

# HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

VOLUME 8, NUMBER 1

SPRING 2000

## Three Decades of Organizing: Observations on the Future from the Past

By Terry Mizrahi, Ph.D.

**M**uch of social work at the end of the 20th century has a “back to the future” ring to it. “Community” is back in vogue, as a context and as method and level of intervention. Those of us who began our social work careers in the expansionist era of the 1960s saw community organizing grow within and outside of social work. Yet even then, while it seemed like the place to be, exciting, romantic even, it still represented a small place and minority position in the profession in spite of the rich tradition in which it was embedded. The schisms between clinical and macro level interventions were there even in the friendly times, when it felt like the community organizing/social change perspective had a disproportionate influence on the field, given the relatively few students, faculty and schools with such concentrations.

As the political climate began to shift (and it has been moving to the “right”

ever since), the flourish of visible social work activism in schools of social work and in social work agencies quickly diminished. Community organizing was replaced at first with a shift to planning and policy in the 1970s. Then, by the mid-1980s (with a few exceptions), it almost disappeared as a major area of curriculum and career path, or was submerged within a more constricted administration/management or “macro” track. During this same time period, social work activism was primarily geared to creating a profession, modeled on law and medicine. Its goal, to gain control over the organization, structure, and relationships with clients, saw some measure of success in law and regulation at the federal and state. Currently however, managed care is stifling the autonomy of all clinical professions, including social work.

Beyond the historic marginalization of community practice within the dominant professional social work paradigm, the community organizing component of so-

cial work has been largely ignored by or is unknown by the greater world of social change, where most community organizers, advocates and policy change agents are not social workers. In that sphere, social work has been either identified with a clinical/mental health career or with the public child welfare and public assistance sector. At best, social work has been viewed by progressive social change groups as helpful in its counseling role, and at worst, as a social control agent for an oppressive society.

My introduction to social work in the 1960s was through a volunteer experience during college in a settlement house in New York City, where grant and local government initiatives focused on improving the conditions of housing, schools, welfare, the courts, and hospitals for low and moderate income New Yorkers. The model of service then was “case to cause to case,” without necessarily labeling it as such. There was a feeling that doing for oneself was inextricably intertwined with doing for others. It appeared that people participated in community activities to better themselves and their neighbors.

Staff at that settlement house were both committed and competent; they were about providing services, but they were also about “empowerment” of disenfranchised and marginalized people and groups. There, it was white ethnic poor and working class constituencies of all ages who needed voice and visibility. The settlement created programs and structures inside and outside its doors for that to occur. “The personal is political” is not just a slogan; it translated into the context and process of the work I began to do then. Reciprocity was the watchword; there seemed to be a recognition of the mutual benefits to be derived from doing for others. We were practicing a “strengths” perspective before it was formally conceptualized. The recent re-

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# From The Editors:

As pioneers in a new field, health advocates are still defining their roles and responsibilities, as well as the education they need to do their jobs. In the broadest sense, health advocates are all who take action in support of patients and their families. This inclusive definition reflects the reality of our fragmented health care system, in which it is necessary to maneuver through many points of contact.

The list of those who can and do act as advocates is long. Doctors, nurses and other clinical professionals, teachers, social workers and therapists, journalists and writers, development experts and PR firms, employees of local, state and federal agencies, attorneys and lobbyists, police and court officers, and patients and families, may perform advocacy functions.

Social workers have responsibilities that often require them to act as advocates. In this issue we focus on social work as advocacy, with a lead article by Hunter College and Sarah Lawrence College professor Terry Mizrahi that takes a sweeping macro view of thirty years of pro-active social work. Advocate and social worker Denise Arieli gives us the micro view with her profile of one Native American mother in New York who was forced by her child's grave illness into becoming an advocate. In future issues we will highlight the work of other professionals who function as advocates.

Of course, many advocates are, or once were, or will be, patients or family members themselves. From the need to fight for their own rights, people develop the skills necessary to advocate effectively for others. Because the patient's perspective is of such central importance to advocates, the *Bulletin* is pleased to announce the inauguration of a new feature called "The Patient Eye." We begin the series with a first-person account of "what it's like" by a patient with a very serious condition, our co-editor Karen Martinac.

With this issue we are extremely pleased to welcome Deborah Hornstra as new co-editor of the *Bulletin*. We send our profound thanks to former co-editor Irene Selver for her three years of dedicated service to this publication, and our best wishes to her in her new position at Gay Men's Health Crisis in New York.

We are thrilled to be associated with what we hope will become an increasingly valuable publication in health advocacy. Please contact us at any time with story ideas (your latest project, perhaps?), and drop us a line if you know anyone we should ask to write for "The Patient Eye."

— Karen Martinac and Deborah Hornstra

# HAP Goes International

A team of HAP faculty and former students gave a well-received workshop at the 28th annual meeting of the Society for Healthcare Consumer Advocacy last fall in Toronto, Canada. About 35 people attended the optional one-day session, where they heard presentations by program director Marsha Hurst, Terry Mizrahi, Alice Herb, Rachel Grob and Deborah Hornstra. Herb and Hornstra also headed breakout sessions the next day in ethics and the Internet, respectively. A list of advocacy links used in the Internet session is posted on the HAP website at <http://www.slc.edu/~health/Torontobookmarks.htm>. Audiotapes of all sessions can be ordered on the SHCA website at <http://www.shca-aha.org>.

The all-day workshop was designed to acquaint professionals in health advocacy with master's level learning and to introduce them to current critical issues in health care policy and organization. The presenters also sought to further the group's understanding of the use of advocacy tools and techniques, including new media, for solving problems at the individual (case), collective and institutional levels. The ultimate goal of the HAP crew was to get the participants thinking of themselves as core change agents in their communities, agencies and institutions.

Over 200 health advocacy professionals, most of them hospital-based patient representatives, attended this year's SHCA conference. The Toronto setting insured a larger-than-usual number of Canadian participants, which made for lively discussions of differences between the health care systems in Canada and the U.S.

The Society for Healthcare Consumer Advocacy was founded in 1972 as the National Society for Patient Representation. A personal membership group of the American Hospital Association, SHCA has over 1000 members — not only patient representatives but also physicians, nurses, social workers, and others employed in hospitals, health maintenance organizations, home health agencies, long term care facilities and other health-related organizations. For information on their 2000 meeting in San Antonio, Texas, or to join the organization (individual rate is \$125/year, group discounts are available), visit their website at <http://www.shca-aha.org>.

<http://www.slc.edu/~health>

The HEALTH ADVOCACY BULLETIN is published twice a year by the Health Advocacy Program at Sarah Lawrence College, One Mead Way, Bronxville, New York 10708.

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# Searching for Grace: The View from Inside the Cage

By Karen Martinac, M.A.

**A**ren't you grateful to the doctors?" a friend inquired over the telephone. Moments went by while I sucked in my breath. Grateful. Grateful. . . The answer finally slipped out. "No. At least not yet."

It seems as if one is supposed to feel grateful. After all, I *am* still alive, not at all a sure thing before a cervical spine fusion a few months ago. And the numbness and clumsiness in my arms and legs is receding. Nearly gone, actually. I'm alive, I'm not paralyzed, I have a safe warm place to live. I should be feeling grateful. And I am, to my own stout heart and power to heal. But – to the doctors?

The truth is, it's damned difficult to feel grateful when there are four pins bolted into my skull, my entire upper body is encased in metal and plastic diabolically called a "halo," so heavy I cannot right myself from a lying position and sufficiently ill-fitting to not allow my back to straighten when I stand (doctors do not care: one size fits all and it's not *them*). It's difficult to feel grateful to people who decide I will wake up on a ventilator and be taken off all medication so we can all be sure I can breathe, but who don't tell me any of this before, during or after. Difficult to feel grateful to doctors who tell me at 7 a.m. that my 12-hour surgery of the day before went perfectly and return a few hours later to say that actually they think I need another procedure and want an MRI right away and my ICU nurse is on the phone fending off Radiology and explaining that I cannot *be* in Radiology right now because I haven't even been extubated yet. Difficult to feel grateful to a surgeon in whose hands - and ten years experience – I have placed my life but except

for the surgery itself leaves me in the charge of a fourth-year resident and is inexplicably content to rely on second-hand accounts of my recovery.

And yet, there is the looming importance of acting grateful - and cheerful - regardless of how one really feels, even if one feels absolutely terrorized by medical procedures "they" consider "help," and has no idea if the universe is even going to allow one to live in any manner one could consider acceptable. What does one do with so much fear? Fear, not of dying, but of what living may require. To be cranky, even hostile, is, to a totally dependent patient, to risk an equal reaction, even abandonment, by the caretakers. Unacceptable risk. To encapsulate the fear, as an oyster protects itself from a grain of sand, to surround it with layers and layers of preferably iridescent conversation, curiosity, humor and "courage," seems the only safe course. But the effort is monumen-

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But – to the doctors”*

tal, prone to breaking down into tears or anxiety attacks. No wonder periodic retreat into Valium or a morphine drip seems a welcome respite from the effort.

I *am* grateful to the competent, caring nurses (not the ones who couldn't bother because the shift ended in five minutes), the world-class surgeon/department chairman/human being who's known me for 20 years and came to see me every day (including Saturday) even though I was not "his patient" (not the neurosurg resident who conducted a

shouting turf war with an ortho resident over my head in the ICU), to the friends and family who stuck close by and watched out for me, to the MRI tech who stood up for me (not the radiologist who said halo pins were not supposed to heat up in the machine and burn the patient's head and to "do it again"), to the medicine doctors for their patience and daily care, for all the random kindnesses (not pity) that came my way.

I am grateful for the strength and wherewithal and just plain orneriness to insist on what I needed, or would not allow, in a situation where disaster loomed everywhere (staying alive in a hospital is no mean feat). And for the determination to preach to all of you advocates out there: when you need to deal with a cranky patient – look around, maybe the patient is entitled, and it's your job to see that he/she's not penalized for that. And next time you start to say that he/she/they/it is "just here to help you," consider how that "help" might look to the patient. Modern medicine can be pretty brutal. Can you put yourself in the bed, in the halo, in the wheelchair, in the heart and mind of a person living, or trying to live, with a serious problem? Can you always remember, no matter what else interferes – and plenty will – that the first face of advocacy is human? Even I as a patient sometimes had trouble remembering that there was a person inside all the hardware: it just took so much effort.

Maybe, when some of the fear has retreated, and I get over feeling tortured, and am better adjusted to living with a permanently stiff neck (which is more complicated than you think), and maybe come to terms with feeling so appalled and angry at my attending surgeon who was capable of reconstructing a collapsing neck but not of understanding his own power over his patients, maybe I can thank "the doctors" for saving my life.

*Karen Martinac, HA '89, is co-editor of this publication.*

# Three Decades of Organizing

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newed interest by settlement houses and other social service agencies in “community building” is a recognition of a need to return to their roots, albeit reconfigured to fit these times.

“Mobilization for Youth,” the first comprehensive government initiative to combat juvenile delinquency and the forerunner of the anti-poverty programs, also came into being during the early 1960s. I was a graduate social work student doing field work then, and I got another taste of moving from the individual to the group to the system and back again. While there were tensions even then about whether MFY’s goals, and indeed those of the whole movement, were the promotion of individual or group mobility, the solutions for achieving “equality of opportunity” seemed simple. Bring people together and they would articulate their needs and problem-solve. Provide cogent arguments for the need to improve conditions and those in power would acquiesce. Expose unjust policies and they would be changed. Document the environmental obstacles that prevented people from being all that they could be (i.e. from “maximizing their potential”), and the system decision-makers would stop “blaming the victim.”

Obviously, it wasn’t then and isn’t now that simple. But in my view, there were some important differences then that one cannot take for granted 35 years later; first, government, especially at the federal level, was more friend than foe (it was viewed as part of “the solution,” rather than part of “the problem”); second, public and foundation funding and other resources to carry out local organizing and planning were available with seemingly fewer restrictions and caveats; third, a philosophy that services and empowerment were connected translated into formal program guidelines.

There was also a strong belief back then that doing with was better than doing for—a change from the traditional social work health and welfare planning council model of the 50s. Indeed, a major ideological construct of the 60s was client/resident/community participation (depending on the locus of intervention), in formulating agency and public policies, in developing and implementing services, and in evaluating programs. “Maximum feasible participation of the poor” was not just a requirement of the Economic Opportunity Act of 1964: it

became the ethos of the liberal ideology of the 1960s; that is, a belief that political involvement and equality of opportunity would end poverty. The demands for community and client inclusion, supported by many progressive bureaucrats, resulted in formalized mechanisms for heretofore disenfranchised people to participate in the programs that affected them and their communities. Voting rights was only the first step toward enfranchisement. Community control, neighborhood power, and welfare rights, were demands that ultimately brought people from the outside to the table.

Indeed, by the time the 60s ended, almost every government entity had created a structure, and at times a formula, that mandated some form of structured participation. Social workers were part of those movements and many were hired to implement those guidelines. New careers in organizing and planning were predicated on participatory and advocacy planning models, with multiple goals: giving a formal voice to the disenfranchised in their roles as tenants, parents, patients, service recipients, members of racial and ethnic minority groups; developing or improving programs that better met their needs; and positioning clients for jobs that led to educational and economic mobility.

The debates then and now in the community organizing, planning and development fields (both inside and outside social work) have been between those who saw the demand for and subsequent development of participatory structures as inherently coopting and ineffective, and those who saw them as the “solution” to disempowerment and disaffection; between those who saw the need to build client run organizations or alternative agencies/services and those who saw protest and mobilization as the way to gain benefits and empower groups.

Monitoring existing institutions and holding those with the resources and authority to provide services accountable continues to be the agenda of organizations and coalitions seeking equitable and quality services for society, be it schools, housing, hospitals and health care, the environment or the workplace. These groups are not willing to let those who control the major service sectors off the hook. Sometimes that has meant pressuring for a reconfiguration of their priorities or a reallocation of their resources.

Other times that has meant taking over those structures; and still other times, it has meant staying away from them and creating alternative programs. Professional community organizers and planners, including social workers, have worked with all three configurations.

Those professional community organizers including myself, who have helped groups gain visibility and a collective voice, recognize how essential it is to have knowledgeable and committed people working on the inside and outside. Yet, we understand how difficult it is to keep the momentum going on the outside in order to be effective on the inside. However, it is a visible organized presence from the community outside that creates pressure on the allies who work for the system they’re seeking to influence. This then bolsters their position and provides a constituency necessary to justify needed changes. At the same time, it is difficult to keep up the momentum for fundamental change from the inside alone, given its incremental, negotiated, and potential coopting nature.

Social workers in “macro” planning roles have served in roles on the inside and outside, and have also initiated alternative models to traditional health, housing, education and human services in a variety of positions. Sometimes these were developed in traditional non-profit agencies; others were created by planning and coordination bodies, and even occasionally by protest organizations who acquired resources to develop alternative programs. Yet, without a recognition of the different, but connected roles of those on the outside in advocacy or program development roles and those on the inside, a “divide and conquer” strategy is more easily utilized by those opposing change. For example, most of the directors of the 42 social change organizations studied by Mondros and Wilson, organized from a single ideological and strategic perspective, ignoring or opposing others, often to their detriment.

The role for community practitioners today is in making those connections between the inside and the outside, and recognizing that while working in one sphere, others need to be working in the other. It’s not an either/or situation. Some groups make the transition effectively from “adversarial” (outside) and “advisory” (inside) advocacy; others

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need to remain in their original roles, supporting and challenging when necessary those who move into the inside roles. Social workers in alternative service development are also needed to prefigure a more just and open society, recognizing that models alone, without an organized political constituency, won't guarantee that policy makers share power or restructure policies, priorities and programs. Social workers in grassroots organizing, in coalition-building, and in planning and program development are all essential. While macro curricula include the strategic application of different models, greater attention needs to be paid to evaluating interventions and outcomes of community.

First, this is a time of deprofessionalization in US society, promoted by political and economic leaders who extol the virtues of the marketplace, and implicitly or explicitly criticize professionals (be they teachers, physicians, or social workers) for both their ineffectiveness and protectionism. Professionalism as an ideology indeed attempts to create a monopoly on a set of roles and functions, to the extent that there is agreement on what those encompass. The elitism inherent in any organized group, even those that perform an important societal function (i.e. healing), without public scrutiny, is bound to engender distrust. This was most clearly demonstrated in growing criticism of organized medicine by patients, the public, politicians, and other professional groups in the 1960s after this quintessential profession had gained complete control over the education, organization, licensing and financing of its work.

Today, the challenges to professional hegemony which had come from liberals (inside government) and the radical left (outside government), are coming from the political and economic "right." All professions today are experiencing the usurping of clinical judgment and competence by outsiders. Managed care and other insurance corporations impute the very essence of what it is to be a professional, that is, the claim to a unique constellation of knowledge, skills and values of benefit to individuals and society. The outsiders who work for external funding and oversight organizations are removed from the clinical situation and setting and often do not possess appropriate professional specialization or

credentials to evaluate practice.

Second, accompanying deprofessionalization is the downsizing and deregulation by government at all levels. The US has moved far to the "right" since the 1960s, politically, ideologically and economically. This is not just a time of devolution, i.e. the transfer of responsibility from the Federal to state and local governments, but an abdication of responsibility by government to meet human needs by limiting resources and entitlements, and lowering expectations about what government can and should provide its citizens. And this includes the Clinton/Gore administration, not just the traditional Republican conservatives, as evidenced by the former's signing into law and implementing the Personal Responsibility and Work Opportunity Act of 1996, which replaced the 50-year-old social entitlement, Aid to Families with Dependent Children.

Third is the concomitant move to privatization — by many of the same government and political leaders — who point to both the marketplace (corporate "profitization") and charity (volunteerism) as the venues to meet human needs.

Corporations are dominating health and human service industries, and limiting our view of the public domain to an extent barely anticipated in 1980 when President Reagan took office.

Where government funding or oversight is still in the picture, it appears to be contracting with corporations and other proprietary entities; the latter sector assuming a greater role in education, health care, corrections, and child welfare in many parts of this country. One pervasive model moving forward under the banner of limited and inefficient government is vouchers, currently being promoted in a variety of areas: housing, education, social security, etc. At the same time, public service employees are being cut, and greater demands and restrictions are being placed on the contracted or funded non-profit, community-based agencies. Critics see this as a further erosion of public responsibility and accountability and a reduction of resources for basic services that disproportionately affects urban lower class African-American and Latino communities. Ironically,

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## Health advocacy on the little screen

**H**AP graduate Leslie Bank was the principal consultant for the patient relations video *STAT: A Prescription for Good Patient Relations*, available from The Greeley Education Company online or by calling 1-800-650-6787. The video sells for \$255 and can be previewed on the Greeley website at <http://www.greeley.com> (RealPlayer required).

Bank, who has been Director of Guest Relations at Greenwich Hospital in Connecticut since 1986, wrote most of the script several years ago.

Greeley developed an interest in producing training tools for hospitals, and hired a director/producer who used Bank's script on patient relations and problem resolution as a starting point. Bank was subcontracted to add several scenarios modeling various situations, as

well as a quiz on patient relations. She also appears in the video as an expert in the field.

"STAT is not everything I know about doing patient relations," Bank emphasizes, "It's only skin deep, but it presents useful simple constructs." The video includes segments on JCAHO's consumer complaint hotline, patients' rights legislation, and the U.S. Attorney's interest in quality of care and compliance. Bank has also written *Complaint Clinic* and *The Anatomy of a Complaint*, but hopes those are not considered sequels to *STAT*...

In addition to her full-time duties at Greenwich, Bank is a consultant and speaker in the area of patient-friendly billing, a topic on which she addressed the New England Healthcare Assembly last spring.

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many states and localities are assuming a greater social control role over people needing benefits and services in those same service sectors and in work-related welfare initiatives, replacing rehabilitative with punitive policies.

“Compassionate conservatism” is the late 1990s watchword of those Republicans who want to distance themselves from the extreme harshness of right-wing ideology epitomized by Gingrich’s Contract with America (1994), prevalent in the early and mid-1990s. The former group still espouses tax cuts, voucher systems, and limitations on entitlements, while placing greater responsibility and stress on individuals and families to do more, without appropriating the necessary resources and supports. Moreover, with the advent of market solutions to social problems, many non-profits are behaving like their profit-driven counterparts, competitive and concerned more about survival and expansion than about serving and advocating for needy populations.

The fourth trend that has resurfaced in this decade may counter or be consonant with the above mentioned trends, depending on political and economic consequences in the long run; namely, there is a concomitant expansion of interorganizational collaborations and partnerships as solutions to social problems, coupled with the revival of the call for citizenship and civic responsibility.

Supported by large foundations and some Federal agencies and their state counterparts, including the Departments of Health and Human Services, Education, and Housing and Urban Development, the thrust is to mandate that organizations representing various constituencies in a community come together to address social needs. Presumably, because various sectors have an interest in solving social problems such as infant mortality, substance abuse, teen unemployment, child abuse, housing and business deterioration, there are attempts to harness a range of expertise and resources to solve them. Moreover, the goals of many of these programs are to create local ownership and to build a unified community in the process.

If the progressive, yet pragmatic social planning and community organizing framework from the 60s and 70s is to have a meaningful impact on community, civic and client life into the 21st cen-

tury, there are several assumptions underlying these interorganizational and communitarian agendas that cannot be taken for granted. The complexities and contradictions created need to be acknowledged and addressed.

First, an assumption that clients/community residents are represented by the various organizational actors or themselves have formed their own organizations. In fact, rarely can individual clients effectively compete with people representing professional and organizational entities. Second, an assumption that definitions of the problem and solutions posed by the various constituencies (which now includes the business community more overtly), can be reconciled. To the contrary, ideologies shape those perspectives, and create value dissensus as often as consensus. Furthermore, an assumption that these various sectors of society have comparable influence in the decision-making process and structure. To be sure, a parent organization does not have the same clout as the Chamber of Commerce, even if both groups have “one vote in the organizational body.” Fourth, an assumption that it is more efficient, i.e. cheaper, to bring multiple groups together as opposed to funding multiple ones. In reality, it takes more skill, time and resources to calibrate all of the parts of a complex collaboration, although the process and product may be more effective in the long run. Fifth, an assumption that many of these initiatives are about creating and expanding resources rather than about the reorganization and coordination of existing resources. If resources are scarce to begin with, the strengths/asset-based model may not be enough to solve social problems. Sixth, an assumption that outcomes and measures for success are apparent, agreed upon, and value-neutral. At the very least, ideological, power and resource differences in the process of goal setting, and the criteria by which to evaluate goals, need to be recognized before they can be managed or reconciled. Finally, an assumption that democratic participation at the grassroots level by itself, regardless of the racial and economic composition of that community, is progressive and inclusive. Given the long history in the US of the various “isms,” inequitable, reactionary and protectionist NIMBY (“not in my backyard”) politics can be the result of increased civic

involvement.

The expanding number of students concentrating in community organizing, planning, policy and macro practice augers well for the growth of the macro end of social work. At the same time, there is also a need for systematic, profession-wide campaigns to position social work community practitioners in interorganizational and grassroots leadership careers. Greater promotion of the social work profession to the wider community development and advocacy sectors is essential so that they identify the BSW or MSW as a necessary qualifications for their positions. Promoting lateral and vertical career mobility with adequate compensation are also essential.

Community practice has had a rich and complex history within social work. In politically and economically conservative times, its role has been fraught with contradictions; yet, it tenaciously and creatively has anchored its place in and influenced the direction of the profession. As we end the 20th century and the first century of social work, hopefully we will emerge with the perspective that we must continue to focus on the individual and collective levels simultaneously. This is not at all to imply that the real world of social work practice requires a reductionist approach to a least common denominator, generalist framework, but rather requires the configuration of a series of highly competent, multiple and interconnected method specializations. Rather than conceptualizing our task hierarchically as moving from the simple to the complex, we could reconfigure it as a kaleidoscope, where every intervention shifts the pattern and creates a whole new vision of possibilities.

This is our challenge, our chance and our charge.

*Editor’s Note: A longer version of this article will be posted in full text, with complete citations, on our website at <http://www.sl.c.edu/~health>.*

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# Profiles in Advocacy: Irma Laguerre

By Denise Arieli, M.S.W., C.S.W.

*You can only teach what you need to learn.*  
— Anonymous

I arrive at the offices of Nitchen Inc., located on 164 West 100th Street in the Trinity Church, an old limestone structure over 100 years old. I gingerly begin my climb down its stone steps and into its belly, the basement. This is not as easy as it sounds, for the builders have inlaid the steps, mere cobblestone shards, horizontally and vertically to form a crisscross pattern. Visitors must descend cautiously, dipping first toe and then heel, or risk running out of real estate in which to land the foot. The whole process takes longer than I would have thought and as a result, I am late. The road to advocacy winds similarly. It is a day-by-day stick-to-it-ness marked by on-the-job learning. Results are the fruit of patience and persistence rather than any formal training or adherence to a prescribed technique. This story is a lesson in that.

In the spirit of full disclosure, I must confess that this is not my first exposure to Nitchen, Inc., whose name means "our children" in the Lenape language. The Lenape tribes are true native New Yorkers, miners who settled the land at the turn of the century, giving the region the moniker "Red Harlem." The organization was formed in 1994 by Yvonne Beamer and sponsored by the State Office of Mental Health to provide support services and socialization opportunities to families of Native American heritage whose children had medical, behavioral disorders, or were "at risk" for developing these. Today, the organization hosts the Family Awareness Network (FAN), publishes a newsletter, runs mentoring groups, and offers a variety of workshops. I know the organization well and consulted to them as part of my oversight function in city government. What follows is a profile of one of its founding mothers, Irma Laguerre, who is living proof that "you can only teach what you need to learn."

If you eat Mazola margarine, caught the last production of *The King and I* on Broadway or *Jun Darian* at Lincoln Center, you've seen Irma Laguerre as the

Indian girl on the package, the third principal, Lady Tian, and the star, respectively. A graduate of the Manhattan School of Music, her acting credits are impressive. But perhaps her greatest role is the one she plays in real life as the mother of a child with the rare metabolic disorder phenylketonuria (PKU).

It is ironic that the Nitchen offices and the majority of Irma's work would center around the Native American culture, since she had been taught upon her arrival in the United States to "blend in." A well-intentioned father, who knew the stigma that comes from being different, delivered this directive. Armando was an Aztec Indian who overcame his deafness to become a college professor in his native country of Puerto Rico. He married at age 50, late by conventional standards, taking Carmen to be his bride. In 1960, the family of ten emigrated and settled in a railroad flat in the Bronx, an apartment of long corridors and few doors. But despite the proclivity toward assimilation, all the children were encouraged to remember their heritage. The Nitchen offices bear out Irma's personal and the more generalized cultural contradictions of being a Native Indian and an American. Here, computers vie for space with earthenware pots. The fax machine competes with over-flowing plants, wool tapestries and pictures of Native American elders crowd out the public health posters, and boxes of her daughter's medicine share desk space with macrobiotic cookbooks.

Irma was a successful stage performer when, in 1991, she decided she wanted to be a mother too. Despite being considered a high-risk pregnancy due to her age, she continued to accept demanding roles. Eventually she developed anemia, pre-eclampsia (separation of the umbilical cord), and a slight case of edema. Her doctor, Allan Morris, put her on bed rest. Irma and the baby's father worried that her medical condition would affect the child and wanted to rule out any genetic conditions. So, aside from submitting to the usual battery of tests and sonograms, Irma devoted the remainder of her pregnancy to visiting genetic specialists as well. Her daughter's birth, though much anticipated, would be a difficult one marked by contractions but no dilation

and an epidural whose effects had to be reversed when it was discovered that the drug had stopped the contractions. After twenty-eight hours, on February 22, 1992, a baby girl, weighing 8 lbs. 11 oz. and measuring 22 inches, was born in Beth Israel Hospital.

Named for her matrilineal heritage and the spirit that kept her mother alive, Taina-Faith Laguerre and mother would spend the next four days in the hospital so that doctors, worried about the baby's skin tone discoloration, could observe. Irma recalled the infant as being "sweet and sleepy" but she grew concerned when Taina refused to be breast-fed. Nurses at Beth Israel assured the new mother that the baby was "normal" and at the end of the fourth day mother and child were sent home. They had been back barely two days when the Department of Health (DOH) called on a Friday. DOH told her that a routine test performed on her newborn child revealed a positive test for the disease phenylketonuria (PKU) and that her baby's levels were at seven, an indication of classic PKU. Their instructions were to take the baby to a specialized clinic at Bellevue Hospital first thing Monday morning. When Irma inquired about PKU, the friendly voice knew only to say, "It's some sort of enzyme thing." Seven years post-diagnosis and Irma's recollection is as sharp as ever. So too are its associations, which are vivid enough to produce fresh tears.

PKU is a rare genetic condition, an inherited metabolic disorder carried through an "autosomal recessive" gene. For a baby to be born with PKU, both parents must be silent carriers. But even in such a case, there is still only a one in four (25%) chance for each pregnancy that the baby will have PKU. PKU affects one out of every 10,000 babies born in the US and several hundred babies are diagnosed and put on diets each year. Newborn screenings for PKU started in the 1960's. Because early detection has been correlated with positive outcomes, screenings are now carried out throughout the fifty states and in many other countries. PKU can result in mental retardation and other neurological problems when treatment is not started within the first few weeks of life. The disease arises from the absence of a single enzyme, phenylalanine hydroxylase, that normally converts the essential amino acid phenylalanine to another amino acid, tyrosine. Failure of the conversion results in the buildup of phenylalanine, which could be toxic to the cen-

# Profiles in Advocacy: Irma Laguerre

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tral nervous system and cause the severe problems normally associated with PKU. Any child with a level less than 6/mg/dl does not need to be on a special diet and is not at risk for mental retardation. Not every child has the same degree of enzyme deficiency or needs the same strict dietary regimentation.

After reeling from the initial shock, Irma went into supermom mode. Over the weekend, she researched the disorder in her personal medical library, built up from her undergraduate years as a biology and psychology major. She also consulted with friends, and called her doctor. "Two words stuck out most," she recalls, "mental retardation." Well intentioned friends tried to reassure her that she had "nothing to worry about." On Monday, Irma chose one of the baby's godmothers to go with her for support. There she saw two premier metabolic disorder specialists, Drs. Snyderman and Sansariq who, anticipating her arrival, quickly whisked Taina away. Irma recalls waiting at the nurses' station for "what seemed like a lifetime." When the doctors emerged next, sans baby, her heart sank.

The next five days were an emotional roller coaster for Irma. She recalls her feeling of desperation exacerbated by the lack of scientific information, resources, or support from a well intentioned but detached medical staff. Next came waves of anger at the medical specialists, especially the geneticists she had seen during her pregnancy who had not alerted her to the possibility of PKU. (Though given her Native American heritage and family history, doctors had no reason to suspect.) Amniocentesis does not pick up genetic metabolic disorders such as PKU. As she cradled her baby in her arms, Irma recalled the anguish she felt as she thought how this baby's life could be lost. The next few days were spent in the hospital on a cot near her daughter's bed. Helplessly, she watched staff conduct "grounding" tests, blood tests that determine the child's phenylalanine levels. On the fifth day, with her daughter's arms full of track marks from the needles, it was confirmed that Taina did have PKU and that she would need to adhere to a strict dietary regimen consisting of two synthetic formulas: one for calories, the other for nutrients. "The doctors were good at answering questions," she re-

calls, "as long as I knew what to ask."

The diet for the most severe form of PKU eliminates all very high protein foods, since all proteins contain phenylalanine. Initially, for Taina, all concentrated forms of protein had to be eliminated. In general, the diet does not allow meat, fish, poultry, eggs, cheese, ice cream, legumes, nuts, or products containing regular flour. The diet is supplemented with special low protein foods (phe foods), which must be carefully weighed, or measured amounts of fruit, vegetables, and some grain products. Being a new mother is stressful enough, but Irma faced the next few months in a state of panic. Feedings were marked by a ritual of mixing, pouring, and carefully measuring the formula. In the first few years of life, it is critical to get the doses right. "I was a wreck knowing that an error at this point could be fatal," says Irma, who called the hospital to inquire whether a spoonful should be loosely or densely packed.

In the early days of PKU treatment, clinicians believed that the diet had to be maintained only for the first 6-10 years of life. It is now known that cessation could result in serious problems such as drops in IQ, learning disabilities, behavior problems such as hyperactivity and irritability, neurological problems such as tremors or eczema, and personality disorders. But due to advancements in detection and prevention, PKU has been downgraded to a condition rather than a disability. This reclassification has proved a mixed blessing. For example, PKU children are not qualified to receive disability payments as part of Social Security (SSI) even though

their condition is chronic and if left unattended, disabling. Aside from the vigilance involved around diet and nutrition, families must absorb steep financial burdens. Medical foods such as formulas and now bars average \$600.00 per month and medical visits could cost \$800.00 per month depending on the blood tests indicated. Despite her advocacy efforts and medical testimonials, Irma's application for SSI has been denied three times.

When it comes to formula, a number of states have mandated that insurance

*“Irma recalls her feeling of desperation, exacerbated by the lack of scientific information, resources, or support from a well-intentioned but detached medical staff.”*

companies provide coverage. In some states, The Department of Health provides formula. During the first year of diagnosis, Irma had health insurance through the Screen Actors Guild. She read her contract carefully and discovered a statement extending care in the case of a child born with a medical condition. Though this brought her some relief, her plan did not cover formula and later she discovered that many other claims were not paid. Unable to shoulder the financial burden, with her insurance exhausted, in 1994 Irma began taking on small acting roles. During this time, she was forced to borrow money, and rely on public assistance such as Women Infants and Children (WIC). While WIC provided coupons for food, including one of the two prescription formulas Taina was on, it did so for only



# Conversation with a Flavorful (Alice) Herb

by Deborah Hornstra, M.A.

Since 1996, the savory Alice Herb has been teaching Health Advocacy III, better known as Ethics, typically one of the last courses taken by students in the Health Advocacy program. HA III entails the sometimes contentious discussion of dozens of case studies in health care ethics. Many of the cases are drawn from Alice's own vast experience at the State University of New York (SUNY) Health Science Center at Brooklyn, commonly known as Downstate Medical Center, where she is both Assistant Clinical Professor in Family Practice and Associate at Law in the Division of Humanities in Medicine.

Downstate Medical Center began life in 1856 as a dispensary providing care for poor immigrants, and eventually became the Long Island College Hospital. In 1858, the hospital opened a medical school that was the first in the nation to train doctors by the hospital bedside and not only in the classroom. The name "Downstate" came into use after 1950, when the hospital and medical school became part of SUNY.

At Downstate, Alice's responsibilities are wide and deep. She teaches an Ethics in Science class, coordinates and co-teaches a B.A./M.D. program in collaboration with Brooklyn College, and serves as a resource for the second-year "Doctoring Experience" (part of the medical school's new curriculum). Very capable of doing several things at once, she also interviews applicants for the medical school and is a member of the Institutional Review Board.

As an ethics instructor, Alice keeps people on the subject while insisting that a rigorous understanding and application of ethical principles inform the debate. These formidable tasks she accomplishes with abundant humor and goodwill, always leaving students hungry for more discussion at the end of each class.

Over coffee in New York City one afternoon last fall, Alice explained that as a Holocaust survivor, "fighting unfairness wherever you find it was etched into my being." The future ethicist came to the U.S. from Vienna as a six-year-old refugee in 1939, settling with her parents

in Harlem, west of Broadway. "It was all refugees above 157th Street," she recalls in her deep voice with the unmistakable New York accent. "I always felt like an 'other.'"

Not that she let it stop her. A quick study even in a new language, Alice graduated from high school at age 16 and then polished off a bachelor's in political science in just three years at Syracuse. Advised to go to law school at a time when very few women were practicing law, Alice remembers being flattered. "It was not my grand master plan to go to law school," she says playfully, flashing one of her extra-wide smiles. "I was only 16 when I went to college, where I really majored in social life."

There were exactly five women in Alice's class of 125 at New York University Law School, a situation she found uncomfortable. "We women lawyers knew we were tough and smart because there weren't too many of us. But it was depressing with no women in the profession. I would say 'I'm a lawyer' to people and there'd be drop dead silence."

But the law was a good way to pursue her lifelong desire to fight injustice, and Alice originally thought she'd go into labor law. As a newly minted attorney in a world where "We don't hire women" was almost a mantra, Alice took the first job she could get, in personal injury law. This lasted only six months, and was followed by a stint in general practice. Alice then ran a solo practice in estate law from her home.

In her "spare time," Alice had two sons with her husband, a Korean War veteran who worked in the television industry. When he died, Alice used her considerable powers of persuasion to get her landlord to evict someone from another apartment in her building to make room for her parents. They quickly moved in to watch her kids while she worked, and Alice decided to leave the law for her late husband's field, TV, which had long interested her. That was her first big career switch.

In 1966, Alice joined ABC as a political researcher, eventually becoming chief researcher and then a producer of documentaries and special event pro-

gramming. Her initial assignment was for a three-month period, but she ended up staying 15 years, during which time she remarried. After leaving ABC, Alice formed her own production company and produced a series called *Newsweek Woman* for the fledgling Lifetime Network, which she describes as "hard-hitting stuff put into a two-hour pink context." During this period Alice also did a show called "Style" for CBS Cable and produced the programs "Looking East" and "One World" (shooting in Singapore, Thailand and China for a Chinese audience) before she grew weary of broadcasting.

"I got tired of TV in the early 80s; it had sunk to such low levels. While I was at ABC I had become an adjunct in journalism at Columbia. One day I took my students out, because we wanted to do a medical story. I had to talk to the head of transplantation at St. Luke's to facilitate it, and by the time we finished talking, I was fascinated, and he invited me back to discuss doing some medical shows."

One of the first of her medical shows was a piece on surgery from a surgeon's point of view. "I went to see all these operations," says Alice in her investigative mode, "I became a surgery junkie." Meanwhile Alice's personal life was again thrown into turmoil with the deaths in quick succession of her elder son and her second husband.

At this point in her life, Alice had an epiphany. "I needed a new life, and I wanted to do something cutting edge. I thought ethical issues were so profound, so I made a conscious decision to connect with bioethics. To get a job, I started researching the field and networking just the way I would do for a story." And that effort led ultimately to her second big career switch.

With her usual intensity of purpose, Alice set out on her course, going back to NYU for a master's in law and doing an internship at Montefiore Medical Center in the Bronx. At Montefiore, home to one of the first comprehensive AIDS centers in New York state, Alice was exposed to the complex issues involved in AIDS care. Her participation on Montefiore's Institutional Review

# Profiles in Advocacy: Irma Laguerre

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five years. Ever persistent and resourceful, Irma continued to research her options and with the help of her sister, discovered that she could apply for disabled Medicaid-Medical insurance for low-income people who had lifelong conditions. But Taina qualified for limited Medicaid only, which meant that visits and treatment were authorized in blocks—usually of two to three months (15 visits)—at the end of which, Irma would have to continually re-apply. And, though office visits were now paid, Medicaid had restrictions on the number and type of formulas it would cover. For example, liquid formula was covered but bars, solid versions of the liquid, were not. The implications for this are not just financial. Given their portability, taste, and convenience, the bars allow PKU children the option of a more normalized lifestyle, or at least one characterized by fewer disruptions. This is especially important for Taina, whose school day is marked by disruptions for feeding.

In New York City, the PKU Program operates out of Mt. Sinai's Metabolic Unit where the pioneer, Dr. Sansariq, still practices. Aside from the medical staff, the unit has a part-time social worker, a nutritionist, and medical specialists. Though medical advances have been made and families now have the PKU network, there is still no organized support group on-site and Irma watches many of the horrors she experienced repeated with each diagnosed case. Recently, there has been some effort by the unit staff to turn this around. The unit sponsors a PKU picnic, holiday parties, and other one-shot events. The picnic is a big draw. Recently, there has been an interest in formalizing a support group for families. Family support aside, PKU children spend the bulk of their time relating to adults and experiencing social isolation. Ironically, mental health treatment is not a core component of medical care. Perhaps it is the Western ideology, the mind/body schism, or the tendency toward specialization. Perhaps it is the lack of funding, trained staff, etc. Either way, Irma must supplement Taina's medical visits with psychotherapy. And of course, both mother and daughter belong to FAN.

Not only did this mother cum advocate have to negotiate a complex medical

and public assistance system, but now Irma had to take on the schools who insisted her daughter should be in Special Education, not because of scholastic aptitude or IQ, but due to her medical demands. And, though Taina was assigned a para to take care of her during school hours so that she could remain in a mainstream setting, the school still recommends she be placed in Special Ed. The ongoing battle to keep Taina living a "normal life" is fraught with new challenges daily. Nitchen, Inc. not only advocates and sustains Irma, but she currently works there, using her experience to help others. And she never misses an opportunity to engage a parent during her visit to the Mt. Sinai clinic, where she shares information, sympathy, and herself. She and Taina have come a long way. "I never set out to become an advocate," she tells me. But imagine if she had!

*Resources Mentioned in this Article:*

· **Family Awareness Network**—Irma Laguerre 212-749-9494

· **Mt. Sinai Hospital-Metabolic Unit**—Accepts Medicaid and Private Insurance 212-241-8544

· **Disabled Medicaid**—Contact the State Medicaid Office

· **Form 504**—children who have life-long medical conditions are eligible for district funds, which pay for a para to attend to the child during school hours. Call the Board of Education—Division of Special Education Services at your local district office.

· **Agency for Child Development**—offers free childcare (depending on income) until age 12. Manhattan 212-835-7715; Brooklyn 718-260-6993

*For more information about PKU:*

· **National PKU News**—Virginia E. Shuett, M.S., R.D., Director; and the National PKU Network 206-525-8140

· **PKU Children's Network** sponsored by the March of Dimes. Also on the World Wide Web—treatment centers, newsletters and links at <http://pkunews.org>.

· **PKU cookbook**: cooking for a low protein diet—written by Delia A. Hammock, M.S. R.D. at the NYU Metabolic Disorders clinic.

*Denise Arieli is an M.S.W. who has developed and monitored programs that serve children with special needs in the public, private, and philanthropic sectors. She is currently working as a health care consultant and is interested in writing for advocacy.*

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Board was good training for her current work at Downstate.

Alice's approach to ethics is non-moralizing and non-patronizing. "I'm not a judgmental person, and benevolent despotism doesn't work for me," she declares emphatically. "I'm opposed to all sorts of fundamentalism, to anything too rabid in any direction." Alice believes the proper attitude toward ethics necessitates examining at least two sides of every issue. "In ethics, there's always on-the-one-hand this, but on-the-other-hand that."

Not all doctors, of course, are equally interested in the difficult issues of bioethics. "I've done a lot of resident training and there is always a certain cohort that likes this stuff. Primary care physicians, for example, are our natural allies, whereas neurosurgeons are at the other

end of the spectrum.

"I am always astonished when I interview applicants to medical school," Alice continues. "Good MCATs and a 4.0 do not an M.D. make. I'm looking for heart and soul." When doctors have that heart and soul, says Alice, they can be terrific advocates for their patients.

After all she has done in her professional life, Alice calls herself an "accidental" teacher, but says teaching has become the most satisfying part of her work. "I try to do it with humor and fun," says Alice as the day goes dark. "I am not an academician, but my students are my legacy."

*Deborah Hornstra, M.A., HA '97, is co-editor of this publication. She can be reached at [hornstra@home.com](mailto:hornstra@home.com).*

# Maximum Security Health Advocacy

By Eleanor Cerbone Scarcella, M.S., M.P.S.

In the spring and fall semesters of 1999, the Health Advocacy Program at Sarah Lawrence College spearheaded the College's direct participation in the undergraduate degree program at the New York State Correctional Facility for Women at Bedford Hills. Marsha Hurst, Director of the Health Advocacy Program, saw an opportunity to address the prison inmates' desires to explore issues in health care and health advocacy at a conference she attended at the prison in the fall of 1998. I, as a recent HAP graduate with experience in teaching and as a past volunteer at Bedford Hills, was engaged by Sarah Lawrence to develop a health advocacy course for the undergraduate level and then to follow up with a course in human genetics and health issues. The latter was a cooperative effort with Caroline Lieber and her second-year students in Sarah Lawrence's Human Genetics Program.

Bedford Hills Correctional Facility is New York State's maximum security prison for women and the reception center for all women entering the state prison system. Combined residential and reception population is approximately 800. In 1995, a fifteen-year college preparatory and college degree program conducted by Mercy College was terminated when public funding was discontinued by the state. One hundred inmates were enrolled at the time.

Organization by the inmates and their appeals to prison staff, the college community of the New York area, and the religious and lay community-at-large, resulted in the formation of the College Bound Programs and the nonprofit entity known as the BHCF Educational Center, Inc. The key to this new endeavor is private funding and private contributions of staff and equipment. In February 1997, under the leadership of Marymount Manhattan College, seven colleges formed the College Bound consortium: Sarah Lawrence College, Bank Street School of Education (NYC), Bard

College (Annandale), Berkeley College (White Plains), Columbia University, Marymount Tarrytown College, Marymount Manhattan College, Mercy College (Dobbs Ferry), Pace University (White Plains), and Teachers College contribute faculty, funds, and resources (library access, interns, and volunteers.) The first classes commenced in the spring of 1997.

As of Fall 1999, 140 students were enrolled in college courses. A 60-credit Associates Degree and a 120-credit Bachelor of Science Degree in Sociology with an emphasis on counseling is awarded by Marymount Manhattan. Participating students must adhere to a strict class attendance code and maintain a grade of "C" or better for credit. Each contributes ten dollars per semester (their daytime jobs pay 50 cents an hour) and 15 hours of community service within the prison community.

A "Learning Center" has been established in the school building with a bank of computers to prepare assignments (Internet access is denied all inmates by state law); a library of donated texts is available for research. The schools' counselors may borrow books through the Westchester Library System's interlibrary loan program. Private funds and donations are used to purchase class textbooks when needed. Teachers may bring in printed materials for class work and for individual students' research projects.

The most valuable and accessible resource of the program is the dedication and enthusiasm of the students themselves. Some are building upon a few college credits earned during their civilian days. Some are college graduates who are attending as auditors. But most are students who earned their GEDs at Bedford and are continuing beyond preparatory work to earn undergraduate credits. Their writing style is often not polished and their expressive and deliberative discourse is not standard "academia." Yet their intent and sincerity of view and preparedness to encounter something new and different is in-

tense. College-level credits are indeed earned here.

The first class I prepared for College Bound was a fifteen-week overview of the Health Advocacy Program curriculum. Bedford indicated that there was a need for exposure to the healthcare system so inmates could help themselves provide for their own healthcare and that of their families on the outside. Many are mothers and were caretakers in their extended families. All face daunting hurdles to recreating their lives upon release, among them securing the basics of food and shelter, assuring the continuance of health care, and finding a source of income. The college degrees they earn give them a better foothold in seeking employment. What was sought from the health advocacy class was an exposure to the kinds of careers and community activities the students could participate in.

The curriculum of "Social Dynamics of Health Advocacy," as the course was called, covered the issues and complexities of healthcare: insurance, providers, official and professional regulation, bioethics and social contract, community outreach and empowerment. The presentation of such topics benefited from the addition of guest lecturers from different areas of health advocacy — education, law, public and private counseling. The students were exposed to people who were practicing health advocacy in their careers. They also got practice in recognizing, accessing, and evaluating various methods for presenting and resolving issues.

One such class discussed genetics as a health issue and the role of counselors in educating and advocating for patients. Two students from the Human Genetics program at SLC were our guest lecturers and their enthusiastic review of their experience that evening and the matching interest in the subject matter by the students prompted the development of a new course for the following semester in genetics and health advocacy.

"Sociological Perspective on Genetics and Health Issues" was built on the guest lecturer structure, with two different sets of students from the HGP teaching each week. This had a dual benefit: the graduate students were exposed to the "educator" role of the counselor and the Bedford students had many people serve as sources of information and in-

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teraction. Human Genetics Program Director Caroline Lieber and I developed a course outline that covered the biology of genetics, the issues of exploration and exposure of the human genome, and the scope and intent of genetic counseling — all as subject matter important to an individual's understanding and protection of health and well-being.

Two overriding factors made these two courses possible. One is the unique (and oftentimes sorely tested) willingness of the authorities at BHCF to maintain a fine balance between the maximum security status of the prison and the intent of the education process which exposes the students to many outside resources (and exposes those of us on the outside to the prison.) Secondly, Bedford already has a history of tolerating and then supporting inmate self-help and counseling groups. Bedford had spawned the AIDS Counseling and Education (A.C.E.) program where inmates sought help in dealing with AIDS. These courses brought in a wealth of resources but also gave an academic validity to the process these inmates had learned by themselves and among themselves for addressing some of their health needs.

This second attribute is one Marsha Hurst has seized upon to propose another project that addresses the health needs of women in our nation's prisons. If we know of various inmate groups that help each other on issues of health while incarcerated, could not HAP, through its resources, establish a network aiding such groups in sharing information on who they are, what they do, and what they need? We will keep you posted as this project develops; please contact us if you have any information about or potential contacts on women's health in prisons.

Reference: College Bound Programs: Preserving Higher Education in Prison, Bedford Hills Correctional Facility, New York State.

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# Fordham Professor Bruce Berg Joins HAP Faculty

Political scientist Bruce F. Berg, Ph.D., has joined the health advocacy faculty and is teaching a section of Health Advocacy II. Berg has been at Fordham nearly 20 years and is now associate chair of the political science department. For most of that time he has represented Fordham faculty in their contract bargaining, so he has personal experience in negotiating benefit issues, particularly health insurance benefits. "This has given me a different orientation, aside from my academic perspective," says Berg.

As the former chair of the Fordham faculty's salary and benefits committee, and now as president of the faculty senate (which Berg says is as example of the Peter Principle at work), Berg has negotiated on behalf of hundreds of faculty and retired faculty, and dealt with Medicare and Medigap issues. He has seen directly the problems that have accompanied the rise in managed care.

"At Fordham," Berg says, "we've been lucky. There's been no imposition of managed care, but clearly an offering. In the early to mid-80s, there was only one HMO, HIP. Then at one time we had seven plans to choose from. Now it's down to three, but we are still lucky, and some faculty don't realize that. We've always had a choice of different carriers, and sometimes even different plans with each carrier.

"Still," Berg continues, "fee-for-service is the option chosen by 75% of the Fordham faculty." Berg attributes this to general resistance to change. "People are very slow to change, even when presented with managed care choices that are less expensive. There is a reluctance, an inertia."

In the classroom at Fordham, Berg teaches health policy to undergraduates and graduate students, as well as a course in federal, state and local elections and another in New York City politics. In his spare time, he is writing a book on New York City, which he describes as "an attempt to explain both the formal and informal structure of New York City government and how both have been affected by economic development, race and ethnicity." Berg says his focus is the

ways in which federal and state governments constrain what city officials can do, and he uses the issues surrounding such health problems as AIDS, lead-based paint and asthma as examples.

Berg was a freshly-minted Ph.D. when he got an offer to teach at Fordham, and "New York City sounded great" to this Washington, D.C.-area native who has earned degrees at Franklin & Marshall, Purdue and American University. According to Berg, the main difference between his students at Fordham and those at Sarah Lawrence is that "most Fordham students don't have an intense interest in health policy. They are interested in public policy in general and I have chosen to use health as my example, so they tolerate it. At SLC students are intensely interested in health policy.

"We've had fascinating discussions as to what an advocate is. I lean toward an inclusive definition. I've had very little experience with individual advocates but lots with interest groups. Actually I think you have to use a dual definition. Obviously there are individuals in need of advocacy, but decisions that affect them get made in the political arena."

But SLC students are sometimes too interested in the details, says Berg. "By the time they understand the details, those details have changed. The most important thing is to have an overview that can accommodate all the changes. The environment is constantly changing, while people stay the same. As much as this field has changed in the last ten years, I think it will change twice as much, and twice as fast, in the next ten years." And Bruce Berg will help to keep HAP students on top of all those changes.

The reading list for Bruce Berg's HA II section includes the following:

*Medicare Now and in the Future* (Marilyn Moon)

*The Managed Care Blues and How to Cure Them* (Walter Zelman and Robert Berenson)

*Medicaid and the Limits of State Health Reform* (Michael Sparer)

*Plagues, Products, and Politics: Emergent Public Health Hazards and National Policymaking* (Christopher H. Foreman, Jr.)

# 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

**A**h, 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!*

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