HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

VOLUME 5, NUMBER 3 FALL 1997

A Managed Care Bill of Rights: The Health Advocate's Newest Tool

by Rachel Grob, M.A.

The rapid conversion from fee-for-service to managed care service delivery models in both the public and private sectors is causing seismic shifts in the health care system. Combined with and further propelling the existing movement away from in-patient and towards ambulatory care, this change augers a concomitant shift in the focus and practice of health advocacy.[1] The need for both "case" and "class" advocacy is and will be greater than ever since cost saving is the primary motivation behind managed care, and since such saving is achieved primarily by restricting utilization (a potential conflict with what's optimal for the enrollee) and forcing providers to compete on the basis of price (a potential impediment to the development of high-quality delivery systems). But how can the advocate protect the interests of patients and promote the delivery of high-quality services in this tightly controlled, geographically dispersed environment?

Happily, the New York State legislature (with plenty of pressure from advocates!) recently passed managed care legislation that will serve as an excellent tool for health advocates as we work both within and outside of the new systems of care. Nick-named the "Managed Care Bill of Rights," the legislation amends the Public Health and Insurance laws to provide a variety of protections to enrollees, including the following:

- **Mandated disclosure of information to enrollees.** Managed care plans must make available to enrollees and potential enrollees materials that describe the plan's benefits, procedures for getting access to services, training and experience of providers, and procedures for filing written and oral grievances.

- **Mandated access to specialists.** Managed care plans must provide an enrollee with a referral to a provider outside the plan's network if no provider within the network has training and experience appropriate to meet the particular needs of that enrollee. Plans must also provide adequate access to specialty centers, allow enrollees with a life-threatening, degenerative or disabling condition to request that a specialist serve as their primary care doctor, and allow enrollees who need on-going specialty services to request a "standing referral" for such services.

- **Mandated standards for grievance procedures.** Enrollees are entitled to be well-informed about their rights to file grievances and appeal decisions. Grievances called in to the mandated toll-free complaint line must be responded to by the following business day, and responses must be made in writing within 15 days. If delay in rendering a decision about whether a referral or service will be covered by the plan would pose a significant risk to the enrollee's health, the plan must respond within 3 days. Enrollees have the right to appeal decisions with which they don't agree, and to request information about how such decisions were made. Plans

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In This Issue

Plus

From the Editors:

Advocacy has a broad range of applications in the field of health care, but we concentrate in this Fall issue on advocacy with a political focus.

Are health advocates political? Of course.

Being an advocate — standing up for oneself or others — is by its nature a political process: listening to disparate points of view, searching for common ground, working toward compromise and resolution while defending the needs of one's client or constituency. We have different personalities, styles and issues, we may be urban, rural or suburban, we may work on a local, state or national level, but we are all, in some form, in a political arena.

In this issue we look at a few of the ways in which health advocates are interacting with the formal political system, and at the necessity of working with government as it affects our personal options in both simple and profound ways. The relationship between politics and patients is direct — regulation, "rights" legislation, funding — but complex — access, enforcement distribution — to name some of the issues. Government entities are doing, at least in theory, the same thing we do: listening to what people want and trying to do something about it. Government officials, at all levels, are representatives of the people. So are we, and we are in direct and daily contact with the patients whose needs may or may not be met. Whether we work in a small local agency, a big city institution, or the United States Congress, we all have to be politically aware, savvy about the power structures within and without if we are to be successful.

As health advocates we have a constituency and a voice and the skill to engage and impact the political process. Many thanks to those who have contributed their experience and insight to this issue of The Bulletin.

— Karen Martinac and Irene Selver

Please Note

The Sarah Lawrence *Health Advocacy Bulletin* will now be published twice instead of three times a year. We are committed to creating a quality newsletter and to this end we are extending the time between publications to give us the space in which to explore issues in greater depth. Should you have a topic you would like to see covered and/or an article you would like to submit, please let us know. **Phone:** Irene Selver at (212) 222-2576 or Karen Martinac at (253) 761-3070. **E-mail:** healthad@mail.slc.edu. **Mail:** *Health Advocacy Bulletin*, c/o Graduate Studies, Sarah Lawrence College, 1 Mead Way, Bronxville, NY 10708.

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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Mental Health Legislative Update

by Rebecca A. Sullivan

The New York State Council for Community Behavioral Health Care in Albany is the advocacy organization for community mental health centers in the State. Among the New York State legislative issues in the area of behavioral health that the Council has identified as being critical are the following:

Mental Health Parity

The purpose of parity legislation is to prohibit insurance discrimination against people living with mental illnesses. The bill prevents insurance companies from including limitations on the number of inpatient stays or treatment sessions for mental health care. It also prohibits insurance carriers from imposing co-payments, deductibles and co-insurance requirements for mental health treatment which are inconsistent with physical health treatments. This legislation (A. 8315-A), sponsored in the Assembly by Mental Health Committee Chair James Brennan, and passed by a vote of 141-2, represents a major victory for mental health. Advocates are preparing to pressure the Senate for passage in the next session.

Sale of State Psychiatric Properties

This summer, the Committees on Ways and Means and on Mental Health, Mental Retardation and Developmental Disabilities held hearings around the State on the proposed sale of the State's closed psychiatric hospital properties. Proceeds from the sales, after repayment of bonds, are earmarked for reinvestment in community-based mental health services through the Community Reinvestment Act of 1993. To date, the Administration has withheld almost 50 percent of the funding anticipated through Reinvestment, inhibiting the growth and development of community-based mental health programs. Advocates are putting the issue of reinvestment at the top of their legislative priorities for next session.

Rebecca A. Sullivan is currently enrolled in the Health Advocacy Program at Sarah Lawrence College. During the summer of 1996 she was an intern with the NYS Council for Community Behavioral Health Care.

A Managed Care Bill of Rights…

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are legally prohibited from retaliating against enrollees who file grievances, or against health care providers who advocate for enrollees, file complaints against the plan, or report the plan to a regulatory agency.

- **Adequate access to emergency care.** Plans are prohibited from requiring enrollees to obtain prior authorization for services to treat an emergency condition. An emergency condition is defined in the legislation as a "medical or behavioral condition, the onset of which is sudden, that manifests itself by symptoms of sufficient severity, including severe pain, that a prudent lay person…could reasonably expect the absence of immediate medical attention to result in…serious jeopardy…impairment…dysfunction…or disfigurement." Plans must pay for emergency services even if they were provided out of the plan's network, as long as the above conditions are judged to have been applicable.

> *…the gap between law and its implementation is often tremendous. Advocacy — health advocacy — is what is needed…*

- **Adequate numbers of doctors, and adequate geographic dispersion.** The New York State Commissioner of Health is required to assure that licensed plans have sufficient medical staff to provide enrollees with a choice of at least three primary care providers within specified geographic range, and enough specialists to meet the needs of enrollees. Plans must also develop linguistically and culturally competent networks of care.

- **Protections for persons who do not speak English.** The legislation requires plans to develop policies and procedures for meeting the needs of enrollees who do not speak English, including assuring that such enrollees are able to file grievances and appeals.

Although the "Managed Care Bill of Rights" provides critical legal protections for consumers, we know from our experience with the "Hospital Patient's Bill of Rights" and other legislated entitlements that the gap between law and its implementation is often tremendous. Advocacy — health advocacy — is what is needed to ensure that the provisions of this new law become reality for the millions of people who are or will shortly be enrolled in New York's managed care plans. Health advocates must be in place across the spectrum of care — working for the plans and in watchdog groups and in government and in advocacy organizations[2] — to enforce, monitor, publicize, refine, report on and interpret the "Managed Care Bill of Rights."

Advocates should participate in what are sure to be lengthy and contentious definitional processes pursuant to the legislation. For example, how and by whom is it determined whether the plan has adequate specialists, or whether the enrollee receives an out-of-plan referral at no cost? How is it determined who "requires" and who does not "require" a standing referral to a specialist? What constitutes "meeting the needs" of enrollees who do not speak English? What exactly would a "prudent lay person" do in this or that situation? Advocates should be available to enrollees as they grieve and appeal decisions. Advocates should be involved in developing systems for collecting data on quality and quantity of services provided under managed care, and on the new law's implementation.

As managed care enrollment proceeds apace, we will need to continue to forge innovative advocacy roles and to redefine our positions within the health care system. In the meantime, we should call problems with managed care plans into the New York State Department of Health's Managed Care Hotline (800-206-8125), and continue to report on developments in managed care advocacy on the pages of this bulletin.

> *Advocates should participate in what are sure to be lengthy and contentious definitional processes pursuant to the legislation.*

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[1] A number of other changes in the health care system are also occurring, such as rapid privatization and the development of "integrated care networks." These shifts have profound implications for the practice of health advocacy as well: however, investigation of these issues is beyond the scope of this article.

[2] For an excellent example of advocacy work, see the Gay Men's Health Crisis' publication "Managed Care Bill of Rights for People with HIV."

Rachel Grob, H.A. '92, currently works at the Westchester County Department of Health as special assistant to the Deputy Commissioner, and is pursuing a doctoral degree in sociology at the City University of New York's Graduate Center.

Readers interested in a copy of the managed care legislation can contact Rachel at (914) 637-4952.

Profile:

Sue Kelly, Advocate for Half a Million New Yorkers

by Debra Hornstra, M.A.

It is just over 50 scenic miles from the Westchester County Medical Center, at the southern tip of her district, to Sue Kelly's main office in Fishkill, New York. I clocked the distance as I drove there in September to interview Kelly, my Congresswoman and a 1985 graduate of the Health Advocacy Program. As I traveled almost due north through Westchester and Putnam counties, the landscape got greener, the hills started to rise and swoop, and exit ramps and other signs of civilization all but disappeared. The journey's upward trend in elevation caused my ears to pop just as I crossed into Dutchess, by which time New York, Yonkers and even White Plains seemed far, far away.

Congresswoman Kelly's office sits behind a Taco Bell off a divided highway filled with similar establishments. On the day I visited, the activity level inside was high but things were very much in control. Phones rang steadily and youngish aides remained in almost constant motion as they attended to matters high and low. I was a bit early, so I flipped through the military and senior citizen magazines available in the outer office, and took note of the many citations on the Congresswoman's walls.

I already knew something about Sue Kelly's eclectic brand of politics. In her very first campaign for elected office in 1994, Kelly, then 58, defeated Hamilton Fish 3d, and was sent to Washington to represent the half million people of New York's 19th Congressional district. Mr. Fish was the son of the retiring Congressman, but he was also the former publisher of The Nation, and much more liberal than his father. Ideologically, it was Kelly, and not the heir apparent, who conveyed the values of the elder Hamilton Fish, and that's what voters wanted.

Kelly's 1996 re-election campaign was notable for the way she outclassed upstart challenger Joseph DioGuardi for the Republican nomination before defeating a relatively weak Democratic opponent in political newcomer Richard Klein, M.D. DioGuardi, running on the Conservative and Right-to-Life tickets, had moved to the 19th district specifically to challenge incumbent Kelly for the nomination. DioGuardi's strategy was essentially to brand her with the dreaded labels "liberal" and "radical" for her support of abortion rights and lifting the ban on fetal tissue research, as well as her vote to keep funding the National Endowment for the Arts. It didn't work.

Kelly has indeed proved herself quite electable in her district, which includes all of Westchester north of White Plains, Putnam county, and parts of Dutchess and Orange counties. Voters here have consistently supported candidates of either party who favor conservative economic approaches and relatively liberal social policies . Kelly's ideas are a concoction of liberal and conservative thinking that goes down well with the locals.

> *…I found myself advocating for the overworked, underpaid doctors and nurses as much as for the patients themselves.*

A doctor's daughter, Kelly grew up in Ohio, where she majored in botany and bacteriology at Denison University. She met her husband, real estate developer Edward Kelly, while working as a researcher at Harvard. The couple raised four children in Katonah while the future Congresswoman forged an active civic life: she founded the Bedford chapter of the League of Women Voters, served a stint as president of her children's PTA, and held leadership positions in organizations as diverse as the American Association of University Women, the Westchester County Board of Tourism, and the Bedford Presbyterian Church. For decades, Kelly was also actively involved in local Republican politics, and she ran a couple of small businesses, including a flower shop.

Kelly continued her education, finishing two years of law school at Pace University, and later pursuing a Master's in Health Advocacy at Sarah Lawrence. She completed the program in 1985 and took a fulltime job as a patient representative at St. Luke's-Roosevelt Hospital in New York City. Kelly had done her final placement at St. Luke's, spending a lot of time in the emergency room, a rewarding experience that led her to become a rape crisis counselor.

While at St. Luke's, Kelly concluded that "the best patient representatives can swallow their own power, put themselves in someone else's shoes, and 'feel their pain.'" While acknowledging that empathy has become something of a cliché, Kelly maintains that the most effective patient reps she knew "could walk away after having dealt with a patient and have a good cry."

Congresswoman Kelly's approach to patient advocacy hardly ends at the tissue box, however. "Patient representatives should look at hospitals as an organic whole," she suggests. "When I was a patient representative I found myself advocating for the overworked, underpaid doctors and nurses as much as for the patients themselves." Some of that took the form of lobbying the hospital board for more money. Kelly is concerned about the trend toward downsizing patient representative departments. "I think cutting back on patient representative departments sends the wrong message to patients, and I bet my bottom dollar that as patient representative departments are cut back, there will be more lawsuits."

Later, Kelly returned to Sarah Lawrence to teach Health Advocacy II, using the book she says was most influential during her own advocacy training, *Getting to Yes,* which presents a strategy for coming to agreements developed by the Harvard Negotiation Project. (Kelly says she uses the techniques in this book "all the time," and particularly recommends re-reading it if you're called to jury duty!)

In 1994, newly-minted Congresswoman Kelly went to Washington with 71 other Republican freshmen, many of them washed in with the tide that was Newt Gingrich's "Contract with America." Kelly signed the Contract, but her voting record still reveals no particular form of political correctness. She generally votes pro-business and anti-tax, but she supported the minimum wage increase in 1996; her record on the environment is mixed.

> *…Kelly is adamant that promises made to the elderly must be promises kept.*

Kelly is a champion of deregulation; she thinks the unemployed and uninsured will benefit most from business-friendly policies that allow entrepreneurs to create jobs that pay good wages and offer health benefits. In her capacity as Chair of the Subcommittee on Regulatory Reform and Paperwork Reduction, Kelly works to lessen the administrative burden on small businesses and thereby free them for more productive and socially useful activities.

She is tough on crime and illegal drug use and a strong defender of the right to bear arms. Kelly is on record as favoring expansion of the federal death penalty, more federal prisons, and limits on appeals by death row prisoners. In 1996, after she reversed herself to support the repeal of the assault rifle ban, the National Rifle Association told gun owners to "enthusiastically lend their support to Sue Kelly, who," they said, has "consistently supported us at every opportunity."

But the Congresswoman also favors increased funding of homeless shelters, low income housing projects, and drug and alcohol rehabilitation centers. She wants tax incentives for companies that hire and train homeless people and an increased tax deduction for individuals who contribute to charities that help the poor. Kelly is against imposing time limits on welfare recipients. She likes term limits and the flat tax, and was one of only five Republicans who voted with President Clinton against the ban on so-called partial birth abortion, which she once called a decision between "a woman, her doctor and her God."

In other health matters, Congresswoman Kelly has distinguished herself as an outspoken advocate of the rights of senior citizens. Seniors, Kelly notes, "grew up in another world, and they have different expectations." As she said in her address to the 1996 Republican convention, Kelly is adamant that promises made to the elderly must be promises kept. She has consistently supported reforming Medicare to ensure its survival into the next century. In a recent poll of sixty-five special interest groups, only the 60 Plus Association gave Kelly a 100% rating. (Other groups rating Kelly at 90% or above were the National Abortion Rights Action League, the Business-Industry Political Action Committee, the National Federation of Independent Business, Associated Builders and Contractors, Zero Population Growth, and the National Tax Limitation Committee.)

Kelly is also a co-sponsor of the *Women's Health and Cancer Rights Act of 1997* which she hopes will make it into law this legislative session. The act would guarantee coverage of second opinions for all forms of cancer, and ensure that doctors are not penalized by HMOs for recommending a longer than average hospital stay. (Thanks largely to pressure from U.S. Senator Alfonse D'Amato, whose Long Island base is hard-hit by breast cancer, a similar bill has already become law in New York state.)

"The health care system in the US," says Kelly, "is in such a state of flux right now that it's hard to judge whether things are good or bad. And the changes are happening too rapidly for Congress to deal with them. One thing is clear, people in this nation want freedom and flexibility. "She went on to clarify, however, that she thinks it reasonable to impose certain limitations on the freedom and flexibility afforded Medicaid recipients, "since others are paying the bills."

Congresswoman Sue Kelly credits the Health Advocacy Program with teaching her to believe in herself. "I had done a lot of things before I came to Sarah Lawrence, but I never thought of myself as strong. I never thought my opinions were important. At Sarah Lawrence, they believed in me. Not only did they believe I could do the course of study, but they believed I could hold a job and do it well. At Sarah Lawrence, I came to see myself as a strong woman.

"I would advise new graduates to consider all their options. I prefer to work inside the system because it's easier; you're not viewed as the enemy, you're viewed as an agent of change. Current students should kick back and enjoy the program, it's a wonderful program."

> *I prefer to work inside the system…; you're not viewed as the enemy, you're viewed as an agent of change.*

Debra Hornstra, H.A. '97, writes on health topics and is currently building a Website devoted to advocacy issues. Ms. Hornstra is particularly interested in maternal/child health and seeks to incorporate an international perspective in her work.

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Saturday, February 7
9:00am – 2:30pm

Performing Arts Center – Film Viewing Room

Grant Writing Workshop

Presented by:
Dr. Liane Reif-Lehrer, President
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Political Advocacy: It's Better to Give than to Receive

by Scott Penn, M.A.

Hard to believe, but it's been 17 years since I enrolled in the Health Advocacy Program's first entering class. It is an understatement to say that, for me, the world of health advocacy then has little resemblance to today. For me, "then" represents the "pre-AIDS" world. The term wasn't even in our vocabulary when we graduated during December 1981.

After graduation, I worked as an office temp for a few months, before landing a job as a patient representative at the New York Hospital in May of 1982. Anne Coté and Susan Mascitelli were brave in hiring someone a few months shy of his 25th birthday for such a high-powered job. Being a patient representative at the New York Hospital was, indeed, a "rock and roll job." In retrospect, I was probably too young for the job and took it all far too seriously. This wasn't a good strategy in a job where you dealt with only the worst problems and the most difficult situations.

Of course, being a young gay man working at "ground zero" of the AIDS pandemic didn't help either. Those of you who worked in tertiary hospitals during the early 1980's know that it was a terrible time. People were dying left and right, often during their first admission. It was a difficult time to try to succeed at a new job in a new career.

My first experience with political advocacy was on the receiving end. The New York Hospital had received some bad reports in the gay press regarding alleged abuses of AIDS patients. (Remember that in the day's before universal precautions, every AIDS patient had "enteric precautions" and "blood and secretion precautions" stickers placed on the door to the room. This served as a neon warning sign to apprehensive and under-informed staff. Lots of unacceptable stuff happened to our patients. In addition, before we knew about AIDS-related dementia, we had difficulty reconciling many wild stories with what might have actually happened.) The *New York Native* ran an issue with the banner headline: "Is New York Hospital Abusing Gays?" Soon thereafter, the New York Hospital was the target of a letter writing campaign.

I recall that in early 1983, I received a telephone call from a man who said he was Mel Rosen of the Gay Men's Health Crisis. Mr. Rosen wanted to complain about the treatment that one of our patients was allegedly receiving. I recall him saying, "Kenny [the patient] is scheduled for a spinal tap this afternoon. He doesn't want to have it. I order you to cancel the procedure!" I remember replying that I had never heard of Mr. Rosen, nor had I heard of the Gay Men's Health Crisis, and that as far as I was concerned, he was just a voice over the telephone, and that only the patient had the right to cancel his spinal tap. ("You're just a voice over the telephone," was my favorite line when trying to protect a patient's privacy.) Mr. Rosen replied by asking me if I were gay. I told him that my being gay or not didn't have anything to do with the conversation. (This was still during the time that I thought it would be professionally dangerous to be too "out" at work.) He said, "Well, it *sounds* like you *are* gay and you should consider coming to volunteer with us. We need the help." I was reticent in my reply, saying something along the lines of "I give at the office." Before hanging up on me, Rosen's parting comments were, "Well, next year, there's going to be five hundred cases! In five years, there's going to be 3,000 cases! Let your conscience chew on that!"

> *Of course there is no escaping the AIDS pandemic or AIDS-related political advocacy.*

Fast forward to 1986. I left the New York Hospital and the City to return to Cape Cod to become the administrator of Health Associates of Provincetown - a rural community health center. In 1987 we merged a second health center into our operations. I became the Executive Director of Outer Cape Health Services, Inc. — a position that I still hold today.

Of course, there was no escaping the AIDS pandemic or AIDS-related political advocacy. Provincetown has a large gay population and has the second highest *per capita* rate of AIDS in the nation. By 1988 Outer Cape Health and I were the targets of a "die-in" in our waiting room, staged by ACT-UP Provincetown. (If you're unfamiliar with political theater of the late 1980's, a "die-in" involved people occupying an area, lying down on the floor for a few minutes, then rising and chanting, "Shame, Shame, Shame" while pointing their fingers at the target of their anger. There's no snappy comeback if you're on the receiving end.)

I didn't know it at the time, but apparently that day in August 1988 was meant to be a day of coordinated protests throughout the country. I maintain now as I did then that the "charges" that ACT-UP leveled against us were bogus. We were the *only* place on Cape Cod that was offering medical services to people living with HIV/AIDS. Even though the memory of it still stings, I now realize that this demonstration had to happen — it served a necessary purpose. Outer Cape Health and I weren't the enemy — we just happened to be the only place resembling "The System" that the "activists" could reach by bicycle in Provincetown.

Many of the people who participated in that "die-in" are now dead themselves. The man who organized the protest in 1988 is now a good friend and political ally. But I did decide that I wasn't going to be on the receiving end of AIDS advocacy any longer. (Think Scarlet O'Hara vowing *never to go hungry again!*)

So, a lot has happened in the last nine years. In running a hand to mouth, community-based health care organization, advocacy for me has meant advocating for funding. As part of our community health center practice, Outer Cape Health now provides medical services to more than 270 people living with HIV/AIDS. *Over 100 of these individuals are uninsured.* This is expensive. More and more, we rely on government grants to support our costs. This means I have to advocate with the Massachusetts

Legislature and with our Congressional Delegation to make sure enough money is appropriated for our programs. Then I have to advocate with the Massachusetts Department of Public Health and the United States Public Health Service to make sure that enough of the appropriated funds come our way.

I have found that one of the legacies of ACT-UP and the AIDS activist movement is that government is more likely to listen to and to respond to a wider range of consumers and community based organizations than they did in the past. This came true for me in two significant ways. For three years I was a member of the Massachusetts HIV Tax Fund Advisory Committee. This was the group that approved the state's plan for spending the money raised from a voluntary check off line on the Massachusetts income tax return. My role turned out to be making sure that the funded programs served people beyond Boston — including Cape Cod.

The most exciting chance I had to do some political advocacy was being one of 300 invited participants in the first ever White House Conference on HIV and AIDS in 1995. Despite my deep-seated cynicism, I do believe that the conference was more than "window dressing" and did make a difference in services for people living with HIV/AIDS. (It didn't even bother me when we had to walk through a gauntlet of ACT-UP demonstrators calling us "sell-outs.")

The conference organizers divided the 300 participants into several working groups. Each group leader was to report back to the President with the rest of us in the audience, that afternoon. I attended the group looking at primary care services. There were a lot of high-powered folks in the room. As the discussion climbed through the stratosphere of lofty goals in an ideal world of medical care, a man from the AIDS Action Council in Washington brought us back to Earth. He reminded us of the current political realities of Congress. (Remember that December 1995 was the half-way point of the first "Republican Revolution" Congress.)

The man from AIDS Action said, "Look. We're only going to have five minutes to get our message to the President. We have to be clear, concise, and on target for an immediate issue. The Republican Congress is trying to destroy Medicaid as we know it and turn it into block grants to the states. Not all the states will do the right thing with a block grant. For many people living with HIV/AIDS, Medicaid is their only hope to have adequate health insurance. The message has to be, *'For God's sake, Mr. President, don't let Congress destroy Medicaid!'*"

That was the message that our group leader reported to the President later that day. During that time in Washington, saving Medicaid was a crucial issue. I remember watching the news after I got back to my hotel room. There was videotape of the President — wearing a tie that had the AIDS ribbon as its design — vetoing a Republican-driven bill that would have weakened Medicaid. I like to think that the message from the White House conference that day helped to bolster the President's position.

1997 has been a big year for me — both personally and professionally. I turned 40 this summer. (I know, I know — *nobody* has any sympathy for me!) I also received a nice professional award. The Massachusetts League of Community Health Centers named me their "Community Health Center Director of the Year." It's been a strange journey from the Health Advocacy Program to where I am today — the executive director of a community health center with a $4 million budget, 70 employees, and 32,000 annual patient visits. We write off over a half million dollars each year to free care to low-income, uninsured persons.

Who knew?

Scott Penn, H.A. '82, is the Executive Director of the Outer Cape Health Services, Inc, a rural community health center on Cape Cod with sites in both Provincetown and Wellfleet.

Advocacy "By the People"

by Sara Collins, M.A.

Advocacy is derived from advocate which literally is defined as "one who pleads another's cause." While advocacy in this manner should receive wholehearted support, there is another side to advocacy which is not as obvious: to educate and enable the client or constituent to advocate on his/her own behalf.

The old axiom "Give a man a fish and he will eat for one day. Teach him to fish and he will eat for a lifetime," illustrates the point quite well. An advocate may step in and assist a client or constituent on one issue and have it resolved. However, if you teach a person to advocate for himself, he will not only be able to handle the matter at hand, but other issues that may come up in the future. This is especially true in the type of work I have pursued, legislative advocacy.

While walking through the Capital on the way to pay a visit to a Congressman, I saw high upon a wall "For the people, by the people" inscribed. I had seen it before, but at this moment it imprinted itself on my consciousness. Too often as policy makers we are sure that we know what is best for our constituents. But, unfortunately, many times we are so far removed that we can only go with our best guess. When I was doing my internship at an AIDS organization advocating on behalf of people infected with HIV, it became clear that I would not be able to understand all the needs of the many divergent, and often disenfranchised, groups. How would I know what it is like to be a gay man scorned by society and taunted with ''faggot" as I walk down the street? Or a woman in an abusive relationship unable to ask my partner to wear a condom although I know he is having sex with other women? Or a drug user who knows that it is dangerous to share needles but nonetheless has no alternative because clean needles are illegal without a prescription and there is a long waiting list for drug treatment slots?

One option is to educate people through community organizing. Through informal trainings, people are taught how the government works and how best to access elected officials. It is amazing to see that once individuals are given the knowledge and implicit permission to use the system for their own advocacy work, they blossom. They become information hounds, wanting the latest update on what is happening in Congress. It also gives people with disabling and unpredictable diseases, such as AIDS or multiple sclerosis, some control over the personal chaos they experience. Equally important is that elected officials are hearing from those who elected them, those who represent their districts, letting them know that yes, people in their district do have HIV or multiple sclerosis. Finally, it fulfills what was originally intentioned by the creators of our government: a government by the people, for the people.

Sara Collins, H.A. '97, is currently working at the National Multiple Sclerosis Society as a Federal Legislative Associate tracking health related legislation and keeping the grassroots informed of federal legislation relating to MS.

Cultivating the Seeds of Political Action in Our Communities

[Editors Note: New York Citizens AIDS Network (New York CAN!) is GMHC's grassroots advocacy effort. This volunteer-driven project can be reached by phone (212) 367-1231 or via e-mail at nycan@gmhc.org. The following is reprinted by permission from THE VOLUNTEER, *July/August 1997, p. 4.]*

by Andy Stern

The New York Citizens AIDS Network! (New York CAN!) was launched in the fall of 1994 to provide an outlet for New Yorkers everywhere to hone the advocacy skills necessary to effect positive political action on behalf of people with HIV/AIDS. Michael T. Isbell, GMHC's Associate Executive Director and one of the architects of New York CAN!, summarizes the driving motivation behind GMHC's sister advocacy group: "It is our conviction that people living with HIV/AIDS and their caregivers not only can but must speak for themselves, tell their own stories, and communicate their specific needs directly to their elected officials. Only through political awareness and the exercise of our collective voices can we achieve meaningful legislative change for people with HIV and AIDS."

Isbell recalls the group's early years. "Our community organizing unit spent much of its first two years on the recruitment and basic advocacy training of GMHC clients, volunteers and staff. As our ranks expanded and our voice strengthened, the network began to take on a life of its own, extending far beyond the walls of GMHC and reaching out to communities throughout New York City and beyond."

At this point in New York CAN!'s journey, more than half of the group's time is spent working in coalition with other organizations, conducting advocacy trainings throughout New York State, and providing technical assistance to other community-based organizations (CBOs). "We are proud of the more than 1,500 New York CAN! advocates who write letters, make phone calls, register people to vote, and meet with elected officials," says Ed Galloway, New York CAN! coordinator. "But we are just as proud of the partnerships we have developed with other organizations throughout the state and across the country."

Over the last two and a half years, New York CAN! has conducted trainings in all five boroughs of New York City, working with such diverse groups such as the Staten Island HIV CARE Network and the HIV Parents Education Network (HAPEN) in Staten Island; East New York/Brownsville HIV CARE Network in Brooklyn; South Bronx HIV CARE Network in the Bronx; and Steinway Family and Children Services in Queens, among many others. Outside of the city, New York CAN! has traveled to the Mid-Hudson Valley HIV CARE Network and AIDS-Related Community Services (ARCS). In addition to this kind of community outreach, New York CAN! always provides a substantial number of PWA scholarships for people wishing to attend its annual advocacy skills-building conference. This year, for example, well over fifty percent of conference participants from all parts of New York City attended the two-day conference at no cost.

> *Coalition work and partnership is where all real change must occur.*

While many agency representatives and consumers have decided to join the New York CAN! network, many others have chosen to take the tools and information they have acquired to develop and further their own advocacy agendas and projects.

"We think of New York CAN! as a resource to the AIDS community, one place among many where people can access information and develop their advocacy skills," says Galloway. "One of the most exciting elements of our outreach efforts is observing those people who spend the day with us, then depart and are not heard from for a while, but whose actions later attest to the success of our efforts — we plant seeds, help them take root, and then hear back about the fantastic work being done by our fellow advocates."

Last February, New York CAN! took a major leap forward, traveling to the Albany region for an all-day advocacy training in collaboration with the Northeastern New York HIV CARE Network and the New York AIDS Coalition (NYAC), which has a long-standing record of building consensus and coalition among AIDS organizations fighting for the needs of people living with AIDS. According to Amy Herman, Executive Director of NYAC, "Politicians need to hear from individual consumers as well as AIDS service organizations, working hand-in-hand to create the groundswell we often need to effect significant change. The training in Albany presented a valuable opportunity to reach people who live in strategically critical areas of the state."

As a direct result of the Albany training, two constituents of Congressman Gerald Solomon's district (important because Solomon chairs the Rules Committee for the House of Representatives) attended AIDSWatch '97 and met in Washington with the Representative's aide on health issues. It was the first time constituents met face-to-face with an official from Solomon's office in the 7-year history of the national lobbying event. "Our visits confirmed for me how important it was for us to be telling our elected officials about our issues," says Lenny Hoffman, one of the constituents who first came in contact with New York CAN! during the Albany training. "It was clear to me that they were uninformed about exactly what the personal issues were

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New Pap Technology as Catalyst to Unite Women for Promoting Mutual Benefits

[Editors' Note: The following article is an advocacy piece written by a graduate of the Sarah Lawrence Health Advocacy Program. It does not reflect the position of the editors nor is it an endorsement of a specific product by this publication. It is a topic of interest and one that will be pursued further in subsequent issues. Should you wish to make a contribution regarding this topic, it will be welcomed.]

by Susan Titus Glascoff, M.A., M.S.

This article is a call to health advocates to use their professional advocacy training to improve cooperation among women on topics of mutual benefit. Women must emphasize their mutual needs and downplay their differences if they are to accelerate progress. A case in point is the Pap controversy. What is frightening and puzzling is that even women in knowledgeable positions in the media and medical fields are promoting acceptance of 1940's Pap smear technology, while one computerized Pap test basically eliminates human error with up to 99.2% accuracy (the percent reported by the International Academy of Cytology).

Numerous sources are encouraging women to keep faith in the 50 year old Pap test despite the fact that there was a 1988 US congressional directive for better screening because of a 5-50% false negative rate, the highest rate being for the most invasive carcinomas. All sources acknowledge promise in at least three new procedures approved by the FDA a year ago, but few actively endorse them. Why is there a reluctance to adopt the test with the highest sensitivity rating? How much is cost a factor?

According to the American Cancer Society, cervical cancer causes at least 5,000 deaths and 15,000 hysterectomies per year, yet has a near 98% cure rate if caught early. Treatment is usually a simple cauterization. I know. I had one seven years ago. Virtually all sources who do not endorse the most sensitive test justify their decision on the fact that most cervical cancers are slow growing and will be caught on the following Pap or by one of the cheaper tests which do improve results. Some cancerous lesions, however, are faster growing, and the less sensitive tests are even more markedly less accurate for these faster growing cancerous lesions. The August *Obstetrics & Gynecology* reported that Cytyc's ThinPrep improved results 65% in normal screening populations and 6% in hospital high risk populations. Their product insert reports fewer high grade lesions and carcinomas than the conventional Pap in several studies. NeoPath's AutoPap product insert states they have approval to re-screen the 10% of conventional negative slides deemed most likely to be false, a 50% improvement. The January-February “International Academy of Cytology” documents for Neuromedical's PAPNET up to 99.2% accuracy, the best being for invasive carcinomas. The October “Human Pathology” grants them 95-97%.

> *…cervical cancer…has a near 98% cure rate if caught early.*

Lawsuits against labs and pathologists because of false Paps are the fastest growing area of liability. Not only do many women not get a yearly Pap, but slow growing cancers often accelerate for many reasons, one being pregnancy. Several lawsuits have been won because re-tests clearly show precancerous cells on five-year-old Pap slides. Such a case is highlighted in the July 1997 “Reader's Digest,” where Karen Smith's family was awarded $6.3 million after her death at 29.

For Karen Smith's case and many others, repeated Paps yielded false negatives even when read by two technicians. This has happened in labs noted for highest quality control. There are countless reasons. The traditional Pap smear often has 300,000 cells. The lab technician manually screens each slide in about ten minutes. It has been likened to finding a needle in a haystack. Many cells are often obscured by blood, etc., and the most deadly cells are the smallest. Furthermore, no one is constantly at peak efficiency. By filtering away some of the obscuring tissue, ThinPrep also eliminates some indicators and probably even some of the tiniest, deadliest cells and cell formations. PAPNET's computerized re-screening has a FDA improvement rate of at least 7.1X (710%) for false negatives because of its patented neuralnet technology, magnification, and marking of questionable cells. Personalizing these numbers, for every 1000 women receiving negative Paps, the required 10% quality control re-screen catches 5 false negatives, AutoPap catches 7.5 and PAPNET 35.5.

Two key articles, written by women, are very disturbing. The 28 page special pullout section on women's health, in the Sunday, June 15 New York Times, had an article about cervical cancer, “I hope women aren't losing faith in the Pap smear.” It dwells on the least worrisome ASCUS category, barely mentions new technology, and ends by suggesting women should wait four years for results from a $20 million follow up study by the National Cancer Institute. The second article entitled “Smear Campaign” in *Mirabella's* July / August issue discusses PAPNET, asking “Is this a case of fear-mongering by greedy medical entrepreneurs, or important information about how women can increase odds that deadly cervical cancer won't sneak up on them?” It expresses fear of “flagging too many lesions,” ignoring the fact that PAPNET does not diagnose but just facilitates the process.

Harvard Medical School's “Women's Health Watch — Enlightened Choices” stated “We can do more to reduce our risk by having regular Paps than by specifying how

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New York Organ Donor Network

Organ and Tissue Donation: Saving Lives is a Shared Responsibility

by Denise Payne, M.P.A., R.N.

Did you know that thousands of men, women and children of all ages and backgrounds are suffering from a health care crisis **WITH** a cure? Over 54,000 Americans — including more than 4,000 New Yorkers — are waiting for a donated organ, while hundreds of thousands are in need of tissue transplants, such as corneas, bone and skin. Yet, until health care professionals ensure that all eligible patients are considered for donation and more families say “yes” to donation, 10 Americans will die every day for lack of a donated organ. Health professionals and the general public all play a critical role in saving and improving lives through donation.

Organ and tissue donation is the result of a series of events, all of which must take place within a short window of time. Hospital staff must notify its local organ procurement organization (OPO) when a patient is declared dead and the OPO will determine whether a patient is a suitable donor. Then, of course, the patient’s next of kin must grant consent for donation to occur.

The Role of the OPO

The Donor Network is one of 66 OPOs in the country responsible for coordinating all organ and tissue donation activity. The Donor Network is responsible for a racially and ethnically diverse population of 11.7 million residents within the Greater New York area. Donor Network staff are assigned to geographical teams and work around the clock, responding to potential donor cases and coordinating all aspects of organ recovery and transplantation.

The donor process begins when hospital staff notify The Donor Network when a patient has died or when brain death is imminent. The Donor Network will dispatch a transplant coordinator, who will go to the hospital to evaluate the patient as a candidate for organ and tissue donation. The transplant coordinator is responsible for coordinating a series of important events within a short time frame, including: administration of a series of clinical tests on a patient to gather a clinical profile and rule out HIV and other contraindication to donation, performing clinical tests to declare brain death and working with hospital staff and Donor Network family counselors to ask families for consent.

> *“Over 54,000 Americans… are waiting for a donated organ…”*

After a family grants consent, The Donor Network works with the United Network for Organ Sharing, the national organization that maintains the national waiting list and matches donor organs with transplant candidates, to generate a list of suitable recipient candidates on a local, regional and national level based on clinical factors. The Donor Network will ensure that the entire procurement process moves smoothly so organs and tissues will be viable for transplant.

Educational Outreach

Our on-site clinical activities are complemented by a staff of hospital services specialists, who work with hospital administrative and professional staff on a continual basis to develop tailored protocols for donation. Our teams collect and analyze hospital data to better identify each hospital’s donor potential. This information is used to customize ongoing professional education programs, including seminars, grand rounds and one-on-one consultation.

Ongoing educational activities in schools, media outreach, special events, community outreach and publications round out The Donor Network’s educational outreach efforts.

Who is a Potential Donor?

A review of recent data, collected from an audit of death records from a large sample of the hospitals in our service area, provided us with a picture of the donation situation in New York. Our findings mirror national trends in donation. Data show that victims of gunshot wounds, motor vehicle accidents and other head trauma (once thought of as the “typical” donor) account for less than 20% of the total donor potential.

In addition, Donor Network and national data show that the vast majority of eligible donors are victims of a CVA (cerebrovascular accident or stroke). National trends show that CVAs are the greatest missed potential. Data also reveal that more than one-half of potential donors are over 50 years old.

Role of the Health Care Professional

Physicians, nurses and other hospital staff play a vital role in organ donation. Through the referral of potential organ and tissue donors, you can enable families to make an informed decision about donation and help save and improve thousands of lives. Families often rely on the comforting presence and emotional support of the doctors and nurses who cared for their loved one. A Donor Network transplant coordinator and family counselor will work with hospital staff to approach a patient’s next-of-kin to ensure that they understand brain death and have accepted the grave prognosis **before donation is mentioned**. The Donor Network coordinators and family counselors are well versed in the steps by which to guide a family through this difficult time.

When a physician or nurse calls 1-800-GIFT-4-NY, our 24-hour referral line, Donor Network clinical staff will dispatch a coordinator to evaluate the case. After brain death has been declared by two independent physicians, our coordinator will be joined by a Donor Network family counselor to approach potential donor families for consent.

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Organ and Tissue…

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Aftercare: Special Attention for Grieving Families

Our commitment to these brave families does not end when the consent form has been signed. An Aftercare Program has been established to follow families through the difficult first year after the death of a loved one. If a family elects to do so, they can continue a relationship with our organization beyond the first year. Donor families receive correspondence, newsletters and are invited to an annual Donor Family Luncheon and other special events. Family counselors are available to provide families with resources.

Those of us who chose health care as a career probably did so to help people and touch lives directly. No where is this mission better fulfilled than in the life-saving act of organ and tissue donation and transplantation.

If you have any questions or would like to schedule an educational workshop, contact The Donor Network at 212-870-2240. To refer a potential donor, call 1-800-GIFT-4-NY, 24 hours a day.

Denise Payne, M.P.A., R.N., is the Executive Director of the New York Organ Donor Network, a federally-designated, state-certified nonprofit organization responsible for coordinating all organ and tissue donation activities throughout the five boroughs of New York City and several New York State Counties.

New York CAN!

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that confronted PWAs every day." In the fall, New York CAN! will hold trainings with NYAC in both Rochester and Buffalo, furthering its objectives to recruit for the network, share ideas with the community, plan strategy with local AIDS organizations, and provide technical assistance and support where needed. In addition, New York CAN! organizers will be meeting with their counterparts from AIDS organizations all across the country to develop a national grassroots strategy for the year ahead.

"Coalition work and partnership is where all real change must occur" says Galloway. "As we say in our New York CAN! brochure, GMHC is proud of its leadership on AIDS advocacy. Now more than ever, it is clear that neither GMHC nor any other organization can wage this fight alone."

Andrew Stern is a community organizer in the Public Policy Department at Gay Men's Health Crisis and a coordinator of the New York Citizens AIDS Network (New York CAN!). He served two terms as a Democratic Committeeman in Nassau County and served on CUNY Hunter College's Presidential Task Force on AIDS. He is a founding member of Peacesmith House, *a grassroots organization which works for environmental and liberal political causes.*

New PAP Technology…

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those should be treated." A note from Planned Parenthood said "in a worse case scenario, it takes 2-3 years for a normal pap to progress to invasive cancer so that if every woman had a pap every 1-2 years, the abnormal cells would get picked up on pap before becoming cancerous." They argue PAPNET is not as good as a traditional pap picking up low-grade lesions. To obtain new Pap test coverage from doctors and insurers, women must request it — not fair to those unaware, plus some insurers deny coverage. It should be noted that PAPNET is used in about 25 other countries, often for primary screening, which since July 30 is also being sought in the US. The need for setting some national insurance standards and further review of still overly restrictive FDA requirements are topics health advocates should pursue, especially for preventive care.

> *Women have got to learn to be more mutually supportive in areas of mutual need.*

What is perhaps the most alarming is that many women are reluctant to confront their doctors or insurance companies about any health issue, even when presented with well-documented information. PAPNET, for example, is endorsed by the American Women's Medical Association. Carol Armenti won a lawsuit based on rescreenings of her earlier misread Paps which clearly showed precancerous "slow growing" cells, accelerated by pregnancy. As a result of her cervical cancer, Carol had a miscarriage, a radical hysterectomy, and chemotherapy. She has established a support and educational group for women who have (had) cervical cancer. She is in the process of also creating a national educational program at the high school level to help young women become more knowledgeable and assertive about their health.

Women have got to learn to be more mutually supportive in areas of mutual need. I am hoping this issue of ensuring that the best new Pap technology becomes a "standard of care" will act as a catalyst to unite women for their own health advocacy and other common causes. If you think reducing the false negatives in Pap smear tests is unimportant, ask yourself, "Are you volunteering yourself or a loved one to be in the missed % when it could mean life itself or ability to have children?"

P.S. July 18, 1997, I wrote an expanded version of this article and sent it along with documentation to numerous women's organizations and magazines, some newspapers, Planned Parenthood, many major HMOs, and several particular individuals. Additions are ongoing. Anyone who would like a list of the recipients and / or a full copy of the report for themselves or others, please contact me at 10 Manitou Road, Westport, CT 06880. Tel. 203-454-3193, (1783-fax). Those interested in making donations to Carol Armenti's nonprofit support / educational organization may send it to the Center for Cervical Health, PO Box 1209, Toms River, NJ 08753 or call 908-255-1132 for further details.

Susan Titus Glascoff, H.A.'90, is an investment counselor whose life has revolved around various advocacy projects. This is her third at the national level.

HAP Takes its Show on the Road

by Debra Hornstra, M.A.

Last summer, the Sarah Lawrence Health Advocacy Program sent four distinguished faculty members to the Chicago suburb of Oak Brook, Illinois, to present a series of seminars to patient advocates from Veterans Administration hospitals around the country. The VA is the nation's largest integrated healthcare system, with about 200,000 staff working in 172 hospitals, 376 ambulatory care clinics, 132 nursing homes, and hundreds of other facilities. The VA system is also the country's largest provider of graduate medical education and one of its largest research organizations.

> *The advocates were most interested in improving their clinical and political skills.*

The vastness of the VA system is reflected in its census. In fiscal year 95/96, the last year for which data is available, VA hospitals admitted over 800,000 patients. On an average day, the system filled almost 75,000 beds, including about 11,500 in psychiatric units and some 33,500 beds in nursing homes. If this doesn't sound busy enough, consider that more than 29 million outpatient visits were also recorded. More than $27 billion in federal funds was spent to finance these activities.

Veterans are entitled to medical care in compensation for their service to country. But despite that entitlement and the generally high regard in which veterans are held, the VA system is not immune to economic pressures now forcing change upon all hospitals nationwide. Staff cutbacks and widespread departmental reorganization demand creativity and new thinking, much of that provided by Kenneth W. Kizer, MD, MPH. Kizer has been the VA's Under Secretary for Health since 1994 and functions as the CEO of the Veterans Health Administration and chief architect of the VA's reengineering efforts. Part of his new thinking concerns the role of the VA's patient representatives, now called patient advocates in reflection of their growing influence within the institutions where they work.

Rose Gates, the VA's National Director for Patient Advocates, was the VA's point person for the seminars, which constituted the first formal in-service training ever held for the VA's patient advocates. A nurse who also holds a master's degree in education, Gates first became familiar with the Sarah Lawrence Health Advocacy program through a patient representative at the Philadelphia Veteran's Administration hospital who had earned her master's degree at SLC.

"I was very impressed with her skills," says Gates, "so I asked her who I should contact to learn more about the program, and I got a meeting with (Health Advocacy Program Director) Joan Marks and took a couple of patient representatives with me." Gates says the meeting "far exceeded" her expectations and soon she and Marks were busy developing the seminar series.

Four HAP instructors were invited to participate, each presenting a different aspect of the program. The challenge to Alice Herb, Terry Mizrahi, Marvin Frankel and Michael Fabrikant was to take their semester-long courses and synthesize them into just a few hours. Each admits to some pre-seminar jitters, but the overwhelmingly positive evaluations they received are a testament to their professionalism and preparedness.

"It started off as high anxiety because of the way it was formatted," says Alice Herb, who taught the bioethics component. "But fear is a great motivator. We tried very hard." Accustomed to facing small groups of students at Sarah Lawrence, the faculty also had to rework their presentations for groups of 30 that were characterized by enormous differences in age, educational attainment and career experience.

Gates' goals were clear, as is her satisfaction with the seminars as they were realized. "I wanted to develop a solid baseline of patient advocacy skills, and I feel like that was accomplished." Indeed, almost all of the VA's 200-plus patient advocates took part in the Sarah Lawrence seminars, and they were extremely grateful for the opportunity. After sitting in on all the sessions, Gates herself came away thinking "the content was important and exceptional, but it was also the personalities of the faculty, and their significance as role models, that I saw as crucial. I had never experienced a faculty as dedicated to a project as was this one."

The enthusiasm was mutual. "This was a group of students who were substantially engaged across the board," says Michael Fabrikant, who taught evaluation and assessment of advocacy initiatives. "I was also very impressed with the leadership, especially Rose Gates and (Education Coordinator) Joan Murray. They met with us every day and gave us positive, constructive feedback, usually right on the money."

"The advocates were most interested in improving their clinical and political skills," says Terry Mizrahi, who taught the morning sessions, entitled *A Framework for Health Advocacy: Models of Advocacy Practice.* "We tried to give them a conceptual and theoretical framework for their work: definitions, processes, and strategies."

> *…how can we make things better for the patient?*

Mizrahi says the initially forbidding condensed nature of the seminars was ultimately successful because it forced the instructors to be creative in structure and format, not just content. "This was not an attempt to teach in six hours what you normally teach in thirty," Mizrahi makes clear. "What we found is that these students wanted more off-site credentialling. We satiated some of their thirst for information, but we also whetted their appetite for more."

Marvin Frankel, who teaches *The Nature of Illness and Caring* to SLC's HAP students, led the seminar on *Multiple Perspectives On Talking with the Seriously Ill and Dying Patient*, which emphasized the social construction of illness and death. He found it a challenge to address himself to such a diverse group. "It was very hard to speak to all 30 of them at the same time, there was such an extraordinary variability in participants."

> *We satiated some of their thirst for information…whetted their appetite for more.*

Frankel found that much of his material was new to the VA students, including a segment on the nature of anxiety and a two-hour workshop on developing empathy. "Many of the students could not believe that empathy has anything to do with efficacy. In the role plays, they were shocked at how bad they were at it, and some couldn't bear the difficulties they were having."

Frankel's experience underscores Rose Gates' concern that the VA's patient advocates need a lot more training than they currently get. Michael Fabrikant found that most had never really considered reporting a tool of their trade. "Very few of them had ever thought about using data as an advocacy tool, as a strategy. We were trying to enable people to rethink how and why they develop reports," explains Fabrikant. "The structure of a report will either engage people, or it will disengage them."

Alice Herb found the students had done quite a bit of thinking about ethical issues, however. "Their instincts regarding what was fair and equitable were excellent. Their whole orientation was: how can we make things better for the patient?" Herb presented five cases for discussion each day, all drawn from real-life incidents that had given the students trouble. The cases covered such topics as patient autonomy, informed consent, advance directives, ethics committees, and confidentiality. The segment on advanced directives was accompanied by a film on the subject produced by Herb while at Montefiore Medical Center in the Bronx.

Terry Mizrahi was particularly impressed by the students' level of commitment to their work. "They feel a deep sense of responsibility toward their patients. It's a commitment based on a compensatory model, i.e. you served your country, now we will take care of your medical problems." This promise is threatened by budgetary constraints that began during the Reagan administration, and the attendant increased scrutiny of patients' demands. "The result," notes Mizrahi, "is that the VA's long-standing patient-centered orientation is now up against an anti-bureaucratic, anti-organizational mood."

"The number of veterans is not expanding, and the patient population is getting older," Mizrahi continues. "Resources are shrinking and patients are being pushed into other systems. The VA advocates want to be much better at internal advocacy and they need to be much better at coordinating their activities and offering referrals and joint services."

Chronic illness is another area in which the advocates need more education. "In the past 30 years," says Marvin Frankel, "the medical profession has created a whole new class of people who are chronically ill. Chronic illness requires a quality of care that humans have never before had to provide." Citing the modern tendency to be embarrassed by illness, Frankel says the key question becomes "Under what conditions do people seek emotional support?" The answer bears directly on the patient advocate who must increasingly assist those whose illnesses will not be cured.

Rose Gates, who says she made "friends for life" through the seminars, hopes for continued association with the SLC Health Advocacy Program. "We are really trying to be progressive," she explains, giving Kenneth Kizer "a lot of credit" for encouraging efforts like hers. "Right now we are identifying and getting ready to train mentors, two for each of the VA's regional networks. We're working with the National Education Center in Minneapolis to develop additional curriculum, and we aim to have more classes with Sarah Lawrence, perhaps next for our supervisors. My dream is to provide ongoing education for all the VA's patient advocates."

Left to right seated: Rose Gates, Michael Fabricant and Joan Murray.
Standing left to right: Sandra Braunschweig, Alice Herb, Terry Mizrahi and Marvin Frankel.

U.S. Supreme Court Rules On Physician-Assisted Suicide

by Margaret Keller, Esq.

In two of the year's most closely watched cases, the United States Supreme Court decided in June that there is no general right to physician-assisted suicide under the federal constitutional guarantee of due process. In order to understand the significance of the Court's decisions, we should first be clear about what the Court decided and what it did not decide.

> *Americans are engaged in 'earnest and profound debate…'*

In *Washington* v. *Glucksberg*, the question presented was whether Washington state's prohibition against causing or aiding a suicide offends the 14th Amendment to the United States Constitution. The Federal District Court agreed with plaintiffs' contention that Washington state's ban on physician-assisted suicide is unconstitutional because it places an undue burden on the constitutionally protected interest of a mentally competent terminally ill adult to commit physician-assisted suicide. The District Court also held that the Washington statute violated the Equal Protection Clause's requirement that all persons similarly situated be treated alike. The Court of Appeals for the Ninth Circuit initially reversed the District Court decision, and then reheard the case by a full panel of Appeals Court judges and affirmed the District Court's ruling.

Chief Justice William Rehnquist wrote the Court's opinion in both the Washington and New York cases. There were also separate concurring opinions by Justices O'Connor, Bryer, Souter and Stevens. Rehnquist's opinion analyzes at length the historical treatment of physician-assisted suicide laws in this country. The Court specifically rejected the lower court's views that Supreme Court's decisions in *Planned Parenthood* v. *Casey* and *Cruzan* v. *Dir. Minnesota Dept. of Health* extended the liberty interest of the 14th Amendment to a personal choice by a mentally competent adult to commit physician-assisted suicide.

In a companion decision in the case from New York, *Vacco* v. *Quill*, the Court held that New York's prohibition on physician-assisted suicide did not violate the Equal Protection Clause of the 14th Amendment. In this case, three physicians and three gravely ill patients (who died before the case was finally decided) sued the New York State Attorney General claiming that because New York permits a competent person to refuse life-sustaining treatment and because the refusal of such treatment is "essentially the same thing" as physician-assisted suicide, New York's assisted suicide ban violates the Equal Protection Clause of the 14th Amendment. The Federal District Court had rejected their argument but the Second Circuit Court of Appeals concluded that some terminally ill persons (those on life support systems) "...are treated differently than those who are not in that the former may 'hasten death' by ending treatment, but the latter may not 'hasten death' through physician-assisted suicide." Writing for the Court, Justice Rehnquist held that the distinction between refusing lifesaving medical treatment and assisted suicide is neither arbitrary nor irrational, but rather is one widely recognized in the medical profession and in our legal tradition. In both decisions, Justice Rehnquist referred repeatedly to the reports and recommendations of New York State's Task Force on Life and the Law.

It should come as no surprise that the Court as presently constituted declined to accept the expansive views of Due Process or Equal Protection taken by the two Federal Appeals Courts whose decisions were reversed. The Supreme Court specifically invited further development at the state level by acknowledging that Americans are engaged in "...earnest and profound debate about the morality, legality and practicality of physician-assisted suicide." The Court's opinions "...permit this debate to continue, as it should in a democratic society." Rehnquist's opinions and at least Souter's concurring opinion also suggest that states are free to experiment and permit physician-assisted suicide if they choose to do so. To date only Oregon has voted to permit physician-assisted suicide (and that law has not yet gone into effect because of court challenges). Oregon apparently plans to put the question to its voters again this November.

Some legal experts have projected that within the next ten years they expect the practice of physician-assisted suicide to be legalized in a few states such as Oregon, Florida and California. In that event, there may be some patients who travel out of state to die just as they did to obtain divorces or abortions.

Another expected result from the Court's decisions this year is that attention may be focused on alternatives to physician-assisted suicide such as efforts to improve the training of health care professionals, the clergy and the general public on issues such as how painkillers can be used and depression treated in terminally ill patients.

> *…states are free to experiment and permit physician-assisted suicide…*

Health Advocates will be expected to participate actively in these future developments.

Margaret Keller is a graduate of the Columbia School of Law and of the Columbia School of Public Health. Recently retired from a private law practice, she is on the faculty of the Health Advocacy Program at Sarah Lawrence College.

UHCAN! Back to Basics — Forward to Health Care Justice

by Diana Westgate Armstrong

The Universal Health Care Action Network, *UHCAN!* is a nationwide network of individuals and organizations who believe in health care for all. Founded in 1992, its mission is to create and strengthen nationwide momentum for justice in health care. Their ultimate goal is a national health care system which is "Universal, Publicly Accountable and Affordable," and which provides "Comprehensive, Quality Health Care."

Headquartered in Cleveland, Ohio, *UHCAN!* defines its most important function as providing a clearinghouse and resource center for education, outreach and advocacy. Networking is done through "Alert" mailings, national and regional conferences, and referrals to local health care rights groups. In addition to its role of providing organizing strategies, analysis of current issues, and direct referrals, *UHCAN!* will develop special materials for public education and technical assistance. Educational materials, which can be available in special information packets, cover topics that include health care reform proposals, consumer rights under managed care, the corporation of health care, money and politics, and so forth. Contacts and information for the production of local access TV programs are also possible. A national speakers bureau and an extensive resource center and library are the informational core of the network. These resources include current and historical newsclips, analysis, newsletters, legislation, organizing materials, and videos.

A bi-monthly newsletter, *Action for Universal Health Care*, provides timely information on the issues, strategies and resources available to groups working for health care justice at all levels of society. Circulated in all 50 states, it is currently posted on HandsNet and PeaceNet on-line networks. A *UHCAN!* web site is now in production.

Every year a national conference for grassroots activists is organized in the Washington DC area to share information, facilitate networking and bring leaders together for long term strategizing. This year's conference, *Back to BASICS — Forward to HEALTH CARE JUSTICE*, was held on October 4-5. One hundred and fifty participants, sixty sponsors and twenty guest speakers and resource people attended from organized labor, the religious community, progressive foundations, national organizations related to health, citizens groups from 30 states and two countries, and physician, nurse and midwife alliances. Of the ten or more unions represented, the most input came from the AFL-CIO's Department of Public Policy and from SEIU, Service Employee International Union, the nation's largest health care workers union.

As a unifying philosophy, the conference theme advised participants to learn from the health care struggle of the past as they plan local and national strategies for addressing the current crises in health care. Health care activists were urged to revisit the ideologies of the universal single payer grassroots movement of the early '90's to build fundamental strategies for solving problems related to our rapidly changing American health care industry. These fundamental lessons learned from the past include the need for:

- Public accountability
- Patient protection measures
- Universal health care

Microphone availability in each session and workshop facilitated an easy exchange of ideas so that virtually every person who wanted to ask a question or give an opinion was able to do so. During this opportunity for exchange, a young medical student took the mike. As chairperson of Youth for America's Health (Yah!)/American Medical Student Association (AMSA), he announced that his organization represents nearly 30,000 physicians-in-training who realize the depth of our health care crisis. Yah!s mission is to unite the youth of America around solving the national health care crisis, and they have scheduled a political rally on the steps of the US Capitol Building for March 13, 1998. *Rally for America's Health* aims to bring attention to the crisis of the 44.8 million Americans who are medically uninsured. Information about Yah! can be found on AMSA's internet site (www.amsa.org).

The concluding plenary session and a *UHCAN!* discussion paper, "Looking North for Health Care Reform — Politically This Time," put emphasis on developing a political agenda to build grassroots momentum for the elections of the year 2000. Current campaigns in three areas were stressed as the crucial first steps in building a political strategy for success in the early 21st century: the single payer initiative in California, creative and progressive action in the states, and Medicare for children.

The Conference concluded with a public demonstration, *STOP PROFITEERING IN HEALTH CARE*. The demonstration targeted the offices of the Federation of American Health Systems, the trade association and lobbying arm of the for-profit hospitals, and included a street theater skit that can be used as a model for local groups. Mark Hannay, Director of Metro New York Health Care for All Campaign (and occasional visiting lecturer for Terry Mizrahi's Health Advocacy I class at SLC), produced and directed the street theater skit. The skit encapsulated the themes of the conference and the platform of *UHCAN!* Entitled "A People's Grand Jury Hearing on Crimes Against HEALTH CARE JUSTICE committed by Corporate Profiteers and their operatives within the American political system," the "hearing" presented two charges: (1) "Criminal conspiracy to violate the principles of Health Care Justice," and (2) "criminal conspiracy to plunder the public treasury by looting tax-payer funded safety net programs, especially Medicaid and Medicare."

A long time activist and coordinator of *UHCAN!* Connecticut captured the Conference fervor best in his own personal position paper:

> Network, network, network! Join forces and offer assistance to children's advocacy groups. Work for comprehensive SCHIP legislation in your state. Identify, connect, and work with other health related groups. Get political. Support and work for candidates who support your views on health care. Get to know your way around your state legislature. We are going to win. It is just a matter of time.

As a student, I found this conference a fascinating and exceptionally informative experience that has added immensely to my evolving education in health advocacy. Meeting so many social activists was inspiring, and observing such a broad-based coalition of health advocacy groups was an education in itself. I hope to return next year with a contingent of health advocacy students to renew this one-of-a-kind field and learning experience.

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