

Executive Summary

Background

It started in July of 1997, an idea nurtured through many discussions on content, structure, logos, data formats and just about every other aspect of how to deliver a model ombudsman program to Sacramento, Placer, Yolo and El Dorado Counties. Through the generosity of the Henry J. Kaiser Family Foundation, Sierra Health Foundation, and The California Wellness Foundation, the Health Rights Hotline was born. The California Endowment became the Hotline's primary funder in February 2000.

The Health Rights Hotline is an example of organizational collaboration between the Center for Health Care Rights (CHCR) and Legal Services of Northern California (LSNC). The creation of the Health Rights Hotline could not have been possible without the commitment from these two organizations, CHCR as grantee and primary policy advocate and LSNC as host of the Hotline's day-to-day counseling and advocacy work on behalf of health care consumers.

The Health Rights Hotline helps consumers access needed health care by providing free, independent information and assistance and by educating consumers through a variety of activities. In addition, the Hotline analyzes data collected through its direct services and translates it into systemic advocacy, reporting consumers' experiences to stakeholders and the public. The Hotline was initially set up to serve primarily managed health care consumers, but over time all health care consumers, including the uninsured and persons who receive health care from traditional fee-for-service Medicare and Medi-Cal programs, have been helped by the Hotline.

This report provides a three-year retrospective on how the health care system in the four-county Sacramento area has functioned for consumers. From July 1997 through June 2000, the Hotline directly assist-

ed over 8,700 individual consumers. The report looks at the experiences reported by both insured and uninsured individuals and makes recommendations to health plans, medical groups, policymakers and regulators on actions they can take to make the system perform more effectively for consumers.

Who Calls the Hotline

More than one-third of Hotline callers are commercially insured through HMOs or PPOs. These callers receive their health coverage through their employers, unions, or other large purchasers, or they purchase health coverage themselves. Medicare beneficiaries make up more than one-quarter of Hotline callers. Most Medicare beneficiaries who contact the Hotline are in HMOs. Medi-Cal beneficiaries represent about eighteen percent of Hotline callers with slightly less than half enrolled in an HMO. Approximately fifteen percent of Hotline callers are uninsured.

Consumers with health care coverage who have problems accessing care or who have problems with the care they received represent nearly sixty percent of Hotline callers. About twelve percent of Hotline callers seek assistance with getting or maintaining coverage. While all Hotline callers are educated about how to navigate the health care system, about twenty percent of callers want answers to specific questions, rather than help resolving problems.

Findings and Recommendations

The Hotline's recommendations are addressed to health plans and medical groups, physicians, purchasers and policymakers to foster ongoing discussion of how consumers' concerns can be addressed to improve the health care system.

1. Consumers have significant problems navigating the health care system and these problems have not changed much over three years.

The problems Hotline callers reported in 2000 are essentially the same ones they experienced in 1997. HMO reform legislation and the new Department of Managed Health Care have the potential to significantly impact how consumers experience the health care system. It will be important to continue tracking the problems reported by consumers to see if, and how, they change as managed care reform is implemented and the Department of Managed Health Care moves its agenda forward.

Recommendations:

- The Department of Managed Health Care should:

Conduct a follow-up random survey of health care consumers to determine the types of problems they currently are experiencing with the health care system;

Carefully track and report the rates of problems experienced by health care consumers and analyze changes in consumers' experiences with the health care system over time; and

Conduct a thorough analysis to determine the impact HMO reforms have on consumers' experience with the health care system and publicize those findings.

- Health plans and medical groups should target their members/patients who have ongoing health care needs with educational information about what to do when problems come up and provide referrals to independent consumer assistance programs where consumers can get help with appeals and other problems.

2. Consumers in Network HMOs and Medicare beneficiaries in HMOs report higher rates of problems than consumers in other types of plans or with other types of coverage.

In general, consumers in network model HMOs report a higher rate of problems than consumers in group model HMOs or PPOs. Consumers in Medicare HMOs experience a higher rate of problems than consumers in commercial or Medi-Cal HMOs, in part because they are high users of health care services. Certain health plan and medical groups also stand out as being more or less problematic for consumers.

Recommendations:

- Consolidated oversight of all managed health care plan types, including HMOs, PPOs and other hybrid plans is needed and should be located within the Department of Managed Health Care. In the absence of such consolidation, state and federal regulators and purchasers should collect comparable data and conduct integrated data analysis to compare problems across plan types and payer types. Policymakers need to have a true understanding of the range of issues health care consumers experience as proposals to improve and expand access to health care are considered.
- The Department of Health Services Medi-Cal Managed Care Ombudsman staff and Centers for Medicare & Medicaid Services (formerly the Health Care Financing Administration) beneficiary services representatives should facilitate problem resolution through three-way conferencing with consumers, health plans, and health care providers.
- Health plans and medical groups should designate customer service staff to act as liaisons with regulators and independent consumer assistance programs to facilitate problem resolution when consumers are unable to resolve problems on their own.

- Health plans and medical groups should facilitate problem resolution by conducting three-way conference calls (plan, group, and consumer) so that consumers are not bounced back and forth when problems arise.

3. The source of consumers' customer service and inappropriate care problems has been shifting away from health plans and toward individual health care providers and medical groups. Health plans are the primary source of denials of care.

Individual doctors (both primary care physicians and specialists) increasingly have been identified as the “sticking point” for customer service and inappropriate care problems. Health plans still are the source of most denials of care.

Customer Service – The primary customer service problems reported by Hotline callers related to communication difficulties with their doctors and slow responses to request for information. Consumers commonly reported that their specialists were not giving adequate or complete information about their health conditions or treatment options. Consumers also reported feeling that they were ignored or not taken seriously by their physicians, or that they had been treated rudely by physicians, nurses, or other office staff.

Health plans and medical groups have decreased as the source of customer service problems over three years. The primary areas where health plans and medical groups have shown improved customer service relate to the timeliness of responses to inquiries, communication with consumers, and “in-person” telephone accessibility.

Inappropriate Care – Specialists increasingly have been identified as the problem source for consumers who report problems related to the care or diagnosis they received. The specific problems most frequently

attributed to specialists relate to consumers' feelings that the care or diagnosis they received was inappropriate or inadequate. Inappropriate care problems placed with primary care physicians (PCPs), health plans, and medical groups have declined over the three years of Hotline services.

Denials of Care – Health plans represent the highest percentage of denial of care problems and this percentage has increased slightly over three years. Three areas represent the most common denials of care determined by health plans – prescription drugs, surgery, and durable medical equipment or supplies.

Recommendations:

- Individual physicians (primary care and specialists) need to communicate more effectively, and in a timelier manner, with their patients when the patients have questions or need information.
- Physicians and other health care providers should honestly discuss consumers' concerns when a particular procedure, treatment or test does not turn out as well as expected.
- Consumers need to research the qualifications and experience of their doctors, particularly specialists, to help ensure a high quality of care and appropriate outcomes.
- Changes to health plan formularies should be limited to once per year, and should be approved by the Department of Managed Health Care.
- The Department of Managed Health Care should strongly enforce legislation to ensure that written denials from health plans or medical groups include clear explanations for the reason(s) for the denial, the basis upon which the denial was made, and what the consumer, and his or her provider, can do to appeal the denial.

4. Most callers with health care coverage do not call their health plan when they have a problem, mainly because they do not know what to do. Those who do contact their health plan often disagree with the health plan's decision or find the plan to be unhelpful in resolving the problem.

Sixty percent of Hotline callers who have health care coverage had not contacted their health plan prior to calling the Health Rights Hotline. Nearly forty percent of those didn't know what to do. About ten percent contacted their medical group or health care provider instead of the health plan.

Approximately thirty-five percent of those who did try to resolve their problem with the health plan disagreed with the health plan's decision. About one-quarter of Hotline callers found the plan to be unhelpful in resolving their problem. Some Hotline callers wanted to confirm information provided by the plan because they had received inconsistent information or because they did not think the information they received was correct. Other callers felt the health plan was taking too long to respond to their inquiries.

Recommendations:

- Consumers need clear and concise information about where to go to resolve problems. The Department of Managed Health Care and the Office of the Patient Advocate should conduct a major education campaign to inform consumers about how to use available resources by:

Collaborating with independent consumer assistance programs and health condition groups;

Informing consumers of the availability of independent assistance programs;

Working with employer groups, agents, and brokers to provide information to health care

consumers about available resources to resolve problems;

Working with health plans and medical groups to target information to high users of health care services;

Ensuring that the Department of Managed Health Care HMO Helpline is listed in the Government section, yellow pages and community service listings of telephone directories throughout the state; and

Building on existing educational materials developed by independent assistance programs, ensuring cultural and linguistic appropriateness, and distributing materials broadly through places where consumers receive health care services.

- The State should consolidate its hotlines – the Department of Managed Health Care HMO Helpline, Department of Insurance Hotline, and Department of Health Services Medi-Cal Managed Care Ombudsman, for example – to one number that all health care consumers could call regardless of how they get coverage and what type of health plan they are in (HMO, PPO or other type of health plan).

5. Medicare beneficiaries reported higher rates of problems in each category than all other groups of health care consumers. Categorically "disabled" Medicare beneficiaries (those under age 65) reported higher problem rates than "aged" Medicare beneficiaries (age 65 and over). Problems for Medicare beneficiaries of all ages are most prominent in HMO settings.

Medicare beneficiaries enrolled in HMOs report substantially higher problem rates of problems in each major problem area for which the Hotline collects data when compared to consumers with other types

of health care coverage. Medicare beneficiaries have more health care needs than other groups, so they are likely to encounter more problems. The Hotline compared the experience of different groups of Medicare beneficiaries to each other – by age groupings and beneficiary status (i.e. “aged” and “disabled”).

Access to Coverage issues are reported by disabled Medicare beneficiaries at a rate nearly four times higher than aged Medicare beneficiaries. Medicare HMO enrollees report affordability issues at twice the rate of Medicare fee-for-service beneficiaries. Affordability issues for Medicare beneficiaries most often relate to prescription drug costs.

Customer Service Issues are reported by disabled Medicare beneficiaries at two and one-half times the rate of aged Medicare beneficiaries. Medicare HMO enrollees report customer service issues at four times the rate of Medicare fee-for-service beneficiaries. The most frequently reported customer service problems for Medicare beneficiaries involve difficulty communicating with providers, office staff, or medical group or health plan customer service representatives.

Delays in Getting Care are reported by disabled Medicare beneficiaries at twice the rate of aged Medicare beneficiaries. Medicare HMO enrollees report problems with delays at ten times the rate of Medicare fee-for-service beneficiaries. Delays in authorization processes are the most frequent type of delay reported by disabled Medicare beneficiaries.

Denials of Care are reported by disabled Medicare beneficiaries at three times the rate of aged Medicare beneficiaries. Medicare HMO enrollees report care denials at five times the rate of Medicare fee-for-service beneficiaries. The most commonly reported denials by Medicare beneficiaries involve prescription drugs, access to specialists, and durable medical equipment and/or medical supplies.

Inappropriate Care Problems are reported by disabled Medicare beneficiaries at twice the rate of aged Medicare beneficiaries. Medicare HMO enrollees report receiving inappropriate care at three times the rate of Medicare fee-for-service beneficiaries. The most frequently reported inappropriate care problem for Medicare beneficiaries is that the care or treatment they received or the facilities used are inappropriate or inadequate.

Payment Disputes are reported by disabled Medicare beneficiaries at one and one-half times the rate of aged Medicare beneficiaries. Medicare HMO enrollees report payment disputes at three times the rate of Medicare fee-for-service beneficiaries. For Medicare beneficiaries, payment disputes frequently involve payment for emergency services or billing of dual eligibles (persons with both Medicare and Medi-Cal).

Prescription Drug Issues are reported by disabled Medicare beneficiaries at four times the rate of aged Medicare beneficiaries. Medicare HMO enrollees report prescription drug problems at four times the rate of Medicare fee-for-service beneficiaries. Prescription drugs issues most often relate to denial of a brand name or non-formulary medication, disagreements over whether, or how much, the beneficiary must pay for prescription drugs, and concerns over the affordability of needed prescriptions.

Specialty Care Issues are reported by disabled Medicare beneficiaries at about twice the rate of aged Medicare beneficiaries. Medicare HMO enrollees report specialty care problems at six times the rate of Medicare fee-for-service beneficiaries. The most frequently reported specialty care problems relate to denials of referrals to specialists, inappropriate care provided by specialists, and delays in getting appointments with specialists.

Consumer Education Issues are raised by disabled Medicare beneficiaries at more than three times the rate of aged Medicare beneficiaries. Medicare beneficiaries in Medicare fee-for-service and Medicare

HMOs call the Health Rights Hotline more frequently than any other group of health care consumers for consumer education.

Recommendations:

- The Centers for Medicare & Medicaid Services (formerly known as the Health Care Financing Administration) should take an intensive look at how disabled and aged Medicare beneficiaries experience the health care system and develop policies that will improve the care and treatment of disabled beneficiaries.
- Health plans and medical groups should involve consumers in identifying problems and developing solutions to improve Medicare beneficiaries' experience with the health care system.
- Congress should pass legislation to provide prescription drug coverage under Medicare. The Centers for Medicare & Medicaid Services (formerly HCFA) should require health plans that offer prescription drug coverage to include both brand name and generic drugs. Health plans should increase the amount of prescription drug coverage offered to Medicare beneficiaries.
- The Department of Managed Health Care should include information on health plan and medical group performance for disabled and aged Medicare beneficiaries in its report card.
- Health plans should expand their case management services to high users of health care services to assist consumers in navigating the health care system and ensure adequate and timely care.

6. It is hard to know if the rate of problems experienced by consumers in the Sacramento area is "acceptable" or not.

The Health Rights Hotline cannot determine whether problem rates reported by consumers are

"good" or "bad." The Department of Managed Health Care, serving consumers across the state, is in a much better position to assess the overall experience of consumers with the health care system, taking into account regional variations and the maturity of the managed health care systems in different areas.

Recommendations:

- The Department of Managed Health Care should survey health care consumers to determine if the problems consumers experience have changed as a result of legislated reforms.
- The Department of Managed Health Care should set a standard for acceptable problem rates, evaluate the impact these problems have on consumers, and work with the plans to make the health care system more responsive to consumer concerns. Tools to establish standards should include the results of a survey of health care consumers, the rate of problems received through the Department's HMO Helpline, the rates of problems through grievances filed with health plans and medical groups, and the rate of problems reported through independent consumer assistance programs.

7. Callers find the Health Rights Hotline to be helpful and, compared to the general population, have their problems resolved more quickly and to a higher degree of satisfaction.

The Health Rights Hotline conducts follow-up surveys of many of its callers thirty to sixty days after providing assistance. Eighty-two percent of survey respondents found the Hotline to be very or somewhat helpful in resolving the health care problem or providing the information needed by the caller. Nearly three-quarters of survey respondents indicated that the problem they had contacted the Hotline about had been resolved. More than half were satisfied with the resolution of the problem.

About two-thirds of those whose problem had been resolved at the time of the follow-up survey, had their problem resolved in less than a month. Nearly half of those had their problem resolved in one week or less. More than one-third had spent at least a month trying to resolve the problem.

Twenty-seven percent of follow-up survey respondents reported that their problem had not been resolved at the time of the survey. Nearly eighty percent of callers whose problem had not been resolved spent more than two months trying to resolve their problem. Only four percent spent a month or less trying to resolve their problem.

Recommendation:

- The Department of Managed Health Care should evaluate the types of problems that take more than two months to resolve to identify whether there are trends in particular health plans or medical groups. DMHC also should determine what the impact is on consumers when their problems are not resolved within 30 days and recommend ways to reduce the length of time problems remain unresolved.

8. Many health care consumers who contact the Health Rights Hotline experience major problems, such as a significant loss of money or time from main activities, or have experienced actual physical harm or a worsening or prolonging of their health condition as a result of the problem.

The Health Rights Hotline measures the severity of callers' problems through its follow-up surveys with Hotline callers. Seventy-three percent of survey respondents reported that their problem had been resolved. About twenty-seven percent of survey respondents indicated that their problem was not resolved at the time of the survey.

Callers whose problems were resolved

Nearly one quarter of follow-up survey respondents whose problems were resolved, reported some financial loss as a result of the problem of which more than half suffered a loss of \$200 or more. About forty percent reported pain and suffering or a worsening of the health condition as a result of the problem. About thirty percent reported a loss of time, usually less than a day, from main activities due to the problem.

Callers whose problems were NOT resolved

Callers with unresolved problems reported more severe problems than those whose problems were resolved. Whether considering financial loss, physical injury, or time lost from major activities, the longer the problem remained unresolved, the more severe the impact on consumers.

More than forty percent of survey respondents with unresolved problems reported some financial loss. Eighty percent of those suffered a loss of more than \$200 and half reported a loss of \$5,000 or more. Half of the survey respondents reported potential or actual injury, eighty percent of who reported pain and suffering or a worsening or prolonging of a health condition. About half of survey respondents whose problem was not resolved reported some loss of time from main activities due to the problem, and about ninety percent of those reported a loss of two days or more.

Recommendation:

- The Department of Managed Health Care should closely track, and report, the length of time problems remain unresolved based on the severity of the problem as an indicator of how health plans perform for their members who have the most pressing needs for medical care.

9. Nearly sixty percent of all Hotline cases take between thirty minutes and five hours of counselor time and consume half of the total counselor time spent on cases.

The problems posed by Hotline callers often involve complex issues that require significant time to diagnose, investigate and work to resolve. Nearly sixty percent of Hotline cases require between thirty minutes and five hours of counselor time to resolve. Six percent of Hotline cases take more than five hours of counselor time to resolve. Thirty five percent of Hotline cases are handled in less than thirty minutes.

Recommendation:

- The state should fund independent consumer assistance programs as a supplement to the work of the Department of Managed Health Care, particularly for complex cases that require significant staff time and support to resolve.

10. Health plans and medical groups still do not promote the Hotline to their members or patients. Despite three years of developing solid credibility with health plans, medical groups, and other health care stakeholders, less than seven percent of Hotline referrals come from health care providers.

Less than seven percent of all referrals to the Health Rights Hotline come from health plans, medical groups, health systems, and individual providers. Forty percent of referrals from health care providers came from individual physicians.

Health plans and medical groups have expressed concern that if they helped to promote the Hotline as a resource, this would affect their problem rates and reflect poorly on them. However, when one large medical group distributed promotional flyers through its physician offices, it did not result in a higher rate of problems for that group compared to other groups.

Further, the Hotline's promotional materials consistently direct consumers to contact their health plans and/or providers before calling the Hotline.

Recommendation:

- Health plans and medical groups should promote independent assistance programs to consumers who need help navigating the health care system, especially Medicare beneficiaries, persons with disabilities or chronic illnesses, low income populations, and populations with limited-English proficiency.

11. The Health Rights Hotline has demonstrated that independent consumer assistance programs can identify systemic problems, propose solutions, and effect changes to improve the health care system.

The Hotline has been both an "independent ear" and an "independent voice" for health care consumers. The Hotline has successfully brought a consumer perspective to the health care system by producing reports based on consumers' experiences and by helping to create a consumer-oriented Department of Managed Health Care to regulate health plans in California.

Recommendation:

- The state should fund community-based independent consumer assistance programs to resolve complex consumer problems, identify systemic problems and work with the appropriate federal, state, and county agencies to resolve patterns of problems.

12. Many health care consumers do not understand their health care rights or how to obtain objective information and assistance to exercise those rights.

An important part of the Health Rights Hotline's mission is to educate consumers about how to navigate the health care system. Nearly twenty percent of

the issues raised by Hotline callers relate to education about their rights. Medicare beneficiaries, persons who speak limited or no English, and people who are transitioning from employer-based coverage, often know very little about their rights and options.

Hotline counselors explain how the managed health care system works and help consumers understand the basics of their coverage. Counselors provide guidance on how to choose a health plan or health care provider, and advise consumers about the importance of learning about their health condition(s). Counselors also inform consumers about their rights to continuation coverage under COBRA and HIPAA. For callers who are non- or limited-English speakers, counselors act as interpreters with health plans and providers.

Recommendations:

- Report cards produced by the Department of Managed Health Care should include information on quality of care and rates of problems experienced by consumers in health plans and medical groups. Comparisons of commercial, Medicare and Medi-Cal health plans should be included. The report cards should explain how consumers can best use such information and what the information means.
- Health plans should ensure that their enrollee materials are understandable to enrollees, keeping in mind that many people still do not understand basic managed care concepts.
- Federal and state agencies charged with enforcing the requirements that health plans provide culturally and linguistically competent services should more rigorously enforce these mandates.
- Health plans serving Medicare beneficiaries need to further educate their enrollees about how to use their plans, including clear explanations of what benefits are covered. Medicare beneficiaries need

better information about how to access care such as the need to work with their PCP and get referrals to specialists. Health plans should identify high users of the system and reach out to assist them and answer their questions.

- The Department of Health Services should publish a list of Medi-Cal providers by county so that fee-for-service beneficiaries can find a Medi-Cal doctor without having to call individual providers asking if they accept Medi-Cal patients.
- The Department of Health Services should develop creative ways to reach people – particularly those for whom English is not their primary language – about how to use the managed health care system.
- The Centers for Medicare & Medicaid Services (formerly known as the Health Care Financing Administration), the United States Department of Labor, the California Department of Managed Health Care and the California Department of Insurance should increase their efforts to educate health consumers and employers about COBRA and HIPAA.
- The Department of Managed Health Care, charged with enforcing HIPAA in California, should ensure that health plans are complying with their duty to affirmatively offer individual coverage to HIPAA eligible individuals.
- Employers should clearly explain to all departing employees and other persons qualified for COBRA about their right to elect COBRA coverage and the process for obtaining and maintaining coverage. Employers also should inform employees eligible for COBRA about their right to HIPAA plans after COBRA coverage is exhausted.

13. Individuals who are uninsured have few options when faced with a need for health care coverage or services.

The Health Rights Hotline receives a large proportion of calls from individuals who are uninsured. In the Sacramento area, it is estimated that approximately 200,000 individuals (11-14% of the population) lack health insurance coverage. The vast majority of persons who are uninsured are working, are dependents of working people, or are childless adults.

Uninsured persons report difficulties with eligibility for health coverage, being unable to afford health care coverage, or needing immediate medical attention. Some uninsured callers receive bills that they cannot afford to pay.

The uninsured can obtain care for life-threatening needs at hospital emergency rooms, but have many other health needs that often go unmet. Hotline counselors assess if the callers are eligible for any programs such as Medi-Cal or county medically indigent programs and make appropriate referrals. Callers not eligible for these programs are referred to clinics that have sliding scale fees as well as to health condition groups.

Recommendation:

- The Department of Health Services should simplify access to Medi-Cal. Outreach efforts should be increased to enroll as many eligible persons in Medi-Cal and Healthy Families as possible.
- The state should encourage and assist counties in developing creative solutions to provide comprehensive prevention and primary health care to childless workers and undocumented persons. Initiatives are needed to expand current programs and provide incentives to employers, community clinics and other providers to provide coverage to childless workers and undocumented workers and their families.
- The Managed Risk Medical Insurance Program (MRMIP) should be expanded to provide coverage for the large number of Californians who need it.
- Employer and worker education about HIPAA and COBRA and enforcement of these crucial laws should be increased.

Health Rights Hotline Systemic Advocacy

The Hotline identifies patterns of problems encountered by consumers and proposes improvements to the health care system. The Hotline serves as a “finger on the pulse” of the health care system in the Sacramento area and shares its findings with health plans, medical groups and with consumer advocates, legislators, health care purchasers as well as other stakeholders.

Over its first three years, the Hotline worked on a range of systemic projects to improve access to care for many consumers. Systemic projects were identified through the Hotline’s tracking of issues presented by callers. These projects include:

- Bringing a consumer perspective to the health care system by producing reports based on data from Hotline callers;
- Helping to create a consumer-oriented Department of Managed Health Care;
- Educating persons with chronic pain about their rights to adequate treatment;
- Tracking the problems experienced by consumers when medical groups go bankrupt and reporting these issues to the state regulatory agency that oversees health plans;
- Ensuring Medi-Cal beneficiaries receive the full scope of benefits, such as chiropractic care;

- Working with the State Department of Health Services to remind pharmacies that they cannot collect prescription drug copayments from Medi-Cal beneficiaries;
- Improving access to health plan services for Medi-Cal beneficiaries whose primary language is not English;
- Developing consumer education materials;
- Assisting the development of other independent consumer assistance programs; and
- Contributing policy options for health care system improvement.

The Health Rights Hotline's goal is to hold health plans, medical groups, purchasers, regulators, and others accountable for their service to consumers, not to replace them. Data collected from Hotline callers guides the development of solutions for consumers and provides a vehicle to ensure that existing health care resources work effectively.