HEALTH ADVOCACY BULLETIN
The Journal of the Health Advocacy Program at Sarah Lawrence College
Volume 19 • Number 1 • Spring 2012

## Letter from the Director

By Vicki Breitbart

# The Myths and Realities of Health Care Reform

As the Presidential campaign heats up, there is an increasing amount of talk about health care reform. When asked about the most important issues in the 2012 election, polls show that health care is second only to the economy as the most pressing issue on the minds of the U.S. electorate. Health care reform as presented in the Affordable Care Act (ACA) has become extremely politicized. The term "Obamacare" is frequently used to describe the plan even though it was instituted by an act of Congress, not by executive fiat. Several myths have emerged that have distorted the reality of the ACA. Even if we would want it to be, it is not a government takeover of health care; it will not cost a dime to implement it if the cost-saving reforms go into effect; it only mandates health insurance if you can afford it; and it will benefit millions of us even if we already have insurance. The plan is not perfect, and it does not benefit everyone, but the fact that many individuals are already being positively affected is being lost in the debate.

There is a lot of misunderstanding about the ACA and support for it is being eroded by political rhetoric. While the polls show a decline in support, more people today think that the plan should be expanded, not repealed. In a recent poll, people changed their attitudes about the ACA once they learned how it could benefit them. As advocates dedicated to creating a health care system that is equitable and advances a just and humane society that benefits us all, we need to counteract the myths surrounding the ACA and not overlook the already existing and potential benefits of the law. This letter will cover just some of the pieces that have already been implemented and foreshadow some of what is to come.

*"We need to counteract the myths surrounding the ACA."*

Part of the lack of understanding of the law's significance is that it is complex and the full effect of the law will not be seen for years to come; the benefits are incremental. The act started by covering some of the most vulnerable first--those with pre-existing conditions who have been without health care coverage for at least six months. Children under 19 years of age with pre-existing conditions cannot be denied coverage. You can no longer be dropped by a plan because you get sick or have some problems with the paperwork. Lifetime limits were banned and insurance companies are being held accountable for increases in premiums. Seniors have been provided $250 to offset the gap in coverage called the "donut hole," and it has been shrinking each year. As mentioned in my last letter, many young adults up to 26 years of age have new coverage options and can stay on their parents' health insurance plans.

*"The ACA is a historic accomplishment, but it is only one step toward affordable, accessible quality care for all."*

There is an emphasis in the ACA on expanding primary and preventive health care services. There are increases in payments for primary care services and support for a list of preventive services without co-pays. Immunizations, preventive care for infants, children and adolescents and additional preventive care and screenings for women are already covered.

As part of the ACA, small businesses and non-profits are also seeing the benefits of the plan. Early on, small businesses received tax credits. Some who had to pass on increases in premium costs to their employees are now receiving financial assistance with their insurance costs. Also built into the plan is money for the expansion of the health care work force. There is support for dealing with the nursing shortage and the development of training programs that focus on primary care models and programs that integrate physical and mental health services. Money has also flowed to Community Assistance Programs to help individuals become more aware of their increased benefits and rights.

*continued on page 3*

# Letter from the Editor

By Barbara Robb

Our focus in this issue is on health care reform. Vicki Breitbart's Letter from the Director and Lois Uttley's Point of View article both address implementation issues associated with the Affordable Care Act (ACA). HAP student Brenda Shipley has written about her Capstone project involving the health policy action process at Connecticut's Office of the HealthCare Advocate (OHA), a public sector Consumer Assistance Program.

Law, ethics and long-term care are also covered in this *Bulletin*. Maureen Eisner has written about her work in clinical ethics consultation at Westchester Medical Center; Marleise Brosnan describes the work of the AARP Legal Counsel for the Elderly in Washington, DC; Cathey Bienkowski describes her work with the Long-Term Care Ombudsman Program in Memphis, TN.

We're also introducing a new feature: interviews. Our first interview is with HAP student Elizabeth Bailey, whose book, *The Patient's Checklist: 10 Simple Hospital Checklists to Keep You Safe, Sane & Organized*, was published in January.

If you're interested in interviewing someone for the Bulletin or in writing an article about your work or a Point of View article about a topical issue, please contact me at brobb@sarahlawrence.edu. If you have a new job, degree, certification or volunteer position, please let us know about it. Send the information to Gloria Escobar-Chaparro at gescobar@sarahlawrence.edu.

## 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. Shawna can be reached at shawna.irish@gmail.com.

## Errors and Omissions:

Paying credit where credit is due….Photo credits were inadvertently left out for a few of the photographs published in the Fall 2011 issue. The photo of Mary Morrissey and Shabani Jumanne (on page 3) was taken by Sister Nuala Horgan. The photo of Linda Koebner with her dog, Spirit (on page 5) was taken by Dana Maxson. The photo of Julie Buyon, Dana Gage, Rima Grad, Steve Lewis and Heidi Weiss (on page 8) was also taken by Dana Maxson. We apologize to the photographers for these omissions.

**www.slc.edu/health_advocacy**

The **Health Advocacy Bulletin** is a publication of the Health Advocacy Program at Sarah Lawrence College, One Mead Way, Bronxville, NY 10708.

Program Director: Vicki Breitbart
Editor: Barbara Robb
Email: vbreitbart@sarahlawrence.edu

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*The MA in Health Advocacy Program is supported by: The Fund for Sarah Lawrence*

# Save the Date

October 11, 2012
Margaret Keller Lecture Series

## Dorothy E. Roberts, JD
## The New Biopolitics of Race and Health

Roberts argues that we are witnessing a new biopolitics of race that relies on reinventing the political system of race in biological terms, using cutting-edge genomic science and technologies. A critical aspect of this new racial politics is attributing race-based health disparities to genetic differences. In her writings, she shows that race is not a natural division that produces unequal health outcomes at the genetic level, but a socio-political category that has staggering biological consequences because of the impact of social inequality on people's health.

Roberts is Kirkland & Ellis Professor at Northwestern University Law School, Professor in the Department of African-American Studies and Sociology and a Faculty Fellow at the Institute for Policy Research. She has written and lectured extensively on the interplay of gender, race and class in legal issues concerning reproduction, bioethics and child welfare. Roberts is the author of *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century* (The New Press, 2011); *Killing the Black Body: Race, Reproduction, and the Meaning of Liberty* (Pantheon, 1997), which received a 1998 Myers Center Award for the Study of Human Rights in North America; and *Shattered Bonds: The Color of Child Welfare* (Basic Books, 2002), which received research awards from the Institute on Domestic Violence in the African American Community and the American Professional Society on the Abuse of Children.

*The Myths and Realities…continued from page 1*

The law has 450 provisions and has only been in the implementation stage for two years; there is a lot more planned. For those who are employed but can't afford to pay the premiums, there will be more options when the law fully kicks in. Expansion of coverage is one of the most striking benefits of the plan. Millions of people will become eligible. In New York State alone, there are almost three million individuals without care; the plan will cover about 32 million people nationwide by the time it is fully implemented in 2019. Starting in 2014, cheaper health care will be available through "health care exchanges," but—as Lois Uttley points out in her Point of View article—many states have yet to plan for these exchanges.

In addition, with the significant organizational and cultural shift that comes with the ACA, there will be shifts in the roles and responsibilities of those determining eligibility. These "patient navigator" roles are still undefined. As advocates, we could play a significant part in addressing the needs of patients in this new health care system.

There is much more to come, but only if the law can be fully implemented. Several aspects of the ACA are under attack. There has been a lot in the news recently about contraception being covered in "essential services" under the plan. An amendment was introduced, attached to a highway funding bill, that would have allowed not only religious groups but any employer with moral objections to opt out of the coverage requirement. This amendment was defeated by a slim margin in the U.S. Senate. However, the Prevention and Public Health Fund designed to improve prevention efforts is already being reduced by Congress. The law is being reviewed by the Supreme Court and the decision can have a severe impact on implementation. The ACA is an historic accomplishment, but it is only one step toward affordable, accessible quality care for all. It is a start to build on, and we as advocates have an important role to play in how it progresses.

## Online Resources on Health Care Reform:

**AARP:**
www.aarp.org/health/health-care-reform

**Alliance for Retired Americans:**
www.retiredamericans.org/issues/health-care-reform

**Consumers' Union:**
www.consumersunion.org/health

**Families USA:**
www.familiesusa.org/health-reform-central

**Health Care for All New York:**
www.hcfany.org

**Kaiser Family Foundation:**
http://healthreform.kff.org

**Medicare Rights Center:**
www.medicarerights.org

**National Association of Insurance Commissioners:**
www.naic.org/index_health_reform_section.htm

**New York State:**
www.healthreform.ny.gov

**Raising Women's Voices:**
www.raisingwomensvoices.net

**Small Business Majority:**
www.smallbusinessmajority.org

**U.S. Dept. of Health and Human Services:**
www.healthcare.gov

# Clinical Ethics Consultation

By Maureen Eisner

When we think of ethics we think of right or wrong actions that are clearly defined, but true ethical dilemmas are those situations in which there are no clear-cut right or wrong actions to take. The problem is determining the best course of action for a particular patient in a particular situation.

I serve as Co-Chair of the Ethics Committee and run the Ethics Consultation Service at Westchester Medical Center, where I am responsible for facilitating consultations, authoring chart documentation and letters of the Ethics Committee's recommendations to state agencies and physicians, setting the agenda for the Committee and providing house-wide education for clinical staff on various ethical topics. I am also on faculty at New York Medical College and teach bioethics to first- and second-year medical students, as well as teach philosophy and ethics at William Paterson University in New Jersey.

> *"The problem is determining the best course of action for a particular patient in a particular situation."*

One area of focus in bioethics is end-of-life issues. Unfortunately, across the country many patients are still dying in pain needlessly, even though we have an ethical obligation to relieve pain and suffering at the end of life, instead of prolonging the dying process. Palliative sedation and other tools are available for pain relief, but many times they are not utilized. There is also a common misinterpretation that relieving pain at the end of life can be considered physician-assisted suicide because of the possibility of respiratory depression with the administration of elevated amounts of morphine. It may hasten death, although several studies have shown that there has not been an impact on longevity, just an improvement in quality of life. However, the principle of double effect (an action is undertaken only with the intention of achieving a possible good effect and without the intention of achieving a possible bad effect, although the bad effect may be foreseen) would ethically justify it if it did, and is accepted in the law and religion.

Conflicts between clinicians and families do occur during end-of-life discussions. Futility and autonomy can be in conflict with each other. The patient's best interest standard should be used when there is no surrogate. Families may want everything done, even though this may be futile and offer no benefit to the patient, and actually may prolong suffering. Autonomy and self-determination may overrule what the clinicians deem to be appropriate. Although patients and surrogates can refuse treatments that are needed, they cannot dictate clinical treatment or demand futile treatments that do not offer benefit. New York State requires the consent of either patients or surrogates for Do Not Resuscitate orders. Many times families will not agree to the order, even when it is clinically appropriate. These types of issues can become ethical, especially if more harm would be caused by resuscitating a terminal patient with a very poor prognosis. The rule of thumb is that we never want to do something to a patient that would cause more harm than good. This harm-benefit analysis is one that is widely accepted in bioethics. If we are doing anything that is invasive to a patient, there should be at least equal or greater benefit to that patient. If not, why would we be doing it?

Although this article is too brief to discuss them in detail, some interesting topics have recently arisen in bioethics. They include:

- pandemic illness and how to allocate resources and respond;
- allocation of organs, including whether age should be a factor in determining how organs are allocated;
- dilemmas in the determination of death;
- brain death and religious and moral objections to the concept;
- futility and requests from patients and families to continue aggressive treatment;
- limits of autonomy and patient confidentiality;
- physicians' obligations to patients and duty of care;
- human subjects research;
- genetic engineering and human reproductive issues; and
- stem cell research.

> *"The rule of thumb is that we never want to do something to a patient that would cause more harm than good."*

As you can see, the role of ethics in medicine is expanding every day, as are the role of the ethicist and the criteria for standards within the profession. The American Society for Bioethics and Humanities has established competencies and is recommending credentialing and privileging ethicists so that they are competent to perform in this very challenging, but interesting, role. What I find unique and utilitarian in my role is the perspective that I have as a patient advocate. There are many different titles and roles within the hospital setting that contribute to the ethical considerations of the patient, but that of a patient and health advocate has a clear-cut relation to the best interest and autonomy of the patient.

*Maureen Eisner is an alumna of the Health Advocacy Program.*

# The Long-Term Care Ombudsman Program

By Cathey Bienkowski

***Scenario One:*** *A long hallway with residents sitting along the plain white cinder block corridor, watching the walls, as there is nothing else to do. There is nothing to make this hallway seem less than an "institution," a place where you sit and wait to die.*

***Scenario Two:*** *A long hallway with residents moving along to the activities room to use the computers, play games and socialize, or going to religious services, while music plays in the background. The rooms all have TVs and are decorated with personal items and photographs that help the residents feel that this is indeed their home.*

Both these scenarios are paid for with Medicaid and Medicare funding. Neither location has self-pay individuals. So why is there such a discrepancy between the two scenarios? It's because there is no required transparency in how funding is spent and this is indeed a business, with little or no oversight. Without oversight, profit becomes more important than providing for the elderly. All states inspect assisted living and skilled nursing facilities, but they do not consider how the funds are used if the minimal basics and regulations are met.

I am an Ombudsman and my job is to advocate for the residents in any scenario, self pay or public pay. I do this as a willing volunteer. The purpose of the Long-Term Care Ombudsman Program is to investigate and resolve complaints made by, or on behalf of, older persons who are residents of long-term care facilities. Established under Title VII of the Older Americans Act (OAA), Ombudsmen are available to advocate for all long-term care facility residents, not only those residents in facilities certified by Medicare and/or Medicaid.

> *"The residents in nursing homes comprise a largely disenfranchised group. They are afraid to speak up."*

I am certified in two states as an Ombudsman and have seen both scenarios in several states. New York requires a 36-hour training to become certified (www.ltcombudsman.ny.gov/). Tennessee requires a 15-hour program (www.tn.gov/comaging/ombudsman.html). Both programs cover essentially the same materials. New York provides on-site experiences as part of training. In Tennessee, one goes on site after the training. The differences amount to very little in terms of how well a volunteer can perform the job. The advocacy comes from a desire to fight for those who are too ill, too frail, too scared, too weary to speak up. (We advocate for anyone in the facilities regardless of age, medical needs, race or religion and sometimes we even advocate for the staff.)

The top five resident complaints in nursing homes and other long-term care facilities are:

- unheeded requests for assistance; e.g. the call button isn't answered in a reasonable amount of time;
- problems with discharge planning or eviction notification and procedures; e.g. someone has informed a resident that she is being sent home today, but she no longer has a home;
- lack of dignity or respect for residents by staff; e.g. verbal and physical abuse;
- lack of quantity, quality, variety and choice in food; e.g. cold, undercooked or overcooked, unpalatable or inedible food; and
- improper handling of residents that resulted in unexplained accidents or injury; e.g. residents fall out of a wheelchair or slip in the shower due to inadequate staff training.[1]

> *"…my job is to advocate for the residents in any scenario, self pay or public pay."*

States are required to provide an ombudsman service, but many provide minimal coverage, hiring one professional to cover the entire state and supervise a group of volunteers. Negative reports from a state Ombudsman Program are often seen as a political liability and thus discouraged. In Iowa, for example, the state Ombudsman for the Department of Elder Affairs was relieved of advocacy duties in 2010, days after he issued a report critical of the state's nursing home oversight.

So why do I do this? The residents in nursing homes comprise a largely disenfranchised group. They are afraid to speak up. If they do, they fear the aide might hit them, or not help them, or ignore the call bell. It takes multiple visits before the residents trust me enough to share a complaint. Many families don't visit, so most residents have no one else to represent them.

A resident from the first scenario put it most pragmatically, "I have a warm clean bed, I get a bath 3 times a week, and I get 3 meals a day…beats living under the overpass." What we might see as deficient, someone else sees as a better alternative. There is much that can be done to improve this alternative. Call your state Department of Aging and volunteer.

*Cathey Bienkowski is an alumna of the Health Advocacy Program.*

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[1] Colello, K. J. Older Americans Act: Long-Term Care Ombudsman Program. July 1, 2009. http://www.aging.senate.gov/crs/aging12.pdf

# AARP Legal Counsel for the Elderly

By Marleise Brosnan

A HAP fieldwork placement led me to Washington DC and to a position with AARP—the largest advocacy/lobbying organization in the United States. It is not well known, even in DC, that for 35 years AARP Legal Counsel for the Elderly (LCE) has operated a legal aid/social services agency—serving DC low-income elderly—on the fourth floor of AARP's national office.

The need is great—one out of every six DC residents is age 60 or older, and the District has the nation's second highest percentage of seniors living at or below the poverty level—nearly 15 percent. The vast majority of those we serve are Washington's frail, poor, disabled and institutionalized elderly—and over 70 percent of our clients are low-income women of color.

> *"The vast majority of those we serve are Washington's frail, poor, disabled and institutionalized elderly."*

The Counsel helps low-income, older DC residents by stopping home foreclosures and evictions, preserving and promoting affordable housing, representing seniors victimized by scams and predators, working directly with the courts to oversee and administer guardianships, and by preparing hundreds of wills, powers of attorney, advance health directives and other "end-of-life" legal documents. LCE is a strenuous advocate for both homebound and nursing home DC residents.

LCE provides free legal services to older DC residents in need through a number of programs and projects.

**Pro Bono Project** refers cases to private sector and government attorneys who handle them on a pro bono basis. Pro Bono handles more than 500 cases annually. Typically, the problems our clients face fall into one of these categories:

- Social Security and Supplemental Security Income (SSI) denials and appeals, including disability and overpayment issues;
- Landlord-tenant law, including evictions and public housing grievances;
- Real property and predatory lending issues, including foreclosures;
- Guardianships and conservatorships;
- Nursing home law;
- Wills, living wills and powers of attorney for finances and health care;
- Debt relief;
- Consumer fraud against older people; or
- Entitlement to public benefits, such as Medicaid and food stamps.

**Alternatives to Landlord/Tenant Court Project** brings together a coalition of housing providers, legal service providers, landlord attorneys, social workers and volunteers to provide a wide range of resources to prevent eviction of DC's low-income older tenants. The Project focuses on addressing tenants' underlying problems that often prompt housing providers' complaints against them: hoarding and housekeeping issues, non-payment of rent, unauthorized occupants (usually caretakers), financial mismanagement and mental health issues. In 2010, the Project assisted more than 200 tenants.

The Alternatives Project utilizes an innovative program called **Elder Buddies**, comprised of volunteers from schools and community organizations who assist older tenants with housekeeping and de-cluttering, and provide companionship for lonely or isolated elders. With these supportive services, older tenants can continue to reside in their homes and landlords save the time and expense of taking them to court.

**DC Long-Term Care Ombudsman (DCLTCOP)**—the Office of the DCLTCOP is charged by federal law and DC Statute and with the following responsibilities:

- Advocate for the rights of persons who are residents of nursing facilities, assisted living residences and community residence facilities;
- Investigate and resolve complaints made by or on behalf of residents of a nursing facility, assisted living facility or community residence facility; and
- Monitor the quality of care, services provided and quality of life experienced by residents in long-term care facilities to ensure that the care and services are in accordance with applicable DC and federal laws.

**Consumer Protection and Financial Abuse Unit** focuses on preservation of home ownership and on abusive debt collection practices. Consumer Unit staff attorneys help keep DC seniors in their homes despite pending or threatened foreclosure actions.

**Homebound Elderly Project** utilizes a full-time staff attorney, para-professional support, and a cadre of pro bono attorneys, private law firms and government organizations to (1) interview clients at home regarding legal problems(s); (2) draft legal documents that seniors may need such as powers of attorney or wills; (3) administer a "public benefit" check-up to ensure that they are getting all the benefits to which they are entitled; and (4) analyze their housing situations concerning landlord problems or consumer problems or, in the case of homeowners, any problems with home repair, predatory lending or deed fraud. These are clients and cases that otherwise might fall through the cracks, including instances where low-income seniors, many of whom are in desperate need of legal services, have been found to be living without running water, amidst heightened levels of infestation, surrounded by clutter due to hoarding or otherwise incapable of handling much needed applications for public benefits.

More than 500 volunteers, interns and fellows contribute thousands of hours of pro bono service to LCE's mission every year. LCE's attorneys, paralegals and volunteers help more than 4,500 elders each year, with monetary benefits totaling over $5 million.

*continued on page 7*

*AARP Legal Counsel for the Elderly…continued from page 6*

LCE has a longstanding affiliation and partnership with AARP, and we are one of the ways AARP gives back locally in the District of Columbia. In addition to support from AARP and individual donors, LCE is funded by grants from the Administration on Aging (AoA) and the District of Columbia Office on Aging (DCOA).

As Senior Business Unit Associate, I recruit and manage our law school and social work interns as well as our attorney and paralegal volunteers; monitor, manage and report on the AoA and DCOA grant process; manage our online communications and social media platforms (Facebook and Twitter) and act as project manager to the redesign of LCE's website. As a DC notary, I act as a witness to the execution of wills, powers of attorney and advance directives for our homebound clients.

My work with LCE provides a perfect complement of large-scale system wide advocacy and individual advocacy. On my long Thursdays from 9:00 am to 7:00 pm at 45 Wrexham between 2007 and 2009, I would not have believed it if someone had told me that my HAP education would guide me to a new city and a meaningful career with AARP as an advocate for older adults.

*Marleise Brosnan is an alumna of the Health Advocacy Program*

# Improving State Health Policy Through Principled Decision Making

By Brenda Shipley

The Affordable Care Act (ACA) recognized the role of consumer advocacy in improving our health care system. Insurance companies have powerful lobbying capabilities to make and change policy to protect their business interests, while people struggling to recover from illness, or those coping with a sick child, spouse or parent, are marginalized by industry bureaucracy. For even the savviest of health care consumer, it is difficult to fend for one's self. Consumer Assistance Programs (CAPs) work directly with individual consumers to solve health insurance problems. This enables CAPs to spot trends and take legislative policy action on behalf of all health care consumers. This is a matter of social justice.

For my Capstone project, I partnered with Connecticut's Office of the HealthCare Advocate (OHA), a public sector CAP, to take a look at its process for health policy action and recommend ways to strengthen it. State health policy is shaped and changed during the annual legislative session. Using best practice program design tools, I developed a theory of change and logic model to propose a project to innovate OHA's process for health policy action. If OHA used consumer-centric principles to routinize its health policy action decisions, then it would reinforce its social justice role with consistent, logically integrated and publicly defensible policy positions. It would increase its capacity to quickly and effectively develop legislative testimony and briefings. It would reinforce key messages and gain additional recognition as a public policy thought leader.

I began drafting principles by gathering information, talking with stakeholders, reviewing previous policy decisions and observing day-to-day decision-making. OHA's actions—every day and during the legislative session—are grounded in fighting on behalf of consumers. My advocacy approach was not to replace, change or add to the values that already guided OHA, but rather to codify the right action currently at the heart of its work through participatory design. Each OHA staff member contributed to the development of principles. Put to paper, the principles became the explicit basis for OHA health policy action and communication.

Borrowing from my corporate experience using "the four Ps" for marketing decisions, I developed a policy analysis matrix for health-related legislation decisions: Principles, Population, Politics and Position. While principles serve as the basis for decision-making, population serves as a determinant of coalition support, politics as a determinant of policy strategy and Position as a determinant of policy action.

> *"I developed a policy matrix for health-related legislation decisions: Principles, Population, Politics and Position."*

We launched the consumer-centric principled approach to health policy action a pilot test with the opening of the 2012 legislative session. OHA's policy team meets daily to discuss proposed health bills and their impact on consumers. The principles and policy analysis matrix help frame our discussion. Using the principles as a basis for decision-making has changed an initial gut reaction in some instances. A bill may have felt like the right thing to support, but then became a stretch to align with a principle of consumer benefit. The principles have increased the efficiency and effectiveness of policy activities beyond decision-making. In the frenzied pace of drafting testimony and providing legislative briefs to staff, principles are the consistent sound bites reinforcing OHA's social justice message. More importantly, the principles serve as touchstones grounding decision-making that could easily be swept up in the swirling current during the legislative session. One member of OHA's policy team told me it's easy to get caught up in politics; the principles help us take a step back and say "wait a minute, what is it exactly that we are trying to accomplish here?"

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# Interview with Elizabeth Bailey

Elizabeth Bailey (Photo by Tim Ives)

Elizabeth Bailey's book, *The Patient's Checklist: 10 Simple Hospital Checklists to Keep You Safe, Sane & Organized*, was published in January by Sterling Press. The book has received a great deal of attention in the media. *The New York Times* Science section, *The Washington Post*, NPR's health blog, msnbc.com and *USA Today* have all run articles about the book.

As Laura Weil writes in her foreward, "the hospital can be a dangerous place." Elizabeth is very aware of that, having seen her father suffer the long-lasting consequences of medical errors. The checklists in her book are designed to help patients and families guard against human error, as well as to improve communication and compassion in hospital care.

Elizabeth graciously agreed to be interviewed by *Health Advocacy Bulletin* editor Barbara Robb.

**Barbara:** What was your background, Elizabeth?

**Elizabeth:** My background was in film, as a music video producer. One of the things I loved so much about filmmaking was that it was just so collaborative. You worked with a group, everyone had their area of expertise. That's why I think the hospital felt so familiar to me. Everyone had their specialty, everyone was hopefully working on the same page. I understood that people were good at different things and you had to bring them together for one vision. And that to me was always the patient.

**Barbara:** When did you start working on your book?

**Elizabeth:** While my dad was in the hospital for so long, the first time. My sisters and I all live in the city and we were all there, but I was the one who had the freelance job, so I was the one who was there more often. I was just used to working with checklists from production and organizing a notebook a certain way. I wanted a certain clarity, so that my sisters would understand what I was handing over to them.

One of the things that's essential in film is continuity. You're constantly focusing on the big picture and, at the same time, on details in the moment. I was always a nontechnical person in a technical environment, and so I always had to ask questions. There's a lot of overlap [with health care] in a strange way.

**Barbara:** What was the writing process like?

**Elizabeth:** When my dad got sick, I essentially read every book that was out there. What I didn't like was that you're in crisis and you open up a book and there are 400 pages of text.

Writing is a lonely endeavor. It's a very solitary enterprise, publishing. Being a first-time author is a lot like being a patient, actually. You really have to make your way through a maze, through a lot of unfamiliar territory.

This book, in my mind, had to be "one size fits all." I feel like I gave people a basic map. I've always loved maps, especially the 1972 subway map. I love subway maps in general. If you go anywhere, you can find where you're going. They make it really easy to find your way around, they're not intimidating. So I like that idea that this a basic wayfinding tool. It won't tell you everything you need to know, but it's framing the questions you need to ask. It's giving you a starter pack of questions.

**Barbara:** As far as I know, you're the first health advocacy student who has published a book while in the program.

**Elizabeth:** I know. The funny thing is, the book got rejected by virtually everyone. First it was agents, trying to find an agent, then trying to find a publisher. I essentially created a template, a spiral-bound book with tabs that in many ways was very similar to this finished product.

People said, "just write a book proposal." I felt people wouldn't understand it if I just wrote a book proposal. Form and function are so interconnected with me. You have to see it. I've always worked that way, with design a huge component.

I got rejected by one publisher after another. They'd say, "it's too depressing, but can I keep this?" That was the standard response, "it's too depressing, but I want to keep it and give it to my sister."

**Barbara:** Where did the decision to apply to the Health Advocacy Program fit in?

**Elizabeth:** I felt a calling in a way, I felt useful, that I intuitively "got it." I felt that here's my second act. I looked at the Narrative Medicine program at Columbia and the Health Advocacy Program. I said to my husband, "this book is getting rejected by everyone, so I'm just going to go to graduate school." As it turned out, I sold the book and got accepted to Sarah Lawrence within weeks of each other.

**Barbara:** Your marketing has really taken off. Was that due to the publisher's efforts?

*continued on page 9*

*Interview with Elizabeth Bailey..continued from page 8*

**Elizabeth:** The book was coming out January third. It happened to fall on the *Science Times* day. No one knew the *Times* was going to review the book. The publisher had said they weren't going to even approach any traditional press [because] "no one's going to write about this."

I thought it was going to tap into something, so what I wound up doing was spending my entire advance on short-term press. I felt I had gotten to this point, so I wanted to keep going. I hired an independent press person. I felt, if it doesn't work, it doesn't work, but at least I can say I tried. It's been a good thing to be a middle-aged woman really upending my life and taking a big risk.

**Barbara:** Where will you go from here?

**Elizabeth:** I don't know. I'm very committed to working within the hospital setting. My next internship is going to be in the outpatient clinics, because that's such a portal to the hospital. I think the outpatient clinics and the emergency room are like the Ellis Island of medicine. People are coming in, they don't speak the medical language, they might not have the right documents, they don't necessarily have the right insurance, they don't really understand what's going on.

When I've dealt with patients as a patient rep or with my family or friends, if it doesn't feel right, something's not right. There's some detail, something that's happening with your treatment that's not right, that doesn't feel right to you. You have to believe in your intuition. It's really hard to do, certainly in a medical crisis or in anything you don't understand. In any new situation you're vulnerable.

Here's a really important and powerful thing that I've learned from working in a hospital. Patients really don't have it easy and it's really dangerous for them, but doctors and nurses and providers don't have it easy, either. The system isn't working for anyone. All of us are powerless to varying degrees. I don't think there are going to be any systemic changes [in health care] unless patients and providers cross that divide and really work together for change.

I feel that health advocates have to align ourselves with the people that we have the most in common with, who have the same goal. I think physicians, the patient, the family, they all want the same outcome—the best possible health outcome for the patient. We need to pool our resources and power bases if we're going to make any systemic change in the health care system.

*Improving State Health Policy..continued from page 7*

I had contemplated longer-term impacts of my Capstone project, such as usefulness as a model for policy action by other CAPs. However, I had not considered the project's power to influence other areas of state government. The State's Healthcare Advocate sits on the board of the Health Insurance Exchange. The fourteen-member board is pressed to make many complex decisions quickly, and has yet to consider a framework for doing so. The State's Healthcare Advocate is now championing a movement for the Health Insurance Exchange to establish principles to guide its decision-making—a ripple from my Capstone pebble.

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

## Certificate in Mediation for Health Professionals

The Health Advocacy Program and the Center for Continuing Education are pleased to announce a new Certificate in Mediation for Health Professionals, launching in the fall. The program will be held on Friday and Saturday, September 28th and 29th and October 5th and 6th.

This is the first program to blend basic training in mediation with an emphasis on applications in the health field.

For more information, contact Crystal Greene at cgreene@sarahlawrence.edu or 914-395-2602.

## 2011 End-of-Year Festivities

The holiday party featured a panel discussion with three HAP alumnae: Maureen Eisner, Jessica Miller and Pat Stanley. They described their advocacy work, and their routes from the Health Advocacy Program to their current positions. Maureen Eisner, who has contributed an article to this issue of the Bulletin, is Director, Patient Experience, Advocacy & Medical Ethics at Westchester Medical Center; Jessica Miller is a patient representative at Memorial Sloan-Kettering Cancer Center; Pat Stanley teaches in the Narrative Medicine master's program at Columbia University's College of Physicians and Surgeons.

The party was the occasion of a special award to Crystal Greene, who has served as the HAP Administrative Assistant for 12 years. Crystal was recognized for her dedication, support and provision of continuity to the leadership of the program. As Vicki Breitbart noted, all have been done "with exquisite grace and warmth." Our thanks to you, Crystal, for all your help.

# Health Care Reform Victory Leads to Implementation Marathon

By Lois Uttley

After years of work, you've finally achieved passage of a law that will provide health care coverage for millions of uninsured people. Time to celebrate and go home for a well-deserved rest? Sorry, but your work is just beginning. It's called implementation.

Health care advocates have been facing that unwelcome reality ever since President Barack Obama signed the Patient Protection and Affordable Care Act (ACA) into law on March 23, 2010. Our jubilation over finally enacting a health care reform law—even a less than perfect one—after decades of failure sometimes has been difficult to remember in the daily blur of activity needed to make sure the law actually is carried out.

> *"Well-financed special interests…have been busy trying to shape implementation of the law to their advantage."*

**Fighting off attacks on the law**

ACA supporters have had to become extremely nimble advocates, leaping from one policy arena to another to face repeated challenges:

- Congressional opponents of the law, emboldened by mid-term Tea Party victories, have sought to repeal the ACA or deny funding needed to carry out its provisions. As a result, health care reform advocates have had to re-fight some of the legislative battles we thought had been won back in March of 2010.
- Attorneys General from conservative states and other opponents of the ACA have sued to overturn key provisions of the law, bringing multiple court challenges that are expected to result in a Supreme Court ruling in June. In response, health care reform advocacy groups have been pooling our resources and expertise to write and file amicus briefs defending the provisions under attack, while responding to worried questions from our constituents about whether the law will survive.
- Even bishops of the Catholic Church have been on the attack, vehemently opposing the contraceptive coverage requirement as a violation of church-related employers' religious freedom. The Department of Health and Human Services (HHS) rule implements the Women's Preventive Services Amendment to the ACA and was designed to eliminate discrimination against women in health insurance coverage, such as the failure to cover basic women's health needs, including contraception. Women's health advocates have spent countless hours over the last two years urging HHS to issue the contraceptive coverage rule and then opposing demands for a broad exemption from the requirement for employers that object on religious or moral grounds.

Meanwhile, well-financed special interests, such as insurance companies and brokers, have been busy trying to shape implementation of the law to their advantage. They have squads of lawyers and lobbyists working to influence the regulations HHS has been developing to carry out the 2,000-page law. Here again, health advocates have been hard at work, studying the fine print of dozens of proposed regulations and submitting official comments designed to protect the interests of consumers. The learning curve has been steep for many grassroots advocates struggling to grasp the complexities of "medical loss ratios," insurance risk calculations, "adverse selection" and other insurance industry terms.

**Many states are lagging on creation of health exchanges**

Perhaps the greatest implementation challenge of all, however, has been taking place in state capitals across the country. While the Affordable Care Act is a federal law, it relies heavily on states to carry out some of its most important provisions. That reality has translated into a lot of work for advocates of health care reform at the state level.

Under the ACA, state governments have the opportunity to create and operate a health insurance "exchange" through which uninsured residents and small businesses can obtain health insurance plans made more affordable by the availability of federal subsidies in the form of tax credits. These state exchanges must pass federal certification requirements in January of 2013 and start enrolling people in the fall of 2013 for coverage that will begin in January of 2014. This timeline may seem long to those unfamiliar with government administrative processes, but in terms of the bureaucratic work needed, it is actually the equivalent of a 100-yard sprint to the finish line.

> *"Perhaps the greatest implementation challenge of all, however, has been taking place in state capitals across the country."*

With strong pushes from health advocacy groups, a total of 11 states (CA, CT, CO, HI, MD, NV, OR, RI, VT, WA and WV) passed necessary legislation or issued a Governor's Executive Order to create their own insurance exchanges by the end of 2011. Health advocates in these states have been fighting intense battles over such issues as whether insurance company representatives should be permitted to sit on state exchange boards. Another debate with significant implications for consumers has been whether state exchanges should use "active purchasing" to select only those insurance plans that offer good value and a reasonable price, or

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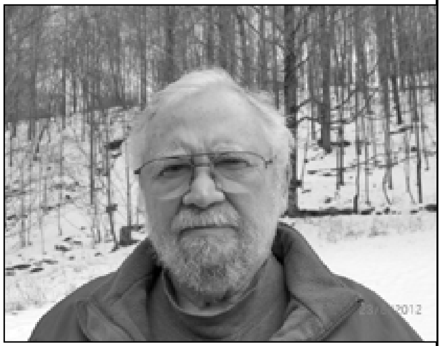
# FACULTY NEWS

## Faculty Profile: Laurence Shute



Larry Shute (Photo by Nancy Brothers)

Laurence (Larry) Shute is filling in for Kim Christensen this spring in the Health Economics course. He has a BS and PhD in economics from Columbia University and did graduate work at the University of Stockholm. Larry has taught at Bard College, Rutgers, U-Mass/Boston and the California State system. He taught in the doctoral program at USC and at UCLA as well. He is the author of *John Maurice Clark: A Social Economics for the Twenty-First Century*, as well as over 60 articles and papers in various journals and edited volumes. His wife, Nancy Brothers, is a clinical psychologist. They have just moved east to Sullivan County from Southern California to be near their only grandson, Sebastian Tobias Brothers, now 5 years old.

In an unusual sabbatical move, Larry returned to his native northwest--he was born in Tacoma, Washington of an Oregon family. Back on the Oregon coast, Larry spent nearly 5 years as captain of the 75-foot trawler Lady Grace, fishing for pink shrimp, Dungeness crab and sole. Larry then sold the boat and returned to the academic world. Several years later the Lady Grace was used in the movie *A Perfect Storm* to represent the doomed Andrea Gail longliner; much of the movie was filmed off the Southern California coast at Dana Point.

In California, Larry was a two-term chair of the Academic (faculty) Senate at Cal State Pomona, and vice-president of the campus California Faculty Association (CFA). He also served several years on the statewide CFA Health and Retirement Benefits Committee.

Larry and Nancy anticipate they will be unpacked by August.

## Cathy Handy's Broadway Debut

Cathy Handy, who teaches the Physiology and Disease course, was the medical technical advisor for the Manhattan Theatre Club's production of *Wit*, which opened in January to much acclaim.

*Health Care Reform Victory Leads..continued from page 10*

whether states should allow insurers to sell whatever plans they wish within the exchange.

By contrast, 28 states have joined legal challenges to the ACA, and most of those have taken little, if any action, to implement the law while waiting for a Supreme Court ruling. By not moving ahead with creation of an exchange, though, these states are risking the alternative spelled out in the law—having the federal government come in and run an exchange for people in that state. HHS, no doubt overwhelmed by the prospect of doing this in so many states, has been offering federal/state partnerships to create exchanges and extending deadlines.

A third group of states, including New York, have used federal grants to study how to go about establishing an exchange and have carried out some of the "back office" work that is needed, such as creating information technology systems that will be used to enroll people in plans. But these states have yet to take the crucial step of legally "establishing" exchanges.

Why the inaction? The problem is often political opposition from one party or one house of a state legislature to doing anything that would look like implementing what they have labeled "Obamacare" in an election year. In other cases, state officials are playing a waiting game, looking to see what the Supreme Court rules in June before committing themselves or waiting for final rules from HHS on various aspects of exchange development. For health care reform advocates in these states, the sense of urgency has been growing with every passing week.

With just under two years left to go before the ACA is due to be fully implemented, health advocates are unlikely to get a rest anytime soon!

*Lois Uttley is President of the Public Health Association of NYC and co-founder of Raising Women's Voices for the Health Care We Need, a national initiative working to make sure the needs of women and families are addressed in health reform implementation. She serves on the steering committee of Health Care for All New York. She studied the perils of implementation with Professor Beryl Radin at the Nelson A. Rockefeller College of Public Affairs and Policy of the University at Albany, where she earned a Master's degree in Public Affairs and Policy.*

# STUDENT AND ALUMNI UPDATES

**Celia Bertuzzi**, BSN, RNC-NIC, HAP 2010, had a Poster Presentation /Abstract/Program accepted for exhibit by the March of Dimes, 34th Annual Perinatal Nurses Conference—Planning Today For a Healthy Tomorrow: Optimizing Perinatal Care, held on March 27 in NY. The conference focused on continued clinical excellence and patient advocacy in health care delivery.

**Cathey Bienkowski**, HAP 2002, is currently a Volunteer Long-Term Care Ombudsman in Memphis, TN, advocating for residents in skilled nursing facilities.

**Gloria M. Escobar-Chaparro**, HAP 2010, will be speaking on a panel at the Civil Liberties and Public Policy Annual Conference at Hampshire College in April.

**J. D'Anne Graham**, first-year HAP student, presented her History of Health Care in the United States conference paper, Maternalism and the Demise of Virginia Midwifery, on March 31 at the 2012 Virginia Forum at James Madison University.

**Rebecca Hudson**, HAP 2011, is working as a Patient Representative at Mount Sinai Medical Center.

**Joshua Lapps**, HAP 2011, started work with the Society for Hospital Medicine in the Government Relations department. He will be working on developing grassroots organizing and strategies with the membership and providing policy support and analysis.

**Lois R. McCourt**, HAP 2005, has been working at Pinnacle-Care, a Private Health Advisory since February of 2006. She is the Regional Director of New York Member Services and also the Regional Director of Physician and Institution Relations.

**Margaret Rubick**, HAP 2010, has begun a private practice as an advocate; her website is http://margaretrubick.com and her first ad appeared in *The Hudson Independent* this month. She volunteers at Phelps Memorial Hospital in Sleepy Hollow, NY, as a patient representative, silver spoons feeder (for those who need assistance eating) and care desk attendant (communicating with families waiting for patients in the OR). She also volunteers with Undoing Racism Westchester. An article extracted from her History of Health Care paper on changes to the DSM vis-a-vis removing labels of sickness from the definition of homosexuality will be published in the Gay and Lesbian Review Worldwide.

**Daniella Samperi**, part-time HAP student, has launched a website www.ms-bridgethegap.com to provide a forum for news on multiple sclerosis from the patient's perspective.

**Jessica Stein**, second-year HAP student, has begun working as a Patient Representative in Mount Sinai Medical Center's Out Patient Clinics.

## Health Advocacy 2011-2012 Events

The Health Advocacy Program has had a full schedule of events in recent months:

**Final Acts: Death, Dying, and the Choices We Make** Nov. 9, 2011; Authors Nan Bauer-Maglin, academic director of the CUNY Baccalaureate Program, and Donna Perry, professor of English at William Paterson University, read from their book, which explores making informed and caring end-of-life choices, and the roles of religion, custom, family, friends, caretakers, money, the medical establishment and the government.

**The Truth About Fracking** Nov. 10, 2011; Doug Wood, Associate Director of Grassroots Environmental Education, and Dr. Larysa Dyrszka of Physicians, Scientists and Engineers for Health Energy discussed hydro-fracking in New York State.

**Patients as Policy Actor** Feb. 22, 2012; Rachel Grob, HAP faculty, currently Scholar in Residence and Director of National Initiatives, Center for Patient Partnerships, University of Wisconsin-Madison, discussed how patient perspectives can be more effectively integrated into a pluralistic conception of policy-making.

**Port Au Prince, Haiti: Activism and Health Advocacy** Feb. 15, 2012; Evenel St. Vil, manager of the AFYA Foundation Rehab Project, a national medical and humanitarian supply recovery organization, gave a first-hand account of the program's work in Haiti. Co-sponsored by the Office of Community Partnerships.

**Does Acupuncture 'Work'? A Discussion on the Role of Acupuncture in Pain Management** March 7, 2012; Pain specialist Ian Koebner discussed the history and current use of acupuncture, the state of acupuncture analgesia research and use of complementary and alternative medicine.

**Patient Advocacy in the Patient Safety Movement: Progress, Pitfalls, and Predictions** April 4, 2012; Rosemary Gibson, a national leader in patient safety, used narratives from the book *Wall of Silence: The Untold Stories of the Medical Mistakes That Kill and Injure Millions of Americans*, to trace the impact of advocacy on federal and state policy to reduce medical errors and hospital-acquired infections.

*Events are announced by email sent by Crystal Greene.*
*They are open to HAP alumnae and others, but advance registration is requested.*