

Director's Desk

Late in April Arthur Frank, Professor of Sociology from the University of Calgary, was our guest in the Health Advocacy Program. Art's main work has been on illness narratives, his own in *The Will of the Body*, and the illness narrative as a "story" that helps us understand the experience of illness in *The Wounded Storyteller*. At the end of Art's seminar with the Health Advocacy class he talked about how he understood the relationship between comprehending the "story" of illness and being an advocate.

We can understand the story of illness as a "restitution" story, one in which illness begets diagnosis begets treatment begets wellness. This story is very focused, goal-oriented and complete. The advocate's role implied by the restitution story is also very focused: get more people diagnosed, earlier, more access to treatment, more effective treatment, more funding for research, more of the good things that bring successful endings to illness narratives.

Or we can understand the story of illness as either a "chaos" story, in which the narrator cannot make any sense of her illness, or a "quest" story, in which the storyteller experiencing illness is on a search for the meaning of the experience, as well as for the cure for the disease itself. If the narrative of illness is understood in this more complex and less complete way, the advocate's role is also broader. As advocates we need to truly hear the illness narrative, be willing to experience a transformation in ourselves when we empathize with the suffering of another, and be prepared to advocate for change in any or all of the institutions and systems that provide care for the sick and dying in our society. The reason, said Art, for an advocate to get an education grounded in the liberal arts is to be able to truly "witness" the illness narrative and move from that narrative into the many and interrelated arenas of advocacy to which the story may lead.

This distinction between the "tunnel vision" school of advocacy, which is very focused, but very narrow, and the broader understanding of the advocacy role has been on my mind recently. The Sarah Lawrence master's program in health advocacy is deliberately grounded in the liberal arts, with a commitment to a broad and interdisciplinary

education for people who intend to advocate for patients, families, consumers and the silent sick or unheard ill in society. We see advocacy not as one task, nor as one position, but as a complex of roles that we can play in many different actual positions in healthcare. Advocacy is a perspective, a way of understanding and a call to action.

This difference was brought home recently by the contrast between two events I attended: the National Breast Cancer Coalition's (www.natlbcc.org) annual advocacy conference and a presentation to the Health Advocacy II class by Maggie Hoffman, co-founder of Project DOCC, a training program for doctors that focuses on the impact of chronic illness and/or disability on families. NBCC is a very effective national advocacy group that has become a major voice for women by focusing on one disease with very long tentacles. NBCC uses the force of the restitution narratives of thousands of women with breast cancer to target specific policy priorities and lobby for more research and better treatment. Project DOCC is a small, locally-based grassroots advocacy group with a goal that is more of a concept than a specific target: they aim to shift the thinking of medical professionals from the hospital to the home, from specific diseases to whole individuals, from individual patients to whole families, from medical interventions to life supports. The stories of parents of chronically ill and/or disabled children are "messy," and Project DOCC tries to teach physicians to really hear a quest or even a chaos narrative in these non-linear accounts.

This question of which story we hear and how it frames our advocacy roles raises a core issue in the movement to credential or "certify" patient advocates. Spelling out the competencies required in a particular advocacy role or position is a way to ensure that an advocate is qualified and knowledgeable, but it also implies that the knowledge needed in a particular role or position has definable boundaries. Perhaps we need to think of a professional health advocate as having three layers of "credentials." One layer would encompass the broadest vision with the most depth. It would consist of analytical thinking, of wise judg-



ment, of clear problem-solving — and underpinning all this would be the ability to "witness," to truly hear the patient's narrative.

The second layer would consist of the competencies an advocate needs in any setting — for direct advocacy, for example, these would include ensuring rights, providing "navigation" assistance, mediating, facilitating, communicating, connecting, coordinating, educating, supporting and so forth. The third layer would comprise competencies — information-based knowledge areas — specific to certain kinds of positions, for example, an acute care hospital, a community health setting, a voluntary association. I am now involved in efforts to think through some of these issues and look at competencies in two different areas of advocacy. The New York State Society for Healthcare Consumer Advocacy (www.nyshca.org) is drafting core competencies for the patient advocate (see page 19). And, encouraged by the new opportunities for patient advocates in other settings, and spurred on by the exciting new fellowship opportunity for a health advocacy student (see page 15), I asked a group of cancer advocates* to help craft a description of the role of the patient advocate in a clinical cancer care setting.

As I continue work on this important area of professional development I am mindful of some of the pitfalls of this approach. We must recognize that our own concern with competencies is part of a larger societal emphasis on standardization and credentialing. After 125 years, even the American Public Health Association is moving toward public health credentialing. We read about this

*Karleen Habin, RN, Clinical Coordinator for The Center for Women's Health's Comprehensive Breast Center at University of Massachusetts Memorial Medical Center, Barbara Belhumeur and Marty Mancuso, HA '00 and Barbara Winrich, HA 01, who will be the first professional advocate hired in the U Mass Breast Center.

Core Competencies Document Authors Seek Input

For some time now, health advocates have considered the notion of credentialing as a means of indicating mastery of certain core competencies needed to do advocacy work. HAP director Marsha Hurst has been working with Ruby Greene, president of New York-based RHG Consulting Services, to develop a document that defines such core competencies and might be used as a basis for credentialing efforts.

Marsha and Ruby, formerly a patient representative at Long Island College Hospital, have drawn up an extensive list of competencies the health advocate should possess. Among them are knowledge of bioethical theories and applications, knowledge of relevant regulations, legislations, and professional and institutional standards, conflict manage-

ment/dispute mediation skills, and cultural and linguistic sensitivity.

Other essential competencies the two have identified are communication skills, the ability to be a health educator, management skills, and problem identification and solving skills. The draft document also calls for advocates to have an understanding of the experience of illness from the patient's perspective, the conditions that affect a community, and current payment issues in health care. In all the authors have identified nineteen broad categories of competencies; many of these are broken down further into subcategories.

Marsha and Ruby will present their paper on core competencies to the membership of the New York Society for Healthcare Consumer Advocacy at the

group's annual meeting on June 8, 2001. Members in attendance will have an opportunity to review the draft document and to propose revisions. HA Bulletin readers are also invited to submit their comments on core competencies and the credentialing process. To review a copy of the draft document, email Marsha at mhurst@slc.edu. ■

HAP Speakers 2000-2001

The Health Advocacy Program continues its tradition of hosting thought-provoking extracurricular lectures and discussions. Featured speakers this past academic year include the following:

Ruby Green, M.P.A., President, RPG Consulting, Inc., spoke on "The Protection of Human Research Subjects in Clinical Research."

Vikram Khanna of State Health Policy Solutions, LLC, addressed "Clinical Trials as a Public Policy Challenge."

"Deafness: Disability or Culture?" was the title of a panel presentation by Abbey Berg, Ph.D., professor of speech & hearing at Pace University; Maryrose McNerney, MA, CCC-A, Director of Audiology Services at HUMC for 20 years; M. Katherine Oelrich, MS, Certified Genetic Counselor, Department of Biology, Gallaudet University; and Sandee Weintraub, parent of a 10-year-old deaf boy and for the past 5 years president of the Alexander Graham Bell Association for the Deaf (NY).

Meg Walsh, CEO of Oncology.com, spoke on the rapidly changing field of ehealth.

Jessica Yu, Oscar winning filmmaker showed and discussed "The Living Museum," a documentary about Creedmor Psychiatric Center. Ms. Yu also visited Marvin Frankel's class to show and discuss "Breathing Lessons," her Oscar winning documentary about Mark O'Brien, poet & journalist, and his life in an iron lung.

Maude Blundell, M.S., Genetic Counselor, Rockefeller University Hospital, discussed "Ethical Issues Within the Mentally Ill Population." ■

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movement every day in accounts of the seemingly inexorable march of standardized testing through our school systems. Just as teachers can find it professionally demeaning to teach to the standardized test, so can it be demeaning to health professionals to have their professions reduced to an enumerated list of requisite skills and the knowledge of specific bits of information.

This means that credentialing both raises and lowers the status of a profession. If a profession is identified with certification, and certification rests on specifiable competencies, is it truly a profession, or is it merely a trained workforce? Outlining competencies and using them as a basis for certification can help insure an appropriate standard of knowledge among those who work in a field, but it also enables others to become managers of the work.

If certification is to mean more than a set of specific skills or a bounded body of knowledge, the key is in that first layer of the credential. When the medical profession consolidated, raising its standards and its status (remember the Flexner report of 1910?) the leadership concentrated on education: rather than outline what a doctor should know, they focused on how a doctor should acquire

knowledge. Lawyers and doctors must pass information-based qualifying examinations in order to practice, but they may not sit for those examinations without first being educated in how to understand law or medicine and how to think in that discipline.

It is our goal at Sarah Lawrence to educate health advocates. Their education must be broad enough to enable them to truly hear the illness

narrative and move from that narrative into the many worlds of advocacy in which they can make a difference. The Health Advocacy core course works with a model of concentric circles that illustrate advocacy as change—from its direct impact on the individual patient to its impact on health care provider institutions, communities, social systems and societal values. The health advocate moves between these levels mentally, even when her job is to work in a very targeted area. As we consider how to strengthen the skills that enable us to be expert advocates in a targeted area, I want to make sure we also strengthen that intellectual scope, because advocating in those larger arenas is what gives our profession the potential to change society—for the better.

—Marsha Hurst