

Director's Desk

by Marsha Hurst, Ph.D.

"I think now what was most important was not what I chose to do so much as that I was conscious of being able to choose, and having chosen, was empowered from having made a decision, done a strike for myself, moved."

— Audre Lorde, upon making a decision to have a mastectomy.
The Cancer Journals, 1980

I stare at the calendar these days in disbelief. So much to do, so little time. We have a wonderful group of students in the program, ten of whom graduate this year; and we have had an incredible demand for health advocacy education. The Internet, the print media, word of mouth, undergraduate advisors, and the turmoil of the health care system itself have led people to our gates. Our large entering class for fall 1999 will challenge the tidy boundaries of the Health Advocacy Program and occasion some creative stretching.

These incoming students reflect the vibrant mix of young people with a vision and seasoned adults with a mission that has become the hallmark of the Program. A health advocate, as most of you readers know, is an advocate in the gut. The most frequent phrase I hear in an interview or see in an application is, "I have been looking for a long time for a graduate program, not knowing which direction to take. When I found Health Advocacy, I knew it was precisely what I had been seeking."

In the Fall 1998 BULLETIN, I wrote about some steps HAP was planning to take to "educate professionals for a world of advocacy that encompasses many arenas." Let me give you an update on those steps.

HA II: The Position of the Health Advocate (see course description on our web site <http://www.slc.edu/pages/h/health/hacourses.htm>) is now concluding its first semester. As promised, the course covered the work of the health advocate from hospital to community health center to interest group to government agency. The faculty team drew on their own work in the field and networked to bring in exciting guest advocates. The course was "keynoted" by Ruth Watson Lubic, CNM, Ed.D, McArthur award winning maternal and child health advocate, who is now setting up a birth center connected to a

multi-service facility for families in Ward 5 in Washington, DC. [See sidebar for other speakers.] HA II will always be a work in progress, since health advocacy is a constantly changing field. Part of the next challenge of course revision will be how to reconnect the fieldwork experience — itself as diverse as the "positions" of the health advocate — to readings and class discussion. Alumnae/i will remember that this was a much simpler task when the health advocate was generally a patient representative and the students in the course were all doing hospital placements at the same time. But diversity of need and opportunity for the health advocate means complexity of educational design, so we will be focusing on this piece in our program development.

Program Outreach. This aspect of my work seems to have a momentum of its own. Although more and more people find us through the Internet, we have not made as much progress as we hoped in making our web site an advocacy resource (definitely on the front burner), but we have moved forward in other ways. Among our best outreach emissaries are our interns, who provide advocacy services while in training to many a staff-starved office, and, in the process, teach the organization that there is a graduate field of study in health advocacy. This year Pat Banta was selected in a competitive process to be a New York State Assembly intern in the Health Care Committee. She is educating Albany about HAP and HAP about the State legislative process. For the first time we had a student, Jill Prosky, interning in the Public Advocate's office in New York City. They wondered at first what this field called health advocacy produced; now they are asking for a regular supply. This summer Margot Eves and Christine Dyer will go to Washington DC, Margot to intern at Families USA and Christine to the Government Affairs office of the March of Dimes. Other students pioneered new internships in areas of their professional interest and also did placements in sites that have become regular training grounds for our well-qualified graduates. [See sidebar for 1998-99 placements].

We have also been encouraging students to attend conferences and professional meetings, not easy given the complexity of juggling work, school, family, and finances. We have, however,

been able to set up a fund consisting mainly of monies that are turned back to the program by guests who either cannot or choose not to accept our small honorarium. We have thus far been able to give some support to students attending the American Public Health Association meetings, an alternative medicine conference, a bioethics conference, and the upcoming National Breast Cancer Coalition advocacy training conference.

Based on the constant flow of e-mail and telephone calls from people all over the country asking for more information about the profession of health advocate, about our graduate program, and about health advocacy services, outreach is definitely happening. Many of you have seen the article in the February 1999 issue of *Working Woman* magazine listing patient representative as one of 20 "hot new careers." The article featured HAP graduate Laura Weil '94, currently senior patient representative at Beth Israel Hospital in Manhattan, and president of the New York State chapter of the Society for Healthcare Consumer Advocacy (SHCA). Since then, other reporters have inquired about health advocacy, some on the same search for "hot careers."

In March, HAP hosted a meeting of the NYS-SHCA chapter featuring Leslie Bank '85, who did a workshop on patient-centered billing, an aspect of hospital care extremely important to patients and families but rarely a focus of advocacy attention. We will also be teaching a special one-day session (October 11) at the Annual Meeting of the National Society for Healthcare Consumer Advocacy in Toronto [see box]. This will enable advocates from around the country who are working primarily in hospital-based advocacy to experience the broader context and content offered by graduate advocacy education.

Advocacy education at Sarah Lawrence College. As promised, the Human Genetics Program and the Health Advocacy Program are working on ways to (1) offer a joint program to more interested graduate students, and (2) collaborate on events and educational experiences that explore the intersection of genetics and advocacy. Interest from prospective and entering students, as well as the rapidly growing body of genetic information with ethical, legal, social and personal consequences, is a source of encouragement, if not downright pressure for us. A number of students entering HAP this coming fall have expressed an interest in doing joint work with Human Genetics, and we are

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all agreed that consumer advocacy in this field is of increasing importance. HGP and HAP share a commitment to the importance of understanding the experience of illness, and an interest in exploring expressions of illness, including literary expressions. Together we went this March to see "Wit," the Pulitzer Prize-winning play about a poetry professor who is receiving experimental treatment for advanced ovarian cancer. We welcome any of you who have found particular works of art, writing, poetry or theatre to have helped you better understand the experience of illness to share them with us (use mail or e-mail).

This spring the Health Advocacy Program gave a course at Bedford Hills Correctional Facility, a maximum-security prison for women. Eleanor Scarcella '98 taught the Health Advocacy introductory course to a class of 15 undergraduates in the prison's College Bound program, with the help of guest appearances from other HAP graduates and faculty. The course was so popular the students have asked for a second semester, and we are looking into the possibility of Eleanor teaching a second HAP/SLC-sponsored course focusing on genetics and advocacy. Sarah Lawrence College helps educate inmates in other ways, including a writing program at a minimum-security prison, and we are pleased to be part of this work.

We are finding that the Health Advocacy Program has a great deal to offer the undergraduate College by helping to add an advocacy dimension to other areas of study. For example, as part of the search committee for an environmentalist to teach at the College, I am very aware of the importance of including advocacy in the environmental studies program, and, of course, the critical impact of environment on health. There are, in addition, undergraduate professors with expertise in other health related areas with whom we look forward to developing working relationships, in the classroom, through mentoring, or through shared interests and work. Linwood Lewis, a psychology professor whose interest in chronic illness in children brought us together last fall, found volunteer undergraduate field placements through a HAP student who is Director of Volunteers at St. Joseph's Hospital, Yonkers.

Ensuring skills proficiency. Students have saved me a great deal of verbiage here. For younger students, proficiency in basic computer applications, word processing, spreadsheets, databases, presentation software and Internet use is a given these days. Our adult students, however, have almost all moved quickly into this world, one that is so important in health care. The new computer classroom in the Sarah Lawrence College Library has been invaluable for holding application workshops. We have also encouraged students to use writing resources offered to graduate students to improve their writing skills. Health education and communication are even more important tools of advocacy as consumers realize that they can and must take a more active role in their care. Writing and presentation skills thus are central to the advocate's role.

A professional master's degree program always has to balance its primary goal of providing a high level of intellectual understanding of the field, including the broad conceptual and analytic perspective prospective HAP students seek, with the professional need for advocacy practice tools. This is a dynamic process as the health care field changes and the tools of advocacy develop. This spring we are offering mediation training to students and alumnae/i and a workshop on doing legislative research. The Evaluation and Assessment Course includes learning to analyze evaluation data using SPSS and understanding statistically-based research in the field. Many courses incorporate case study methodology, which is an important tool for health advocates, again one that connects theory and practice in the field.

Strategic Planning. As promised, the Strategic Planning Committee has been meeting all year to follow up on the report of the Advisory Board and review directions for the Program's future. A draft report is being prepared which reflects the first stage of the Committee's work: mission, short-term budget, curriculum review and expanding models of health advocacy education. I will be reporting on proposed Program changes



as the Committee's work is reviewed and discussed by our stakeholders (in the jargon of the day). In general, the thrust of curriculum changes has been to build some flexibility into our offerings to reflect the range of advocacy career directions and interests. The expanded models we are considering focus on ways to (1) offer continuing education to people out in the field, and (2) provide a distance learning component to prospective advocates who cannot relocate to the metropolitan area.

The growth in demand for graduate advocacy education keeps us constantly aware of our unique role. The dynamic pressure for growth is exciting, but like the advocate who can find him/herself putting on Band-Aids and never getting to address the cause of the wound, we need to use that pressure to see the larger picture, to act as the change agent: that is, after all, what advocacy means.

One last note regarding an unwelcome change. Mary Carroll, our secretary who has been the organizational guru, the students' true advocate, my mentor in learning the administrative ropes of the Program, is leaving the Health Advocacy Program to try retirement (again). We have our doubts as to whether Mary can survive without fully utilizing her wonderful office management abilities. We suspect, however, she can survive without the stresses of cramming the more than full-time work she does for Health Advocacy into the part-time hours she would prefer to work. We wish her well and intend to keep her on a tether for occasional emotional and practical support.

Special congratulations to our ten 1998-99 graduates. I look forward to your careers as health advocates, and your active involvement as HAP alumnae.