

Health Advocacy Program  
1 Mead Way  
Bronxville, NY 10708-5099

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## Letter from the Director

By Laura Weil

As many of you may have already learned, I will be stepping down as Director of the Health Advocacy Program this summer. It's a privilege to have been at the helm during a period of growth and increasing stability, and I have every confidence that the program is now rock solid and will weather a change in leadership successfully at this time. We have had consecutive years at maximum enrollment selected from a large and capable applicant pool. This has been accompanied by robust engagement and retention of excellent students. The College has renewed commitment in the growth and health of the Health Advocacy Program, and the transition to a new director is being managed in an orderly, comprehensive and thoughtful manner.

There is plenty of time to do this right. A search committee is being assembled for a national campaign to select a new Director, and substantial transition structures will be in place so that both continuing students and the entering class of 2011 will see a seamless move forward.

This is an extraordinary moment in time for health advocacy. While we remain the recognized master's degree program in the field, several on-line certificate programs have sprung up as the public recognizes the momentum of the field. While you might think that these certificate programs would be creating competition for us, in reality they are increasing the public's awareness of our program and our "gold standard" status as the pre-eminent health advocacy program in the country. That said, now is the time for the Sarah Lawrence Health Advocacy Program to augment our position by providing additional and independent opportunities for training that will meet the needs of students and professionals who are seeking specialized skills. Identification and implementation of those curricular opportunities and potential collaborations will be a goal in the next phase of the program's growth.

We are planning two Health Advocacy Program community events I'd like you to be aware of: our annual Holiday Reception will take place here at 45 Wrexham on December 15th, and in April we are planning a professional develop-

ment session for alums and current students to address issues of ageism in the career marketplace. We are working with a nationally recognized speaker who will offer practical tactics older job-seekers can use to get past age-related prejudice in hiring. Stay tuned for details.

*"...now is the time for the Sarah Lawrence Health Advocacy Program to augment our position by providing additional and independent opportunities for training."*

You will note elsewhere in this Bulletin that the inaugural Margaret Keller Distinguished Lecture took place on November 22nd. Margaret is a member of the Health Advocacy Program's original faculty group from 1980-81, and she represents a living history of the program through its evolution. We miss her wisdom, expertise and her extraordinary generosity to students and faculty alike. We hope to extend Margaret's contribution to future students through this annual lecture in her honor.

## Letter from the Editor

By Barbara Robb

One of the goals of advocacy is change. Whether it be change in policy or change in attitudes, advocates work to bring about change. It's inevitable that the Health Advocacy Program itself will also change over time. That is particularly evident right now. HAP Director Laura Weil has announced that she will be stepping down at the end of this academic term. The HAP has grown in size and strength under her leadership, with an increased emphasis on the importance of the fieldwork component of the program. I'd like to take this opportunity to thank Laura for giving me

the opportunity to edit the Bulletin these last few years. It has been a pleasure to work with her.

Other changes in the Program have come about as long-time faculty members have retired. Margaret Keller, who has taught Health Law since the inception of the Health Advocacy Program in 1980, retired this year. A new lecture series has been inaugurated in her honor, as we wish her well in her retirement. HAP now has a new professor of Health Law, Karen Porter, as well as a new professor of Health Economics, Kim Christensen. Please join me in welcoming them to Sarah Lawrence. Two members of the Health Advocacy community at the

College have taken on added responsibilities this year: Rebecca Johnson has begun teaching a revised Program Evaluation and Design course and Gloria Escobar-Chaparro has begun a postgraduate fellowship as Fieldwork Coordinator.

HAP students and alumnae/i continue to work for change. In this issue, we include articles about advocacy at Planned Parenthood, the Medicare Rights Center and United Hospice of Rockland, as well as an article about providing information and support for college students with mental illness and an update on student work with Mossville Environmental Action Now (MEAN) in Louisiana.

## Upcoming Events

### People's Policy Institute Workshops

Jan. 6, 2011

Collaborative Policy Design for Community-Based Organizations

Jan. 21, 2011

Policy Analysis for Youth Activists

Jan. 21, 2011

Policy Analysis for Community Activists

All workshops are held in New York City. For more information, see <http://policypeople.org/workshops>

### The Science of Research on Discrimination and Health

Feb. 2-4, 2011

Three-day conference to examine the research and the research methods for investigating the role of racial/ethnic discrimination in health. Conference sponsored by the Applied Research and the Behavioral Research Programs of the Division of Cancer Control and Population Sciences (DCCPS) of the National Cancer Institute (NCI), National Institutes of Health. For more information, see <http://conference.novaresearch.com/SRDH>

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Program Director: Laura Weil  
Editor: Barbara Robb  
Email: [lweil@sarahlawrence.edu](mailto:lweil@sarahlawrence.edu)

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# Reports from the Field

## Advocacy at Planned Parenthood

By Joan Adler

I was moved to write about Planned Parenthood and, more specifically, about the local affiliate in Ithaca where I work, because family planning clinics offer a plenitude of opportunities for advocacy, from the immediate and highly personal to high-level policy and political advocacy. Additionally, I believe that the principles and practices governing our affiliate embody so much of what we advocates strive for in all health care settings.

Planned Parenthood, from the turn of the century, has believed that trust in a woman's capacity to make optimal birth control decisions rests on access, information and individualized care. These priorities are well-suited to the nurses and nurse practitioners who staff family planning clinics.

Philosophically schooled and trained to consider a patient and her presenting needs in the context of the patient's life circumstances and her capacities, they consider it to be an essential part of their work to strategize with patients to promote their successful participation in their health care and contraceptive use.

It's also been a privilege to work for an organization dedicated to improving the quality of health care and access for women (and increasingly, men) who do not enjoy the privileges bestowed on the racial, socio-economic, sexual, physically-abled and age majority. One of our primary tasks, then, is to recognize and respond to barriers that interfere with our patients' access to health care and contraception. Our logistical responses include walk-in clinics, evening clinics and weekend hours. We arrange phone counseling appointments for out-of-town patients seeking to terminate their pregnancies. We mail birth control supplies to patients who can't get to our clinic or to a pharmacy. We enroll our patients in every imaginable government-funded insurance program so they can afford birth control, cancer-screening, annual exams, STD treatment, prenatal care and abortion.

We've learned that the most challenging barriers to overcome, however, are personal ones — the ones that impede self-care, wise decision-making and sexual well-being. We cull insights into the personal barriers of our patients by asking questions on our health history form about sexual orientation, depression, sexual abuse, self-abuse, eating disorders and domestic violence. It is also a testament to the warm,

accepting and non-judgmental attitudes of our staff that patients often reveal their struggles to us, unsolicited. And, because we're all about sex, we regularly see the effects of stigma, stereotyping and social pressure that can cripple self-acceptance and self-assertion and lead to high-risk behavior. Our clinical staff is supported by our counseling department, to which they regularly refer patients who reveal health-threatening issues. We have expertise in many of these areas and where we don't, we refer. If the patient would like, we often sit with her while she makes that first phone call to a referral. In this way, we are able to assist our most vulnerable patients in obtaining help at a time when next steps often seem insurmountable.

*"We live in a time when there is no consensus...that a woman's pregnancy decision is or should be a personal one."*

We've also introduced some "best practices" to contend with stigma and remove barriers. In a rare move for a family planning clinic, we decided to contract with our local health department to serve as Tompkin County's STD clinic. One of the reasons we took on this role is that, in most New York counties, STD diagnosis and treatment is provided in health department clinics on specific days. Patients who cannot afford private care are often ashamed to walk into a public agency when the reason for their visit is apparent because that is the only service being provided at that day and time. In addition to this threat to their privacy, limited daytime hours compromise timely care. By incorporating the clinic into our practice, we address these issues. First, patients who come in for an STD visit are intermixed with patients who are in our waiting room for any number of other reasons. Second, we see patients six days a week. And third, as long as they are county residents, their care and treatment remain free. Unlike a visit to the health department, patients can also discuss birth control at their visit, as well as STD prevention and harm reduction. Having had a non-threatening, respectful experience, the visit often marks the start of a relationship. A new patient may unexpectedly find the courage to schedule her first PAP smear or have a breast lump checked.

Because of the stigma and complexity surrounding the decision to have an abortion, the tenets of preserving patient confidentiality and providing nonjudgmental care receive our utmost attention. This is so whether we are counseling a woman who is unsure about whether to continue a pregnancy, or one who has made up her mind to have an abortion.

Experience has taught us that women make decisions best about this life-changing circumstance in an environment of unconditional support, one that is absent of pressure, coercion and even well-meaning advice. Unfortunately, women do not always find this at home or in the friends they usually rely on for support. Pregnancy options counselors therefore have the awesome responsibility of providing the safe harbor necessary to support authentic decision-making.

At our clinic, an undecided patient can see a counselor for as many visits as she needs to sort out her thoughts and feelings and to gain clarity and equanimity. Also, to help with decision-making, we can provide information regarding gestational sizing, fetal viability, adoption, community services for pregnant women, information on financial support and child-care options.

Counseling is no less important for the woman who has already decided to have an abortion. The decision to terminate can carry with it a host of feelings that also need a safe haven for expression. Though 43% of women will terminate a pregnancy at some point in their lifetimes, few women talk about their abortion(s). The reasons for the silence are both sad and understandable. We live in a time when there is no consensus, even (or especially) among family and friends, that a woman's pregnancy decision is or should be a personal one; women simply do not feel safe saying they are having, or have had, an abortion. This is so even when so many other formerly taboo issues primarily born by woman—incest, cutting, sexual abuse, domestic abuse, anorexia—have moved from darkness to enlightenment and empathic understanding. Women's suffering is compounded by the fact that they neither see nor hear the reasons for their decisions mirrored by the thousands of women who have made the same decision.

Because they don't have access to their usual sources of support, many of our patients feel very alone, almost like pariahs

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# Advocacy in a Non-Profit Organization: Medicare Rights Center

By Joshua Lapps

The Medicare Rights Center (MRC) is a national not-for-profit with two offices (New York and Washington, D.C.). The New York office is staffed by a cadre of professionals and has a complement of volunteers who work on the consumer and appeals hotlines. In Washington, the staff works closely with the government to improve Medicare through policy advocacy.

The major goal of MRC is to improve, through advice, assistance and advocacy, the experience of Medicare beneficiaries. The hotlines, mostly volunteer-based, serve as the primary access point for consumers to call and for counseling to occur. The professional staff members act as caseworkers to provide more in-depth counseling for more complex or confusing situations. They also provide expertise and guidance for the volunteers (and interns) as they work to counsel clients.

As Medicare beneficiaries and their caregivers call the hotlines, the hotline workers try to answer Medicare-related questions and identify the root problems in the situation. Medicare is exceedingly complex, a reality exacerbated by the proliferation of private corporations offering Medicare Advantage and prescription drug plans.

One major problem faced by Medicare beneficiaries is affordability of health serv-

ices and drugs. MRC positions itself as a resource to direct people to state-managed low-income subsidy programs. In New York, MRC works closely to help enroll people into these programs to help make Medicare more affordable.

*"At the MRC, we provide space for trained volunteers and professionals to listen to people's stories and try to help them make sense of a complex, yet necessary, part of their lives."*

I interned with MRC this past summer as my second fieldwork placement. While there, I worked on the appeals hotlines, which put me in direct telephone contact with people who have every right to be frustrated, upset, angry and disillusioned. When Medicare denies payment for a service that one's health care provider indicated was necessary, it is hard to understand how and why coverage would not be extended. Original Medicare, Medicare Advantage and Medicare Part D prescription drug plans all have systems through which an individual (or an advocate working on the individual's behalf) may appeal a denial. Much of the work on the appeals hotlines is outlining the appeals process and helping the caller iden-

tify who they must work with in order to file an appeal. The bureaucratic process can be daunting and off-putting for many people, especially if they are upset over a decision not to cover needed drugs or services. We often helped callers process what was happening and provided advice to troubleshoot the situation.

MRC also offers hotline and direct-contact services for professionals working with Medicare beneficiaries. In these cases, a doctor, social worker or other professional takes initiative to help their client with a variety of different challenges with the Medicare system. In this way, MRC provides comprehensive services to a variety of constituents.

MRC offers a vital service to Medicare beneficiaries by having "real people" answer hotlines and provide assistance. In the age of automated customer service response systems, it is rare to have an opportunity to speak with a representative and explain your story fully. At the MRC, we provide space for trained volunteers and professionals to listen to people's stories and try to help them make sense of a complex, yet necessary, part of their lives.

*For more information about the Medicare Rights Center, please visit [www.medicarerights.org](http://www.medicarerights.org)*

*Joshua Lapps is a second-year student in the Health Advocacy Program.*

## The Hospice Experience: A Conversation with Rockland Residents about End-of-Life Issues

By Louise Becker

Somehow I always wanted to learn more about death and dying. For decades I had been fascinated with Shamanic healers and the afterlife, and had read about near-death experiences. I had lost both my parents after short illnesses, but had no real-world experiences with end-of-life issues. Then last winter I met Mimi Hoffman, the community liaison at the United Hospice of Rockland (UHR). We met through mutual friends, but there was another connection. I had been asked to take part in a fundraising event for a South African hospice, a project connected to UHR through the international

hospice association. I had no idea what to expect from an internship with a hospice, but I was keen to find out.

UHR is a not-for-profit organization that provides care, hope, comfort and improved quality of life to individuals and their families facing serious illness. They also offer compassionate support to members of the community who have experienced the loss of a loved one. Their vision is a community in which all individuals retain their dignity and hope while receiving the best care and support that hospice has to offer.

My first task was to define the internship project. I started by checking on any existing outreach projects, and found that none had

been performed. In fact, the only method of gathering information from those closest to the hospice patient—caregivers—was through standard satisfaction surveys developed by the National Hospice Association, sent eight weeks after a hospice case is closed. In addition, families receive a national survey about bereavement services thirteen months after their loss.

After collaboration with Mimi, the hospice director and members of the ethics committee, I developed an interview protocol and compiled an outline for a caregiver outreach study. The objective of "The Hospice

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## The Hospice Experience: A Conversation with Rockland Residents...

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Experience" was to learn first-hand about the barriers and resistance that people have to face in accepting and starting loved ones on hospice care. Through one-on-one interviews we hoped to learn how people might be more open to hospice care.

We agreed that the results of the research would form the basis of a strategy to:

- improve access to, and quality of, hospice services for Rockland county residents;
- incorporate elements of the Palliative Care model into the UHR program to achieve a more seamless continuum of care;
- collect information to aid state legislative efforts; and
- develop an innovative advocacy platform with tactics to reach opinion leaders such as physicians, nurses and religious leaders, as well as the general public.

*"The objective of 'The Hospice Experience' was to learn first-hand about the barriers and resistance that people have in accepting and starting loved ones on hospice care."*

But be careful what you plan! I had little idea how engrossing the interviews would be, or how emotional. It was as if the sluice gates opened up...my subjects *wanted* to share these end-of-life experiences. They responded with their hearts and shared hours of their time with me—along with family photographs, anecdotes and their fears and deepest feelings. Almost everyone I interviewed felt that Hospice had helped them so much, and now, even though it brought up raw emotions, they wanted to help others get through the difficult period after the loss of a loved one.

Drawing from the Hospice database, a hundred names were selected as being potential subjects for the project. Criteria were that the deceased had been diagnosed with end-stage cancer and passed away in the last two and a half years; and that their caregivers lived in Rockland county or northern New Jersey and agreed to be interviewed in person and to sign Consent Forms.

I conducted a total of fifteen interviews about the end-of-life experiences of, people who had died from eight different types of cancer. In three instances, another family member also took part in the interview, bringing to eighteen the number of men and

women interviewed. Apart from the questions about access to hospice care and hospice services, I also requested a short personal narrative or fond memory of the deceased person.

Quantitative data was easy to collect, with answers falling into definable "Yes," "No," or "Not Applicable" boxes. The long-form answers were more complex. I had to develop a system of reporting on language use, common themes and anecdotal experiences. Sometimes answers came in the form of repetitive language. For instance, these italicized phrases were used frequently when the focus was on caring:

- "Hospice is *there for you*. They know what has to be done"
- "Hospice is wonderful. They know exactly what to do. *They've been there!*"
- "Hospice was *right there*. They had all the stuff I hadn't even thought of...even the meds in a different formulation. It was all about *comfort*. Everyone seemed to want to be there. It was all very upbeat—helpful, friendly—all the good things. It made it easy for me."
- "I mention it all the time. They were *a very big help!*"
- "I'd tell them that Hospice is a HUGE help!"
- "Absolutely I'd refer someone to hospice! I'd talk about the *care*...and as family members what kind of *support* is given, like the *bereavement services*."

UHR proved to be a respected organization in the community, providing essential and much needed services. Those interviewed were grateful for the help and support they received at a very difficult time in their lives. While the services and staff are generally held in high esteem, I found that there were some gaps in communication and general public awareness and education that could further the mission of UHR and help achieve the greater vision for the community. Significant opportunities exist for:

- reframing language around care and services;
- creating new products and services;
- developing an ongoing Advocacy Program for Sarah Lawrence students and UHR volunteers;
- reporting the data collected to community opinion leaders, such as physicians, nurses, administrators, religious leaders and lawmakers, as well as the media;
- expanding and refining existing services, such as bereavement programs, *AssuringYourWishes.org*, the UHR Website and the Palliative care program; and

- creating a public awareness campaign that highlights how the last wishes of residents are honored, while at the same time educating about end-of-life issues.

*"I had little idea how engrossing the interviews would be, or how emotional."*

Because I'd been so close to the project, I met with my collaborator, Mimi Hoffman, to learn her point of view about the impact of the study. According to Mimi, "This study has helped us develop a viable protocol that can be used by interns in the future. It yielded a lot of information. Louise also developed a way to analyze the results. This has become a great guide on issues that needed our attention. For UHR it is a pioneering project! The reason for the project—to learn more about access to hospice services—became very real when we saw the data. For instance, we knew that the Web could be an educational tool, but it was only when we saw how many people used email and accessed our Website that we realized what else we could do."

She summarized other insights gained from the experience as follows:

- We didn't realize how often people refused to accept a referral to hospice. Our medical director will try and use this information in the future.
- We knew bereavement counseling was important, but it now appears more complicated when the end-of-life experience is short. We need to explain bereavement issues better!
- Accessing the caregiver audience was a powerful experience—not only for Louise, but also for UHR. We were touched that these families shared so willingly with us, and we hope to make this an ongoing project in the future.
- Marketing the hospice experience by diagnosis seems to have merit, and we're eager to see the results from another Sarah Lawrence student who is currently interviewing caregivers about hospice patients with COPD.

*To learn more, go to [www.hospiceofrockland.org](http://www.hospiceofrockland.org) or email Mimi Hoffman at [mhoffman@hospice-ofrockland.org](mailto:mhoffman@hospice-ofrockland.org).*

*Louise Becker is a graduate of the Health Advocacy Program.*

# Providing Information and Support for College Students Diagnosed with Mental Illness

By Deborah Teevens Gangl

Throughout my tenure at Sarah Lawrence, I have been interested in the health of college students. I've identified only a handful of health advocates working in university settings. Legally, 18-year-olds are expected to take charge of their own health care, but few are prepared or mature enough to take on this important responsibility and no one teaches them how. Advocates can play an important role in educating young people about how to navigate the health care system.

Advocates can provide support to college students with pre-existing medical conditions. Years ago, students diagnosed with a chronic illness were not able to attend college. With recent medical advances and more effective medication, however, many chronically ill students are now enrolled in colleges and universities throughout the country. Students dealing with a mental health diagnosis are included in this group.

Fellow HAP student Susan Greenberg and I uncovered a huge gap regarding the health needs of college age students when we presented our first paper in Professor Terry Mizrahi's Community Health class. I remember Dr. Mizrahi reminding us to save our work as we might use it in the future. I'm glad I listened, as my Capstone is an expansion of that first-year work.

Shortly before deciding on my Capstone topic, I received a call from a friend who was concerned about a neighbor's son who had recently been diagnosed with bipolar disorder. The young man, a senior in high school, had already been accepted at a prestigious northeastern university when he received his diagnosis. The family had trouble finding information about attending college with this type of mental health issue. They were so frantic for help that the young man's mother considered relocating to New England to oversee care for her son while he attended school.

Remembering my prior college health research, my friend asked if I had access to resources that might help this family. After the call, I put on my advocacy hat and began looking into college mental health programs. Similar to the research completed when I looked at college health centers, I found varying degrees of mental health support among the different universities.

With this story in mind and understanding the need from my earlier research, I met with Professor Rachel Grob to discuss my

Capstone ideas. Dr. Grob encouraged me to follow my passion. After a long brainstorming session, I decided my Capstone project would focus on providing resources and support for students struggling with mental illness.

From the project's beginning, my gut told me there was a need for mental health resources, but I needed to be able to demonstrate that need. I began by interviewing students, parents, guidance counselors, high school teachers, clinicians, practicing therapists and heads of student health centers. Every single one of my interviewees supported my idea and felt such information was difficult to find, but urgently needed.

*"Legally, 18-year-olds are expected to take charge of their own health care, but few are prepared or mature enough to take on this important responsibility and no one teaches them how."*

One practicing psychiatrist who treats young people acknowledged that he has little or no information to give parents who ask "Where should my child go to college?" Another expressed concern over the lack of credentialed counselors at the college level. My research echoed this when I learned that some universities use graduate students to counsel undergraduates. In one case, a student counselor with no experience was assigned to counsel a female student struggling with cutting issues.

Students, parents and clinicians need to know the level of support and service the university can provide. In the case of a small and/or rural school, they need to know whether the school can provide a timely referral in an emergency.

I have identified sample colleges and universities representative of institutions of higher learning throughout the United States. As this article goes to print, I am analyzing college admissions materials, health center literature and the ease of navigation and content of website information regarding college mental health. I'm also looking at health center programs such as Active Minds, which is a campus-based mental health organization, and the Jed Foundation, an organization based in New York City that provides online information for students with mental health issues. In

addition, counseling access and availability, health center hours, resident advisor training, faculty education and involvement, and access to hotlines are some of the areas that will be important factors in evaluating the different college facilities. Timely access is important to students who may be in crisis. The availability of such resources may be critical.

Professor Mark Schlesinger, who along with Dr. Grob is mentoring me for my project, has challenged me to think outside the box in order to promote my advocacy idea. While conducting interviews, I have both marketed and advocated for my Capstone. Many of the clinicians I interviewed have requested updates on my progress. In addition, I continue to raise awareness by speaking to students, parents and teachers. Last week, I met with a small group of parents interested in finding out more about college mental health. Many in the group admitted they were unaware of the health services available at their children's colleges and wanted to know more about what they should ask. Some were surprised to learn that paying the tuition bill didn't automatically allow them access to information about their child's health status.

In the next few weeks, armed with my questionnaire, I plan to visit the sample schools. Being on campus is important. I'll be looking for resources such as hot line numbers, mental health screenings, student-led meetings and information about available help. These important resources should be visible throughout the campus. At one school, pictures of school-aged children, taped on the inside of doors to bathroom stalls, reminded students to take care of themselves during exam week. These clever posters included relaxation tips as well as numbers to call for help with stress and anxiety.

It is my hope that upon completion of my Capstone, I will be able to provide young people living with a mental health issue with the information they need to make their college experience a success.

*Deborah Teevens Gangl is a second-year student in the Health Advocacy Program.*

# Patient Safety Movement

By Brenda Shipley

It's a gorgeous autumn day in Austin, Texas. Outside, the city's river walk is a beacon for bicyclists and joggers taking in a leisurely, sunny afternoon. But inside, at the Consumers Union Safe Patient Project Summit, there's a storm brewing as a group of people unexpectedly and forever changed by preventable medical errors are kicking up dust. These accidental advocates represent the growing patient safety movement that is gathering strength across the country.

There are an estimated 100,000 deaths every year due to medical errors, and a growing suspicion that even this number is grossly under-reported. To put this in perspective, imagine a jumbo jet crashing, killing everyone on board, every other day. Yet, in an atmosphere heavy with complacency, only twenty-five states are outraged enough to mandate reporting of medical

errors by the hospitals and ambulatory surgical centers they've licensed. Just a handful of states verify the data they've collected and disclose it to the public they are accountable to protect.

*"...the patient safety advocates at this summit have their sights set first and foremost on healthcare-associated infections."*

While there are many types of medical errors, the patient safety advocates at this summit have their sights set first and foremost on healthcare-associated infections (HAIs). According to the government's own data, the CDC estimates that HAIs alone add a whopping 45 billion dollars to our country's healthcare bill every year. That's revenue the hospitals make, from making mistakes.

HAIs are the leading cause for many advocates' personal pain and professional calls to action. Says one advocate, "You can't kill my mother and get away with it." Another tells us what her doctor told her, "That's the chance you take when you go into the hospital." Her doctor is right, but we, the consumers, have not been fairly warned.

To end secrecy and save lives, patient safety advocates are campaigning state legislators, departments of public health, self-insured employers and consumer-directed health plans to mandate standard, audited and publicly available reporting of medical errors by hospitals and ambulatory surgical centers. Forecast for consumers: Temperatures rising. Cloudy with strong winds. Eventual clearing, with a chance of zero tolerance for preventable medical error.

*Brenda Shipley is a student in the Health Advocacy Program.*

## Fieldwork Coordinator: Gloria Escobar-Chaparro



*Gloria Escobar-Chaparro*

A hallmark of the Health Advocacy Program is the rigorous field placement component:

- three 200-hour internships;
- participation in the Fieldwork Professional Seminar in year one;
- participation in the Capstone Professional Seminar in year two; and
- completion of a Capstone project.

For me, the field placement component was a key factor in my decision to enroll in the Program. So, upon graduation this past May, when I was awarded a post-graduate fellowship that allowed me to continue on as the fieldwork coordinator, I was thrilled by the opportunity to impact the professional development of the next HAP student class.

During my time as a student I had very positive experiences working with two different fieldwork coordinators and I had fabulous internship experiences. However, I believe I am taking more of an activist approach to the role than did my predecessors.

As the fieldwork coordinator, I am actively working with students to identify the issues they are passionate about, the populations whom they most want to help and the changes they want to see effected in the health care field. The Fieldwork Professional Seminar sessions are being used to provide practical knowledge, such as how for-profit and not-for-profit corporate structures change the way these entities make decisions as well as how to write a literature review. The process of updating the students' resumes to reflect their evolution as health advocates is discussed in both the seminar setting and during in depth one-to-one meetings. I am also working to create a database of active and potential placement sites that students can use to find meaningful internships that meet their goals and interests.

The need for health advocates continues to grow in new areas, for example, in environmental health and environmental justice. As the fieldwork coordinator, I hope to develop new relationships with HAP alumni and other partners. I encourage all to contact the Program if you identify a need or a project that can benefit from having the assistance of a Health Advocacy student (or if you would like to be included in our database!).

When students enter the Health Advocacy Program they may have been anything from recent college graduates to nurses, lawyers or stay-at-home parents, but when these students graduate they are health advocates. My goal is for the students to regard the field placement component of the Health Advocacy Program as a critical factor in this transformation.

# Update on Student Work in Louisiana

## The Mossville Community Health Needs Assessment: Process, Findings and Advocacy

By Rebecca Johnson



Rebecca Johnson, principal investigator and HAP Faculty, at CHNA kick-off event in Mossville. (Photo by Rebecca Hudson)

It was during Spring break 2010 that seven first and second year Health Advocacy Program students accompanied me to Louisiana to help Mossville Environmental Action Now (MEAN) conduct a Community Health Needs Assessment (CHNA). The MEAN CHNA was an IRB-approved interview protocol designed to assess access to and satisfaction with health care for the residents of Mossville. The CHNA had both quantitative and qualitative questions, but the whole process has been guided by the principles of Community Based Participatory Research (CBPR).

CBPR is an approach to health and community based research that can be academic research structured with the needs of the community in mind, but in its most ideal form, academic resources are put at the disposal of community activists seeking to answer questions about health disparities, environmental health, economic discrimination, community development and other problems the community might face. MEAN invited the HAP students to help with this more ideal form. The most tangi-

ble manifestation of community control was a three month process of meetings in which the MEAN leadership learned about IRBs, ethical standards, issues of ownership and control of research data, community data analysis and the nuts and bolts of conducting a randomly sampled, door-to-door interview protocol.

In March we joined together with our co-investigators from Mossville and hit the streets. It became clear fairly early in the process that many residents had left the area to seek medical treatment away from the long reach of the local refinery-controlled health care institutions. We also learned that many people living in the community were very sick. MEAN and the HAP team are still analyzing the results of interviews so we can't share final data at this time, but MEAN has given us permission to share some first impressions.

The MEAN CHNA was based on the National Health Interview Survey. This makes it possible for us to compare the data gathered by MEAN with the data from the NHIS survey conducted, serendipitously for us, from January to March 2010. Already we know that Mossville residents experience chronic diseases such as diabetes, heart disease, hormonal and skin problems and cancer at rates two to three times higher than the general population. Mossville residents are offered rehabilitation and restorative therapies at a much lower rate than the general population and suffer from debilitating degenerative diseases that would be considered rare in other parts of the country. Their access to insurance is well below the national average.

*"I am proud that HAP students and I have played a small part in this decades-long struggle for the health and environmental security of Mossville."*

The first engagement activists have with the requirements of academic research often can be quite rocky. That was not the case with MEAN, but there were moments when community residents didn't understand the need for randomization, the use of a precise script in representing themselves and the

rigors of informed consent. We all learned together how much work is required in protecting a process that today the community recognizes as capturing their situation in ways unexpected and revelatory. The rigor, attention to detail and commitment to both community consent and participant protection has given the community a potent tool for combating the refinery industry contention that they are not being harmed by the pollution and "accidents" that occur regularly a scant half mile from the Mossville town line.

The MEAN CHNA data has added new energy to MEAN's pursuit of a free toxicology clinic for their community. I am proud that HAP students and I have played a small part in this decades-long struggle for the health and environmental security of Mossville.

*Rebecca Johnson teaches in the Health Advocacy Program.*

### Alumnae/i News

Shawna Irish, HAP '07, is Alumnae/i Relations Correspondent for the Health Advocacy Program. Please send her news of your work, personal achievements and milestones to be edited and submitted to the Sarah Lawrence Magazine. Feel free to send anything that's happened to you in the last couple of years. Shawna can be reached at [shawna.irish@gmail.com](mailto:shawna.irish@gmail.com)

# T-tests and Frequencies and Chi-squares: Collecting and Analyzing Health Assessment Data with Mossville Environmental Action Now

By Ashley Gephart

Since their formation in the 1990s, MEAN has been working relentlessly to address the overt environmental racism that continues to plague the Mossville community with grave and sometimes fatal health issues. Mossville residents are not new to being solicited for information regarding their health or the health of their environment, as numerous outside researchers have landed in Mossville long enough to take soil, blood and water samples and then disappear with the community's data. In Mossville, this kind of "helicopter" research where researchers get in and get out, often without the consent of the community from which the research is being appropriated, has often resulted in the community's information being used against it in defense of the local petrochemical industry. Consequently, trust in research and trust in outsiders interested in hearing about health concerns was not at an all time high when the six of us HAP students rolled into town.

Participatory action research, the type of research in which MEAN and HAP are engaged, is in part characterized by a great deal of front-end relationship and trust building that must happen between outside researchers and the community. While HAP students did not have much time to build relationships before hitting the streets of Mossville to conduct interviews, Rebecca Johnson and the leaders of MEAN strategically built in a couple of days at the beginning of our trip that would allow us to begin

to show the community that we came to Mossville with an understanding of our role in the project as MEAN's support team.

*"Participatory action research...is in part characterized by a great deal of front-end relationship and trust building that must happen between outside researchers and the community."*

In order to train for the door-to-door interviews, HAP students were partnered with MEAN members to rehearse the interview protocol, with a lot of attention paid to obtaining interview participants' consent to conduct the interviews. It was imperative that community members know that the health assessment was not being conducted under the guise of any promises that might not be able to be kept, as well as that the information that they provided was confidential and would not be used, as it had been in the past, to harm the community. The interview teams hit the streets and began a dedicated week of interviewing. The teams walked around Mossville knocking on doors and speaking with community members from 10:00 am until sunset. MEAN members, including some of the MEAN Teens, showed up to conduct interviews after work and school and in between other life chores. The dedication and enthusiasm displayed by MEAN and their HAP partners was truly inspiring.

It is challenging to describe the feeling of being invited into someone's home and life in such an intimate manner. Despite all of the excellent theory that I learned in my two years in the HAP, it was my experience in Mossville that truly confirmed the vital importance of being a good listener. Gloria Escobar-Chaparro so eloquently explained to me that, "As people would share their stories with [her] and respond to our questions, [she] always felt that they wanted neither [her] pity nor sympathy—they only wanted [her] to hear the truth of their experiences." The strength, resiliency

and undying spirit of the Mossville community were humbling in ways that will forever be with many of us.

Ultimately, the interview teams conducted 78 interviews totaling approximately 30% of lived-in homes in Mossville. After a couple of weeks of recuperation, the HAP team was back together in NY to discuss data entry and analysis. Those of us who were not familiar with how to create data files or run data tests, like frequencies and chi-squares, were offered training in SPSS, a statistical software program, by former HAP faculty member Mike Smith. Over the course of a few months the team created a data file, entered the survey data and began the preliminary data analysis for MEAN. Rebecca has since made another trip to Mossville and has discussed some of the preliminary data results with MEAN. As I write this article, members of the HAP team continue to work on analyzing the data in an effort to support MEAN in utilizing their research.

For me, being a part of the MEAN-HAP partnership has meant having the opportunity to assist some of the most amazing people I have ever met in their tireless effort to confront environmental racism and protect their community. That alone would have been enough of a reason to get involved. However, this experience has also offered me the opportunity to learn both how to be a responsible advocate and also how participatory action research is conducted from some of the earlier stages onward. I have now seen the theory in practice, which I believe is an invaluable experience that was a necessary component of my training as a health advocate. The Mossville experience continues to provide me with the opportunity to learn how to support research that aims to reallocate power, build community capacity and begins and ends in the communities that will be affected by the research results and subsequent interventions. The research skills and advocacy lens that I gained through my experience working on this project have already assisted me in my professional life. I now have a clearer understanding of what being a health advocate means for me as I go out into the world beyond Sarah Lawrence.

*Ashley Gephart is a graduate of the Health Advocacy Program.*



MEAN-HAP Co-Investigators ready to get some data. Front, left to right: Latoya Scott, Joshua Lapps, Nicole Zolofra; standing: unidentified participant, Eranica Jackson, Gloria Escobar-Chaparro. (Photo by Latoya Scott)

# Faculty News

## Revised Program Design and Evaluation Course

The Health Advocacy Program curriculum continues to innovate, providing important learning opportunities to students. This year the Program Design and Evaluation course underwent a major overhaul. Rebecca Johnson was the lead faculty and she asked to change it in two critical ways: first, she wanted to include an eight-week clinic in which students would work as consulting teams with local and regional clients; and second, she asked not to be the only instructor but to invite two guest faculty to provide expert content in the areas of financial planning and research methods and evaluation. The goal of these changes was to give the class real-world experiences in which to anchor the classroom investigation of program design processes, as well as to include increasingly critical skills such program budget development, reading financial statements and understanding current innovations in program evaluation.

Over the summer Rebecca and HAP Director Laura Weil began interviewing and evaluating potential clinic clients. The clients chosen for the Program Design clinic represented some of the many areas that our students will touch as professionals in the field of health advocacy. Agencies receiving assistance included Project Renewal Homeless Medi-van service (New York City), The Bristol Assisted Living and Winthrop University Hospital (Long Island, NY), The Allston-Brighton (MA) Drug Taskforce and Dominican Sisters Family Health Services (Ossining, NY). The student teams helped clients investigate Medicaid access, discharge and readmission barriers, prescription drug stor-

age issues and resources for non-medical senior community care programs.

Eva Boyce, Chief Financial Officer of Gay and Lesbian Advocates and Defenders (Boston, MA) and Professor Cora DeLeon of New York University have added great depth with their patient and down-to-earth instruction in two areas in which many students have little experience but, at times, considerable aversion—financial management and research methods.

Throughout the semester students are encouraged to think critically and practically about the issues facing nonprofit agencies and for-profit health care providers and about how those issues might help them develop their professional social change philosophy. Early in the semester the four agencies presented the stark realities of the difficult economic decisions health care and advocacy organizations are now being forced to make. At the same time students have had the opportunity to provide important information and resources for addressing some of the problems caused by the economic downturn and current political situation.

A Program Design course is no different from any other component of something as complex as a graduate program curriculum. We learn from students, just as they learn from us. The course will be evaluated by students, the Program Design faculty team and the larger HAP faculty as we continue to build a program that brings rigor, relevance and innovation to the field of Health Advocacy.

## Faculty Profile: Karen Porter



Karen Porter

Karen Porter is Assistant Professor of Clinical Law and the executive director of Brooklyn Law School's Center for Health, Science, and Public Policy. She teaches Public Health Law and runs the Health Law Clinic. She has taught courses at Washington University Law School on law and medicine, AIDS and the law, and legal ethics, and has authored numerous publications related to AIDS policy. She will be teaching the Health Law course in the Health Advocacy Program.

Prior to teaching, Porter held a post-doctoral fellowship at Montefiore Medical Center/The Albert Einstein College of Medicine, Department of Epidemiology and Social Medicine. Her background also includes work as a senior policy analyst and staff counsel to the National Commission on AIDS.

She graduated from Yale College with a B.A. in Philosophy. She has a J.D. from Yale Law School and a Masters in Nonprofit Management from New York University's Wagner School of Public Service.

## Margaret Keller Distinguished Lecture Series

### A Vision of Equality: How Policy Advocacy Can Help Change the World

On Nov. 22nd, the Health Advocacy Program presented the inaugural event in the Margaret Keller Distinguished Lecture Series. Chai R. Feldblum, Commissioner of the Equal Employment Opportunity Commission, described her Six Circles Theory of Effective Advocacy. Commissioner Feldblum described how that approach shaped both the passage of the Americans with Disabilities Act in 1990 and the Workplace Flexibility 2010 enterprise at Georgetown Law School. She sees six roles in advocacy: strategist, legislative lawyer, lobbyist, grass-roots participant, communications specialist and policy researcher, and encouraged health advocacy students to examine their skill sets to see where they best fit. She spoke too about our need to engage as a society to determine how to change the norm, so that true equality can be achieved for all. It is her belief that voluntary social changes must occur in concert with changes in the law in order to achieve that goal.



Chai R. Feldblum (left) and Margaret Keller

Margaret Keller, the guest of honor at the talk and reception, was a member of the original faculty group that started the Health Advocacy Program in 1980. She has taught Health Law in the program since its inception. The evening was an opportunity both to honor Margaret and to mark the 20th anniversary of the passage of the Americans with Disabilities Act.

## Faculty Profile: Kim Christensen

Kimberly (Kim) Christensen received her Ph.D. in economics from the University of Massachusetts at Amherst and, for twenty-five years thereafter, taught economics and women's/gender studies at SUNY/Purchase College. Among other honors, she is the recipient of the President's Award for Innovative Pedagogy, the Purchase Students' Union Letters and Sciences Teaching Award, and the state-wide SUNY Chancellor's Award for Distinguished Teaching.

While at Purchase, Christensen founded and chaired the SUNY/Purchase AIDS Task Force, in which capacity she worked extensively with the Westchester Department of Health to inaugurate the first on-campus HIV test site in the SUNY system and to organize a Westchester County College Summit on HIV/AIDS in the fall of 1999. She also created a ground-breaking course on the political economy of the AIDS crisis that served as a model for similar courses throughout New York State.

For seven years, Christensen was an active member of ACT UP/NY, in which capacity she worked with ACT UP's Women's Committee, Health Care Access Committee, and, for a time, as the group's co-Treasurer. She has also been active around issues of welfare, serving, for instance, on the Executive Committee of the Women's Committee of One Hundred/Media Campaign for Fairness on Welfare.

Christensen's research has been very intertwined with her activism. The topics of her publications include the particular problems of women in the AIDS crisis, a critique of current proposals for campaign finance reform, and an examination of discrimination by race in the labor market. Her current research centers on the position of women, particularly low-income women, in the current financial/economic crisis, and she has been invited to give the Mary Edwards Memorial Lecture on this topic in the spring of 2011.

Since the fall of 2008, Christensen has taught intermittently at Sarah Lawrence College, first as a Visiting Faculty Member in economics, and currently as the Joanne Woodward Chair of Public Policy. She looks forward to teaching the Health Economics course in the Health Advocacy Program this spring. She hopes to help her students to examine critically the varying approaches to economic analysis (including neoclassical, behavioral, and feminist) and to apply these contrasting approaches to two case studies: HIV/AIDS education and the recently-passed health care legislation.