLIENTS, a Windows-based Access program designed for legal services case management, which could be modified to meet their needs. The total cost of the initial purchase and modification of CLIENTS was approximately $30,000.

However, deciding on your MIS is only the first step. Once it is installed, you must also be prepared to deal with ongoing maintenance and changes. The HRH contracts with a programming consultant who has made necessary modifications and provides ongoing support for the application. Ongoing pro-

gramming for fixes and changes costs $5,000-$6,000 per year. (These costs were higher in the first couple of years but have decreased over time.)

Establishing Protocols

Protocols are policies for how counselors should assist callers—both at intake and on an ongoing basis. These should be developed early in the planning process. The first contact a consumer has with your hotline is with the person answering the phone. The manner in which calls are answered and the sensitivity demonstrated by the person answering the phone are essential for a caller to develop a sense of trust and confidence in the program. Protocols also help to ensure consistency in how questions are answered.

Initially, the Hotline's main efforts toward developing protocols and methods to serve individual consumers consisted of meeting with health plans and other stakeholders and collecting complaint and issue categorizations from an array of sources. Research was conducted on other consumer programs, including programs serving Medicaid managed care members. A goal of the program in designing complaint categories was to make it comparable to data collected by other entities such as health plans, state agencies, Medicare and HICAP.

The hotline eventually developed written protocols for counselors and scripts that address specific calls or issues including intake, follow-up surveys, confidentiality, print material availability, referral confirmation, collection of demographic information, callers' fear of retribution for having contacted the hotline, basic information about the hotline and program funding.

Developing a Training Program

Counselor supervision and training are essential to providing high-quality service and collecting credible, valid data. HRH counselors undergo an extensive training program that provides them with the basics in an array of areas, including consumers' health-care rights and rules governing employer-based, Medicare, Medi-Cal and other types of health plans; health plan practices; interviewing; communication negotiation skills. New counselors listen in on calls with experienced counselors and complete case exercises before they begin providing services.

Quality control and ongoing training are a high priority and require a significant investment of management and counselor time. Hotline management staff provide counselors with informal daily supervision, twice-monthly individual supervision sessions, weekly case conferences, data collection/protocol review and ongoing training sessions.

Staffing

Staffing for a hotline will vary depending on your program's size, design and budget. The HRH has 12 full-time staff members—a program director, supervising counselor/attorney, seven full-time counselors, office manager (who also serves as the hotline's computer system and data manager), policy analyst and receptionist. The current counseling staff includes three bilingual Spanish/English counselors and one bilingual Hmong/English counselor. The hotline does not use volunteers to provide direct services.

Some advice: Ideally, a hotline should have a full-time outreach/education coordinator who is responsible for generating and conducting presentations, attending health fairs and other community events, and developing promotional and educational materials. If possible, the positions of the office manager and data manager should be separate so that there are adequate resources to manage the day-to-day office operations, maintain the computer system and generate reports from hotline data.

Handling Calls

In addition to developing protocols or scripts for how calls should be answered, figuring out the mechanics of answering calls is an important implementation issue. On the HRH, initially two counselors logged onto the ACD for four-hour shifts, with a third counselor assigned as backup. When calls came in rapidly, such as when there was media attention for the hotline, the backup counselor would log on and take calls as well. All the phones in the hotline office have the capability to connect to the ACD.

After using this intake system for nearly two years, the hotline analyzed the types of calls that it was receiving. The level of calls the hotline received was much lower than had been anticipated during the planning period. The counselors felt that too much

of their time was spent waiting for the phone to ring and that constant interruptions reduced their ability to manage their caseloads effectively.

The hotline tested, and ultimately implemented, a new intake method. A receptionist answers all incoming hotline calls. She screens calls and forwards appropriate calls to the designated lead counselor, who assists the caller. If the lead counselor is on the phone with another caller, the receptionist takes a message so that the lead counselor can call back. Counselors attempt to contact the person at least twice within 24 hours. The receptionist handles all misdirected calls, routes ongoing case calls to the appropriate counselor and refers out-of-area callers to resources in their communities.

Collecting Data and Quality Control

Accurate data about your callers can be an incredibly useful tool for planning and evaluation purposes, as well as for funding proposals that you may generate. The HRH requires counselors to collect a significant amount of data from callers. Required data fields include: payer type (e.g. commercial, Medicare, Medi-Cal); health plan; plan type (e.g., HMO or Fee for Service); medical group; the health condition that relates to the difficulty; zip code; referral source; issue categories (up to three issues can be coded per case); and personal demographic information such as age, gender, ethnicity, education level, employer type, household size, and household income. The hotline uses 62 distinct issue categories to code callers' issues and problems. In addition, the hotline tracks the subject of the dispute using 28 subject areas (e.g., dental care, emergency services, home health, and mental health).

The supervising counselor reviews a sample of each counselor's cases to ensure the accuracy of the data collected, to ensure that all counselors are collecting data in a similar fashion, and to check the quality and completeness of advice and referrals given. The sampling rate is 1 out of 10 cases per counselor per quarter. The sample size is increased if a counselor's error rate is higher than an established standard. Most counselors pass review at the first level, although some counselors consistently have all of their cases reviewed for accuracy.

Analyzing Call Volume and Time Spent on Cases

At the beginning, the HRH benefited from a lower than anticipated volume of calls because it allowed the counselors and management staff to spend more time on refining protocols, training and refining the information infrastructure. Counselors spend significantly more time on cases than was originally projected. Nearly 60% of the hotline's cases take between 30 minutes and 5 hours to resolve. The average time spent on these cases is 1.5 hours. The table below compares the projected time spent on cases to the actual time spent on cases during the hotline's first three years of operation.

AVERAGE TIME SPENT ON CASES ***Projected Compared to Actual***

CASE TYPE	ORIGINAL PROJECTION		ACTUAL EXPERIENCE (7/97-6/00)	
	Percent of Cases	*Average Time per Case*	*Percent of Cases*	*Average Time per Case*
Brief Cases (< 30 minutes)	70%	.5 hours	35%	.3 hours
Medium Cases (30 minutes-5 hours)	20%	2 hours	59%	1.5 hours
Long Cases (> 5 hours)	10%	7 hours	6%	13 hours

Communicating a Clear Message

Developing a clear and consistent message and public image is critical to the success of your hotline. These enable you to become a trusted member of the community—an organization that consumers will turn to when they have problems. During its first six months, the HRH contracted with a local communications firm. Through a consultant, the hotline conducted focus groups of consumers who had experienced difficulties with their health plans, developed a program name and image, developed initial educational and promotional print materials, and conducted a test launch of the hotline in a small part of its service area.

Working With the Media

Local newspaper and TV reporters can be strong allies to promote a consumer assistance hotline. Over the years, a hotline can establish itself as an expert on consumers' perspectives. Through the data collected and individual case stories, the hotline can illustrate consumers' real-life experiences on particular health-care issues. While the HRH has had mixed success at getting promotional coverage by the news media, it has been able to have a number of consumer education messages placed as sidebars in local newspapers describing the basic steps consumers can take to resolve problems. The hotline frequently is called to provide a case story that illustrates a particular problem being covered by a reporter.

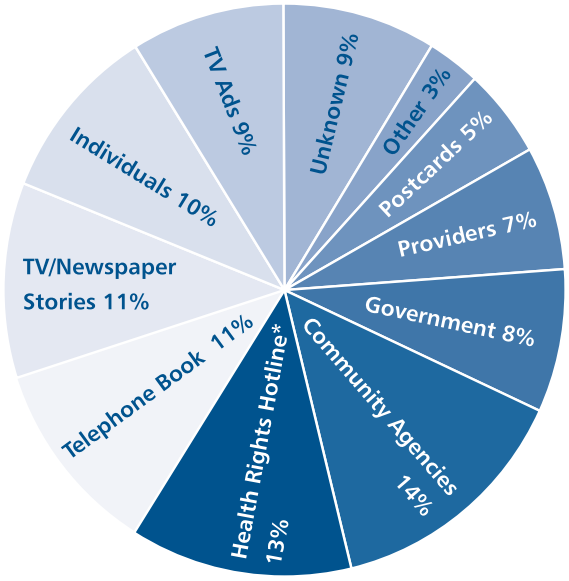
Conducting Community Outreach and Education

The hotline's outreach activities have two goals: 1) to educate consumers to be informed, effective and empowered users of the health-care system; and 2) to promote the hotline as a resource for those who have questions or problems. Letting people know about the availability of its services and evaluating which vehicles have been most effective in generating calls to the hotline have been two of its biggest challenges.

The adjacent chart shows that the primary sources of referrals to the hotline come from community agencies; people who heard about the hotline at a presentation, or other community event; the telephone book; news stories; and other individuals such as family members or friends (word-of-mouth). The hotline tested TV advertising and direct mail as part of its outreach plans, but both of these were found to be expensive compared to the volume of calls generated.

Through community education materials, presentations and attendance at community events, consumers learn how to use the health-care system, how different types of coverage work, how to choose among health plans and medical groups, how to work with health-care providers and how to learn about health conditions. Community education events also serve to educate the community about the services provided by the hotline. The HRH has also produced a variety of materials to educate consumers on how to navigate the health-care system. Consumer materials are distributed to hotline callers, to attendees of health fairs and consumer conferences, and via the hotline's Web site—www.hrh.org.

HRH REFERRAL SOURCES
July 1997 - June 2000



***This category includes people who heard about the hotline at a presentation, health fair, or other community event or who are prior callers. Only about 5% of all consumers assisted are prior callers.**

Using Data to Influence Policy-Making

Information on the experiences of the consumers served by a hotline can be used to educate policymakers, health plans and provider groups, regulators, advocates and the public. Combined with individual

case stories that illustrate the issues that consumers encounter in the health-care system, data are powerful tools for identifying and bringing attention to consumer problems. Data collected by a hotline are used to identify the extent of problems different consumers experience in the health-care system. They show which consumers are having problems, which types of problems are most common and which problems are experienced disproportionately by different groups of consumers. Finally, data also are used to track consumer problems over time.

Evaluating the Hotline

There are a number of different methods that you can use to evaluate the effectiveness of your hotline. Evaluation of the HRH followed two paths. First, the hotline instituted a number of mechanisms to evaluate its own services (e.g., conducting follow-up surveys of clients served and soliciting feedback from health plans and providers through regular meetings). Second, the funders contracted with an independent evaluator, the Lewin Group, to assess the hotline's processes and outcomes.

The cost for the evaluation was approximately $430,000 and included a survey of Sacramento area households, interviews with various health care stakeholders, surveys of consumers served by the Hotline, and analysis of the effectiveness of the Hotline's education and outreach activities.

The findings from the Lewin Group's evaluation of the first 18 months of the hotline were published in the January/February 2000 issue of the journal *Health Affairs*. The Lewin Group "found substantial evidence that the hotline helped consumers to resolve their problems and increased satisfaction with the problem-resolution process and the available assistance resources."[1]

Potential Sources of Funding

At its inception in 1996, the HRH was funded by three of California's premier health-care foundations. Over four years, these foundations provided almost four million dollars for the program and its evaluation. In 2000, a fourth foundation provided a grant that funds a significant portion of the hotline's operations through June 2002.

The HRH presently receives no funding from health plans or health-care providers. The hotline does not receive government funding at this time, though for its long-range sustainability it will have to rely on government funding. Foundations are not likely to support efforts such as the hotline indefinitely.

Beyond foundation funding, other potential funding sources for consumer assistance hotlines include:

- ***Counties.*** Some counties may be required to have ombudsman programs for different populations such as mental health-care consumer, children or older adults. Consumer assistance hotlines could contract with a county to provide advocacy services to distinct populations. Some counties have obtained federal waivers under their indigent health-care programs that provide funding for independent assistance programs.

The HRH funders are:

THE CALIFORNIA ENDOWMENT, established in 1996, makes grants to organizations and institutions to expand access to affordable, quality health care for under-served individuals and communities and to promote fundamental improvements in the health status of all Californians.

THE CALIFORNIA WELLNESS FOUNDATION was created in 1992 as an independent, private foundation. Its mission is to improve the health of the people of California by making grants for health promotion, disease prevention and wellness education.

THE HENRY J. KAISER FAMILY FOUNDATION, established in 1948 by industrialist Henry J. Kaiser and his wife, Bess, conducts and supports a range of health-related activities including policy analysis, applied research to define and measure public health problems, demonstration and pilot projects, and communications activities.

SIERRA HEALTH FOUNDATION, created in 1984, supports health and health-related activities in 26 northern California counties through grant making, targeted initiatives and the foundation's conferencing program.

Independent programs that help people maintain and effectively use their health-care coverage potentially may be funded as a support service for people who are transitioning from welfare to work.

- ***State departments.*** Some states have created consumer assistance programs within their departments of health, human services or insurance. Some programs may contract with community organizations to conduct outreach to specific populations such as Medicaid beneficiaries, Medicare beneficiaries and low-income families with children who may be eligible for the CHIP (Children's Health Insurance Program). There also may be opportunities to contract with the state to conduct training of health-care providers on, for example, the rules and benefits under Medicare, Medicaid and/or private insurance programs.

In Conclusion

Setting up a hotline to assist consumers with their health-care problems requires careful planning. Adequate planning time is a luxury that many programs may not have, but to the greatest extent possible, it is important to build that time into your work plan.

Independent consumer assistance programs are expensive. Substantial sums are required to adequately staff, train, supervise and evaluate counselors and to review the quality and accuracy of the data collected and the advice provided. Many of the problems raised by health-care consumers are severe and often require a considerable amount of time to research issues, provide appropriate advice, consult with the various entities involved in the issues and negotiate solutions on behalf of callers. However, with adequate planning, training and management, hotlines that provide assistance to health-care consumers can have a tremendous impact not only on the lives of individual callers, but also on the health-care system.

[1] Livermore, G.A., Stapleton, D.C., Lee, P.V., and Levitt, L. *"The Health Rights Hotline: Role Of A Model Independent-Assistance Program," Health Affairs* (January/February 2000): 239-241. For copies of this article, please contact the Health Rights Hotline at (916) 551-2100.

About the Authors

Shelley Rouillard is the program director of the Health Rights Hotline, an independent health-care consumer assistance program operating in the Sacramento, California, area. She is one of the founders of the hotline, established its extensive call handling and data collection protocols, manages the hotline operations and oversees the hotline's data analysis and reporting activities.

J. Bridget Sheehan-Watanabe is a policy analyst and staff attorney at the Center for Health Care Rights in Los Angeles. She analyzes Health Rights Hotline data, writes reports and provides expertise to hotline counselors on managed health-care policies and programs.

The **Health Rights Hotline**, the first independent consumer assistance program serving all health consumers, began providing services in July 1997. Administered by the Center for Health Care Rights (CHCR) and Legal Services of Northern California (LSNC), the hotline provides services to health-care consumers in four northern California counties—El Dorado, Placer, Sacramento and Yolo. Since its inception, the hotline has served more than 12,000 individuals. The Health Rights Hotline's mission is to empower consumers to understand and exercise their health-care rights and to improve the health-care system for all consumers by identifying systemic problems and solutions.

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For more information, contact:

Center for Medicare Education
2519 Connecticut Avenue, NW
Washington, DC 20008-1520

Phone: 202-508-1210
Fax: 202-783-4266
Email: info@MedicareEd.org
Web site: www.MedicareEd.org