

Director's Desk – Opportunities for Advocacy

by Marsha Hurst, Ph.D.

As most HAP graduates remember, Diane Borst and I teach a course on “Health Care in Policy and Practice” that includes an assignment called “Opportunities for Advocacy.” The assignment requires a student to create a position for a health advocate and then make a case—including a cost-benefit analysis—for hiring that person. We have always enjoyed reading these papers, and particularly, of course, those that described the need for a health advocate in an entirely new setting.

Frankly, reading the newspaper has become like doing the “opportunities” assignment on a daily basis: there is so much need and so much opportunity for advocacy. The health care system today, however, presents some striking contradictions for the advocate. These contradictions are mainly in “direct” and provider-based advocacy. But first let’s consider “indirect” or issue-based advocacy.

In the news as I write this is Family Health Plus, a New York State plan that will make use of tobacco settlement money and increased cigarette taxes to provide health insurance to a million currently uninsured state residents. Family Health Plus was forged by an alliance of labor (Union 1199) and management (Greater New York Hospital Association) under the skilled political hand of union head Dennis Rivera. The plan is not only important as another, albeit incremental, means of closing the health care access gap in the state, but as an example of the strange bedfellows healthcare policy today can promote. Envisioning the formulation and implementation of this one policy calls forth the need for health advocates working in multiple arenas: advocacy organizations lobbying for universal access; unions, a growing arena for advocates as medical professionals join the growing ranks of hospital workers, nurses and other health care workers organizing for a stronger voice in the health care system; provider advocacy organizations that are increasingly examining issues of concern to patients that spill out over hospital walls; community organi-

zations of all sorts that provide outreach to families who need assistance with enrollment, decision-making and navigating the system.

Two news articles call to mind the increasing opportunity for advocates in rapidly growing areas that wed information access to quality monitoring. In Ontario, Canada, the provincial hospital association has put hospital “report cards” on the Internet, available to the public. New York has just passed a bill to make publicly available doctors’ disciplinary records. Publishers and advocacy services that provide physician information are increasingly moving to make this information easy to access online. A number of “report cards” on managed care organizations (MCOs) are available to the public, including the National Committee for Quality Assurance (<http://www.ncqa.org>) accreditation review results and, in California, a very useful evaluation web site, Healthscope (<http://www.healthscope.org>), sponsored by the Pacific Business Group on Health. As evaluative information becomes available, advocates are increasingly important:

- to provide reliable and responsible information;
- to find ways to get that information to the user public;
- to help interpret and evaluate the information;
- to apply the information to a patient or family’s own situation.

Of course a “rights-based” approach to health care always requires advocates to inform people of their rights and to help them secure the care to which they are entitled. The patient representative position grew largely out of the hospital-based patient rights movement of the early 1970s. Similarly, the patient protection movement that is resulting in widespread—if uneven—state managed care bills of rights as well as proposed federal legislation, requires health advocates to ensure that protection is indeed awarded. Unfortunately, states have been slow to make provisions for the advocacy services needed for consumers. Nevertheless, some, including Vermont, Florida and Virginia, have established ombudsman offices for managed care complaints. Others have health care

bureaus in the offices of the Attorneys General to handle complaints, enforce legislated protections and investigate managed care abuses.

Ron Pollack, Executive Director of Families USA, argues that health care ombudsman programs can help to “resolve health problems quickly and effectively...create more informed consumers ... and restore public confidence.” (<http://www.familiesusa.org/omron.htm>). Advocates should be in the forefront of establishing these programs and making them work for consumers. The Norwood-Dingle Patient Protection Bill [H.R.2723] that passed the House this fall, and provides strong measures of protection to all insured health consumers, failed to include the provision for independent consumer assistance services included in earlier Democratic versions. This bill—and a much weaker Senate version—now has “poison pill” provisions added to it that favor the healthy and wealthy and that are likely to kill the legislation (including a threatened Presidential veto). Nevertheless, consumer protection legislation, whether it is federal or state, cries out for advocates to ensure that these protections actually reach the consumer.

Advocates are important in all aspects of independent consumer protection, including guiding patients through the multiple appeals processes required, even if there is a right to litigation if all appeals fail. A recent medical article reported that doctors don’t appeal MCO decisions because they think it isn’t worth the time and expense, even though analysis of potential gain indicates that appeal would indeed be worthwhile. Advocates working with consumers today know that MCOs respond to squeaky wheels. There are structural incentives that promote a culture of denial (an assumption that cost-saving and denial are necessarily inter-related) but this same culture often responds to active advocacy by the patient or a representative: it makes good business sense.

Grassroots non-profit advocacy organizations have begun to step in to fill the gap in consumer health advocacy. This fall I met an advocate who was part of a small group that founded an indepen-

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dent not-for-profit health advocacy organization in Texas and was contacted by a similar group in Denver (the Patient Advocacy Coalition at <http://www.patientadvocacy.net>). The Center for Patient Advocacy (<http://www.patientadvocacy.org>) in Virginia has been extremely active not only advocating for individuals, particularly those with cancer, but working for national patient protection legislation, and we know there are many others around the country. These organizations often combine direct advocacy—helping individuals and families who are having problems with the health care system or who need information and “navigation” assistance—with policy advocacy, often directed toward patient protection on the state level. As advocates, we have been closely watching the politics of organizational advocacy; some established organizations that have traditionally voiced the interests of providers or mainstream researchers are being challenged by independent advocacy organizations representing patients and families. Older advocacy organizations, like the American Cancer Society, that provide support and information related to particular diseases or conditions, are making efforts to include a broader range of personal advocacy services in their mandate. Some of our graduates are working in these newer patient services areas of established advocacy organizations.

It is not unusual for students in Health Advocacy to pursue interests that are in the forefront of advocacy. Some of these student projects and internships point to new and significant directions for health advocacy opportunities. Two projects spearheaded by students currently in the Health Advocacy Program are focused on end-of-life issues, and illustrate an exciting dynamic between study and action in the program. Lois Steinberg, working under Director of Patient Representatives Gretchen Harris at her St. Luke's/Roosevelt Hospital Center placement, became concerned about decision-making at the end of life. She researched the execution and implementation of advance directives as part of her Health Advocacy II course work, and then did an internship with the New York Public Interest Research Group. NYPIRG encourages interns to focus on research areas of their own interest, and Lois honed in on the legislative history

of the Family Healthcare Decisions Act—a persistently unsuccessful bill to allow families to make end-of-life decisions for a family member who is incapacitated and has no advance directive to express her/his wishes. The research internship encouraged Lois to move into the advocacy action arena, and she has spend this past fall at FRIA (Friends and Relatives of the Institutionalized Aged) rebuilding—and building—a coalition of advocates and organizations to lobby for passage of the Family Healthcare Decisions Act.

As a further outgrowth of her research findings, Lois, together with December graduate Pat Banta and myself, applied for research funding to test the hypothesis that one barrier to people executing advance directives is the concept and language “literacy” required to understand living wills, health care proxies and other advance directives. The concept of “health literacy” has been growing in importance as a way to understand the difficulties people have making use of information about their health and medical care. Lois and Pat were part of a group project in Mike Smith's “Evaluation and Assessment” class that pretested the health literacy survey and assessment instrument.

The importance of health literacy overlaps with another area of growing advocacy interest and student activity: cultural and linguistic competency and sensitivity on the part of health professionals. A number of students are particularly interested in advocacy work with diverse populations, and in gaining the tools needed to communicate effectively in a multi-cultural setting. A group of interested students attended workshops this semester aimed at health professionals who work with people of different cultures and languages. Jody Harris and Cathey Bienkoski, first year students, are both interning with medical school (New York/Cornell and NYU respectively) curriculum development programs focusing on understanding and communicating with people of different cultures and on other aspects of



humanizing medical education. Other students are interning in programs that serve new immigrant populations.

Other field placements this spring point out the arenas of advocacy that should be of increasing concern: an Institutional Review Board of a teaching hospital that reviews research proposals involving human subjects; a mental health facility that does clinical work with young children and is also producing educational materials; a breast cancer outreach program that is specifically looking to reach an underserved southeast Asian population; a hospital ethics program; the quality improvement program of a large multi-service behavioral health provider. Students who have never done direct patient-centered advocacy work in hospitals still do one of their placements in an inpatient setting, and this semester these include emergency room patient representation as well as work with a woman's oncology service.

Health advocates are, in addition, particularly aware of the impact on consumers of a new and powerful genetic paradigm based on an explosion of new genetic information. Some of our students are doing dual master's degrees in Health Advocacy and Human Genetics, and others are taking selected courses in human genetics to be more effective advocates regarding genetic issues. There is recognized need for oversight and protection regarding genetic testing, particularly around informed consent, privacy issues and potential discrimination.

It is a sad irony that in this era of advocacy, at the same time that there is a literal explosion of opportunity for patient advocacy and health policy advocacy, the area that is struggling is the inpatient based patient advocate in hospi-

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tals. Hospitals are in a continual state of cost-containment and budget-cutting. For many hospitals, patient representative services are considered "non-essential," and thus are frozen or even cut. As patient advocates we know that even if the hospital does not feel that having a professional advocate available to stand up for the patient in the hospital setting is essential, the hospital should know that it is good business.

There are some moves afoot to advocate for patient advocacy in the hospital. One is a discussion of certification, which many hospital-based patient advocates feel would be important as a public statement that patient advocacy involves certain professional competencies that are a critical part of patient care. A second route would look at legislative and regulatory avenues to ensuring that hospitals provide patients with advocacy services. Graduate Studies at Sarah Lawrence College has begun to look at ways the graduate programs can provide continuing education to professionals in the field. Health Advocacy expects to be in the forefront of this educational direction at the College. We have already provided this kind of educational experience to Patient Representatives at the Veteran's Administration, and are discussing the continuation of this program. Mike Smith will be giving a full-day workshop on research methods, statistical analysis and using SPSS for health professionals, particularly genetic counselors, this spring semester. And we are planning other educational programs for people in the field. Watch our web pages for more information: <http://www.sl.edu/~health>.

As usual, I look forward to hearing from you. Give me your ideas on any of the above—or any other area of health advocacy that interests you. And when you call, say hello to Crystal Greene, our new Health Advocacy secretary. She comes to us from Westchester Community College where she helped set up the career services database and counseled students on college transfers and careers. It's been wonderful working with Crystal this semester. If you are fortunate you will get to meet her as well.

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Spring Placements

Ah, spring. That time of year when thoughts of HAP students turn to ... placements! Many first-year students are busy interning this semester in hospital settings, generally working as patient advocates. Jennifer Johnson is interning under Director of Patient Relations Gretchen Harris at St. Luke's-Roosevelt in New York City. Theresa Foster joins Ellen Martin, Director of the Patient and Family Relations Department at St. Vincent's Hospital and Medical Center, also in the City. Anu Philip is working under the Director of Patient Relations at Long Island Jewish Medical Center in New Hyde Park. Linda Twomey is doing her fieldwork with Gerri Travali in the Patient Relations Department at Westchester Medical Center in Valhalla, New York. Barbara Winrich is working in the Patient Representative Department at Beth Israel Medical Center in the City.

Others are interning in hospital or medical school settings, but in different arenas of advocacy. Claire Baney is working under the Institutional Review Board Coordinator at the Hackensack Medical Center-Institute for Biomedical Research in New Jersey. Cathey Bienkoski is working on a project related to humanism and medical education under the Director of the Office of Medical Education at the New York University Medical School. In another internship related to medical education, Jody Harris is at the Center for Multicultural and Minority Health at Weill Medical College of Cornell University. At St. Vincent's in NYC, Allison Sole is working under Daniel Sulmasy, Chair of the Department of Ethics. Caroline Greenleaf is completing her internship at St. Rita's Center for Immigrant and Refugee Services, a community center serving Asian, East-

ern European and African refugees who have settled in Queens. Linda Mahoney, who has a background in both nursing and law, is working at the office of the General Counsel of Continuum Health Care. Monica Malakar is doing her first placement at Encore Plus, a national cancer outreach and health advocacy program for low-income minority women, run locally out of the YWCA.

Placements of advanced students this semester are even more varied. Barbara Belhumeur is interning in a new Breast Cancer Center at St. Joseph's Health Services of Rhode Island. Betti Weimersheimer is working under Diane Clarke, Director of Patient Relations and Volunteer Services at New York Presbyterian Hospital's mental health facility in Westchester County. Sharon Chase is interning in quality improvement and evaluation research with F*E*G*S, the country's largest nonprofit health and human services organization, which has a major focus on behavioral health. Ellen Peck Falin is continuing work on the health needs of the rural elderly at the Center for Economic Development at the State University of New York at Oneonta. Lexi Mays-Engler is doing her final placement with the Connecticut Nurses Association, with an emphasis on policy issues. Melissa Haller is pioneering a new internship for health advocacy students with the editorial offices of the magazine *Managed Care Interface*. And Lois Steinberg is completing her fieldwork at FRIA (Friends and Relatives of Institutionalized Aged, Inc.) in lower Manhattan where she has been building a coalition to work toward passage of the Family Health Care Decisions Act in New York State.

Good luck to all our students in their new placements!