

# HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

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## Letter from the Director

By Laura Weil

### Adversity Creates Opportunity for Health Advocates

A recent Commonwealth Fund report, *A Call for Change: The 2011 Commonwealth Fund Survey of Public Views of the U.S. Health System*, says 72 percent of Americans feel that our health care system should be significantly rebuilt. According to the report, nearly three quarters of us had problems accessing health services, experienced poor coordination of care and worried over costs and labyrinthine health insurance procedures. This research confirms our anecdotal and personal sense of a dysfunctional system, providing extensive evidence of wastefulness and disorganization in the way health care is structured and delivered. It builds on earlier findings that exposed unexplained regional discrepancies in standards of care that result in standard clinical outcomes for many.

This comes as no surprise to us in the health advocacy field, but what is surprising is how far the public has moved toward this point of view. It was not so long ago that most Americans strongly espoused health care in the United States as the best in the world. Now, apparently only a minority think this is true. This is a sea change in perception.

Next must come an understanding that the essential structure of our system makes it disproportionately expensive. The dependence on commodified health services and profit-driven commercial insurance reimbursement creates insurmountable inefficiencies and limitations. It pushes people who need primary care into expensive emergency rooms simply because they can't get a timely or affordable appointment in a clinic or doctor's office. Our lack of effective care coordination leads to repeats of expensive diagnostic procedures, poorly controlled chronic disease and expensive and dangerous hospital readmissions. Inaccessible prenatal care leads to increased infant mortality and morbidity at enormous fiscal and emotional cost. Add to that the astronomical expenses of inappropriate end-of-life interventions, and it's no wonder that the U.S. health care system is a shameful outlier among our peer nations in terms of money poorly spent. The growing sentiment in the country that we need a total health system overhaul could give us some reason to celebrate. One can hope that this groundswell of public opinion will eventually push legislators and policymakers to act responsibly and fuel substantive change.

In the meantime, the situation creates challenges and opportunities for us as health advocates. We can drive innovative, patient-

centered programming at the policy and organizational levels, and we can contribute to coordination and efficient navigation at street level.

Atul Gawande's recent *New Yorker* article, "The Hot Spotters," describes an example. Jeffrey Brenner, a family physician in Camden, New Jersey, discovered that just one percent of people in the town used 30 percent of the health care dollars spent. Brenner made the interesting connection that high health care costs in this low-income population directly correlated to poor care. He started a program that assigned what he called "health coaches" to support these high utilizers of medical services. The coach's job is to be available, supportive and proactive in making sure that clients have what they need to keep their chronic conditions under control and stay out of the hospital. It comes as no surprise to health advocates that this innovative program kept people healthier AND reduced health care expenditures by a whopping 25 percent. The result was amazing concentric circles of benefit—healthier, more productive people and reduced costs.

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*"We can drive innovative, patient-centered programming at the policy and organizational levels."*

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Our challenge as advocates is to make this model the norm, rather than the exception—an exception so newsworthy that a national publication commissioned a feature story about it. We need to make ourselves more prominent in the deployment of initiatives like this.

On another note, I've had a privileged four years as director of the Health Advocacy Program, and will always remain grateful to have partnered in this endeavor with extraordinary students and faculty. Their vision and determination leave me with solid confidence in our program's strengths and our profession's ability to foster innovation and promote truly transformative programs. I am so pleased to turn over the stewardship of this wonderful program to Vicki Breitbart, and I have every confidence that under her able leadership the program will flourish and embrace the opportunities of the future.

## Letter from the Editor

By Barbara Robb

This issue introduces Vicki Breitbart, the new Director of the Health Advocacy Program. She is a Sarah Lawrence graduate, so in a sense this position is a homecoming for her. Please join me in welcoming her back to the College. Vicki comes to us with an extensive background in advocacy, as you'll see from her profile on the next page.

The issue also introduces a redesign of the Bulletin. Joan McCann and Jean Smith in the Communications Department at Sarah Lawrence have helped us create a new format, with banner headings to set off the various features. We're starting a new

feature in this issue: Point of View. It's intended to provide an opportunity for those in the advocacy community to express their opinions on topical issues. Our initial contributor is Pamela Willrodt, who has written about the status of health care reform. If you have a topic you'd like to write about, please let us know!

We continue to include Reports from the Field. Nadine Baker, Megan Donovan, Shannon Irely and Valerie McDermott have contributed articles about their work and Brenda Shipley has reported on a policy briefing by the National Academy for State Health Policy.

### 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.

### [www.slc.edu/health\\_advocacy](http://www.slc.edu/health_advocacy)

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## Letter from the Incoming Director

By Vicki Breitbart

I am deeply committed to health advocacy and excited about becoming the next Director of the Health Advocacy Program. My first entry into advocacy was when I was an undergraduate student at Sarah Lawrence College. Several of us had formed an informal group in support of civil rights and went into Bronxville to picket Woolworth, a variety store that segregated its lunch counters in the South. This was many years ago, and my work in support of social justice has taken several different forms since then.

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*“Becoming the Director of this program feels like a capstone of my career.”*

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Over the years, as this country has gone through significant social transformation, I have continued to be involved in organizing for change. My advocacy has focused on day care, reproduc-

tive freedom and intimate partner violence issues—all to address the disparities and injustices I have witnessed. I have worked in a variety of settings: not-for-profit organizations, government agencies, community groups and educational institutions and have had a range of opportunities to do innovative and meaningful work building healthier and just communities.

Meeting students, sitting in on classes, spending time with faculty and talking with the remarkable individuals involved in the Health Advocacy Program made me feel that I was truly coming home. I believe that all the work I have done over the last decades has led me to this place and time. With the emphasis on critical thinking and social justice that permeates all aspects of the program, I found myself feeling very comfortable in all the discussions and classes. I feel I share the values, the approaches and the goals that are so evident in every aspect of the Program. Becoming the Director of this program feels like a capstone of my career as an educator, manager and advocate. The Health Advocacy Program is unique, and I am honored to have the chance to maintain and build on the excellence that has already been clearly achieved.

### Vicki Breitbart, EdD, LCSW

Vicki Breitbart received an MS in Early Childhood Education from the Bank Street College of Education, an MSW from New York University Graduate School of Social Work and a doctorate in Organization Development and Leadership from Columbia University. She is an accomplished public health leader who has dedicated her career, spanning over 40 years, to improving reproductive, maternal and infant health services for underserved New Yorkers. As a researcher and program manager, she has led efforts to assure that reproductive health services and practices are solidly evidence-based and demonstrate effectiveness. With extensive expertise in educational, clinical, governmental and non-profit settings, she has brought an understanding of the need for collaboration between disciplines and sectors in order to address complex reproductive health issues. Many of the programs, partnerships and policies she helped to initiate serve as models for other urban centers across the country.

Working with community and government partners, Vicki's leadership accomplishments include founding the first Bereavement Program in New York City for families experiencing perinatal loss; establishing the Brooklyn Perinatal Network, developing the NYC Department of Health and Mental Hygiene Healthy Teens Initiative, establishing the Coalition of Family Planning Providers; and developing and managing the nationally renowned Women's Healthline, a public information system for the New York City Department of Health.

Vicki recently served as Vice President of the Department of Planning, Research and Evaluation that she created at Planned Parenthood of New York City (PPNYC) in 1997. She has also held positions as Senior Vice President and Director of the Clinician Training Institute at PPNYC. Prior to that, Vicki was Project Director at the Columbia School of Public Health for a national study, funded by the Ford and Robert Wood Johnson Foundations, to review and formulate policies regarding infant mortality, HIV prevention and substance use among pregnant women. She also served as Deputy Director of the Office of Women's Health at the NYC Health and Hospitals Corporation, where she monitored all the city hospital programs for substance-using women and pregnant adolescents.

In recognition of her accomplishments and leadership abilities, Vicki was elected to serve as President of the Public Health Association of New York City in 2010. Vicki has also been invited to serve on the boards of numerous governmental, non-profit and educational institutions that promote public health. She has taught at CUNY School of Public Health, Hunter College; Mailman School of Public Health, Columbia University; and New York University.

## Patient-Centered Care at NYU Medical Center

By Valerie McDermott

When I joined the Patient-Centered Care Department at NYU Langone Medical Center in February of 2010, I was part of a huge growth initiative for the Department. There were three long-time Patient Advocates on staff, but an additional six were in the process of being hired or had been hired as of the first of the year. Hospital Administration was making a huge commitment to patient satisfaction, even before it was known that satisfaction would now be used in calculating CMS reimbursements.

One of the biggest factors in my making the move to NYU was the fact that I would be assigned to a specific area/unit, like all of the advocates here. This allows you to get to know the other members of the care team and also encourages understanding of medical issues consistent with that unit or area. There has been a clear attempt on the part of management to match temperaments and areas of interest with corresponding units. In my interview, I expressed my interest in working with the geriatric population, a group who often have multiple medical challenges. I am the advocate for all of the ICUs except pediatrics, so patient deaths are a large part of my experience. I have had exposure to patients with dementia who are critically ill and whose families are struggling to make the “right” choices—whatever they might be. I have been exposed to families of religious denominations who believe that every measure should be taken to prolong life, no matter how critical the patient. It is my job to counsel and support these decisions as long as they represent the view of the patient, even when they are contrary to my own beliefs. Much of my time is spent with family members, as the patient may be temporarily sedated, on a vent or completely unresponsive. I have been challenged by ethical considerations, which have been thought provoking and have frequently transported me back to Sarah Lawrence and the teachings of Alice Herb. I have been profoundly humbled by some of the most amazing physicians who gently listen and comfort, and then astonished by those who “don’t have time to see the family” or by the one physician who told me that he “never had a problem with patients’ families until there were Patient Advocates.”

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*“I love having the opportunity to engage patients, to hear their stories...”*

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As a member of the care team for the ICUs, I do bedside rounds with nurse managers, as well as regular rounds with social work, physical therapy, occupational therapy, care managers and nurse practitioners. Each patient is discussed. With all the different

departments represented you get a clearer picture of the patient rather than just a diagnosis. You can determine if there is family, and whether they are involved. Is there a Health Care Proxy, and if not, what is the hierarchy of those present at the bedside for decision making? Are there language or cultural barriers? There are also the sticky situations that surface—a wife and a girlfriend are both present, or a family that was splintered a long time ago suddenly has all of the players showing up. It can be very tricky for staff in terms of what to say and to whom.

I wish I could say that every day I am part of a team that rewrites medical history, but like any job, there are days that you are captivated and other days where you’ve gotten your fourth call that someone’s cell phone went out with the linen or the patient’s dentures slipped away on the food tray. But even these moments can lead to something magical. Many times I find that going to see a patient to address a complaint or issue has me 30 minutes later hearing about how the patient met her husband 65 years ago and how they married after one month of dating. I love having the opportunity to engage patients, to hear their stories—to give them the opportunity to tell me who they are rather than what is wrong with them. Similarly, when a family member opens up to me and shares that they have made the agonizing decision to turn off all mechanical support, and then talks about their loved one—someone I have only known as unresponsive comes alive to me through the family when they talk of his love of music, his artistry or his passion for gardening.

The Patient-Centered Care Department at NYU is a net and a resource for patients and families, but we are also a net and a resource for our internal clients—the care teams we work with, the support staff we see every day. By forging a partnership with everyone here, we have reduced the “Fear Factor”—our appearance on a unit is not cause for alarm. Instead, it is met with relief that we are present to support and help resolve an issue.

I probably sound a little “over the top” about NYU Medical Center and Advocacy. In part I think it’s because I can’t believe that I am actually doing this job—light years away from what I used to do as Director of Operations for a number of different retail/wholesale companies. As a kid, I was the fainter in the family—too much heat, riding in the back seat of the station wagon, bus fumes, church—-you name it, I was good for a fainting spell. Visiting family members or friends in the hospital usually left me horizontal with smelling salts under my nose. But here I am, able to visit with patients with necrotic and gangrenous tissue, brain tumor resections, severe car accident trauma or cancer—and be their advocate. I can’t faint now—I don’t want to miss anything!

*Valerie McDermott is a graduate of the Health Advocacy Program.*

## How I Ended Up in Rehab...It’s Not What You Think!

By Shannon Irey

I entered the Sarah Lawrence College Health Advocacy Program with one very clear goal: to work in the field of HIV/AIDS. I wrote my application essay about it, I framed my resume around it and I’m pretty sure it’s all I talked about in my admittance interview with the program faculty. Then a funny thing happened when I began the program. After urging me to be clear about what I wanted and where I was going, the program director and instructors completely reversed their approach to my work, and insisted I truly examine the multifaceted world of health advocacy before deciding where I wanted to focus. Feeling a little baffled, I took my first internship in a completely novel field and found it both inspiring and a surprisingly refreshing break from the world of HIV/AIDS. I continued to examine the many aspects of the public health field in my first year: I wrote papers on everything from the political power behind the March of Dimes to tuberculosis treatment methods in Haiti. I began to appreciate the chance to explore such diverse topics, but I never forgot what motivated me to pursue this degree from the start.

When it came time to decide on the focus for my capstone—sitting with Mark Schlesinger and Rachel Grob at the small table in her Slonim House office—the conversation went a little like this: “What about the topic of childhood obesity?” Mark asked, knowing I wanted to develop a project with the Department of Health for my final placement. “How about prenatal care for minority populations?” asked Rachel, realizing my desire to serve marginalized populations would be satisfied with such a placement. “Oh, definitely not that.” I said, and then I knew what they probably already realized: I would finally return to the topic of HIV/AIDS for my capstone and probably remain in the field long after that.

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*“...it’s flexibility that has been and will continue to be essential in the current job market.”*

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When it came time to look for a job after finishing my degree, I tried to be flexible and tried to get excited about other areas of public health, but I could not escape the pull of HIV/AIDS. Not much of a shock to those who know me well, I now work in a local community clinic’s HIV Department in San Diego, CA. However, I have still been flexible, and it’s flexibility that has been and will continue to be essential in the current job market, both for employees and their employers. I manage a grant from Alcohol and Drug Services, a county agency that funds alcohol and drug treatment sites. We provide on-site HIV/AIDS education and testing for the treatment agency staff and their clients. We also provide one-on-one harm reduction case management for high-risk individuals and group therapy for persons with HIV/AIDS in these rehabilitation sites. I now work in HIV/AIDS but receive funding from county drug and alcohol treatment sites, who in turn receive funding from the California Office of AIDS. I certainly did not

set out to work in the world of drug and alcohol treatment and addiction. However, I found work that I love by being flexible in the means by which I reached my end goal, granted a rather rigid goal of remaining in HIV/AIDS work.

The clinic’s HIV Department is actually growing in size, even at a time when certain HIV/AIDS grants are slashing funding. We currently hold 15 grants from county, state and federal sources. Certain initiatives, such as programs that focus on prevention, are facing major cuts, but through creativity and flexibility the organization has remained not just viable but has strengthened in a weak economy.

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*“My work has proven to be a welcome—and challenging—transition from graduate school.”*

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What I love most about my job is how varied each day can be. At times I am on site at alcohol and drug treatment facilities as a health educator teaching the facts of HIV/AIDS. The groups we provide services for vary from 30 male ex-convicts to a group of six women in a welfare to work program. Other days I prepare reports for our funders and examine our data to identify areas for improvement and trends within the population we serve. I am also actively involved in developing new resources for our presentations to address needs as they arise. My day may end with a webinar, perhaps on the latest research on the relationship between alcohol and HIV.

I wear many hats in my position as I go from teacher to student, from data gatherer to program designer. The program I am working on is a new contract for my agency, so it is a work in progress. My work is both incredibly exciting and also a little intimidating. As I am the first one to hold this position, I have been able to have full control over the program. My work has proven to be a welcome—and challenging—transition from graduate school. At times I wish I had the Health Advocacy faculty here for advice, or a “cheat sheet” from the last employee’s files with instructions on how to accomplish our goals, such as meeting grant requirements. Luckily, my coworkers are exceedingly supportive and I haven’t found the challenges of the daily work and its standards too difficult to handle.

Through my work I also have the opportunity to attend meaningful trainings. I am currently part of a multi-session seminar that attempts to tackle the powerful trifecta of mental health, physical health and addiction. These sessions bring together professionals from various agencies throughout San Diego County. Working together, we are trying not just to change our organizations and learn from each other, but we are also attempting to destigmatize these issues in the county. At the end of the month I will be attending a three-day intensive training to become a certified HIV test counselor. Each of these opportunities is instrumental to my job,

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which is always a powerful and influential opportunity for work in progress within the HIV/AIDS field. I know my Health Advocacy degree prepared me for my current work; I am constantly drawing upon what I learned in my two years at Sarah Lawrence.

When I recall my experience in Health Advocacy, it surprises me that I remember some things so clearly, and that I rely so much on what I learned. What has helped me the most is not the hard facts learned through the masters program, it is the perspective gained and the lessons learned about the advocacy world.

Shannon Ireys is a graduate of the Health Advocacy Program.

## Using Hand Feeding to Enhance Quality of Life for Nursing Home Residents with Dementia

By Nadine K. Baker

In 2008, Schervier Nursing Care Center, part of Bon Secours New York Health System, officially began its SPOON program, which stands for Seniors Partaking of Oral Nourishment. This program describes a new standard of compassionate, end-of-life care designed to enhance the quality of life of advanced dementia residents in nursing homes who have lost the ability to feed themselves. SPOON is also designed to increase family awareness about the terminal nature of dementia, empower family decision-making and improve satisfaction with care.

One of the primary reasons cited for the lack of attention paid to quality end-of-life care in nursing home residents with advanced dementia is that dementia is rarely seen as a terminal illness. Because the length of survival for dementia patients can be several years, physicians and family members struggle to view someone with dementia as dying.

The SPOON Program brings about a better quality of life for advanced dementia residents because in one-on-one feeding, the residents are better understood, the time spent with them in direct relationships is increased, they are able to experience the pleasure of tasting food, and the risk of infections and need for restraints associated with tube feeding are sharply reduced.

The SPOON Program was created in response to a challenge identified by Paulette Sansone, PhD, LMSW, who was the director of social services at Schervier Nursing Care Center for many years, and later the vice president of research and education for the Bon Secours Center for Research in Geriatric Care. Dr. Sansone understood one of the problems faced by many nursing home residents with advanced dementia: the inability to feed themselves. She wrote and received a grant for Schervier from the Fan Fox & Leslie R. Samuels Foundation to help address the issue, thus establishing the SPOON Program.

In the past, failure to feed oneself was recognized as the beginning of the end of life, and plans were made accordingly. With the advent of more modern medicine in the past 25 years, physicians created a "solution," one that can be quite helpful for individuals with short-term feeding problems, but has created a distressing situation when applied to terminally ill dementia residents. The solution that doctors put into motion was the insertion of a gastrostomy feeding tube to enable these individuals to receive passive nourishment. Sadly, tube feeding in nursing homes has grown exponentially in recent decades due to physician, staff and family misconceptions about its benefits and harms. As a long-

term solution, this method has numerous pitfalls, chief among them that the individual's quality of life is severely compromised and the likelihood of a peaceful death is cruelly diminished. Residents become totally dependent for care in the late stages of dementia, because physical and neurological changes increase, joints contract, infantile reflexes develop and the ability to feed oneself disappears.

*"In the past, failure to feed oneself was recognized as the beginning of the end of life.."*

The use of feeding tubes for advanced dementia residents results in these problems because the tubes don't work as imagined. They don't prevent pressure sores, malnutrition nor aspiration, and they don't improve the quality of the residents' lives or their functional status.

Unfortunately, studies have shown that feeding tubes often increase resident suffering as well as the burden of advanced dementia. They decrease quality of life because they remove the gratification of tasting food, which is one of the few remaining "pleasures," and they deprive residents of the socialization and companionship that naturally occur with mealtime, as well as the nurturing associated with hand feeding.

Nurturing is central to the mission of Bon Secours. Specifically, the mission of Bon Secours New York Health System and Schervier is to "bring compassion to health care, and to be 'good help' to those in need, especially the dying." Dr. Sansone felt compelled to find another solution, because she regarded the use of feeding tubes for terminally ill nursing home residents to be contrary to the spirit of the Bon Secours mission.

What was needed was a compassionate answer to help these dying residents both live and die with dignity. The conclusion was simply to hand-feed these residents one at a time. But that solution itself was problematic, because it might take an entire hour to hand-feed one individual, whereas the staff to resident ratio is not one to one. There are not enough certified nursing assistants to hand-feed the residents who need that degree of assistance. That is why we needed more than just our simple idea—we needed a way to make it happen.

Our solution was innovative because it didn't rely solely on paid staff. Instead, in some cases, it relies on "the kindness of strangers." Some of our hand-feeders are strangers. All are volunteers. Some of our volunteers are non-clinical staff, such as myself. Others are family members, recent retirees who want to give back, and teenagers. No one is paid for feeding. But is this method sustainable?

The SPOON Program is a successful beginning. Finding and training volunteers is less of a problem than the frequency with which they are available to feed. We began by offering training to all staff about the issue itself—the terminal nature of dementia and the fact that feeding tubes don't bring about an improved quality of life and death for these residents. We trained 113 employees of all levels, including physicians.

Our goal was to recruit and train at least 20 volunteers and family members each year who were interested and willing to hand-feed safely, appropriately and patiently. We sent press releases to local newspapers seeking volunteers, and utilized our active volunteer program. To date, we have had more than a dozen training sessions for more than 100 diverse volunteers.

Volunteer employees may feed a resident lunch during the workday (and afterwards, eat their own lunch while working at their desk). Others may wait until after work to feed a resident dinner. Some family members visit their loved one daily, and feeding them lunch and/or dinner is something they're willing, indeed, happy to do. Retirees will often volunteer because it brings them pleasure to know they are making a qualitative difference in someone's life.

The benefits of hand-feeding individuals who have advanced dementia are an improved quality of life and death, with a holistic focus on comfort and psychosocial and spiritual needs.

Bon Secours New York's mission is carried out through the services and programs of Schervier Nursing Care Center, Burke at Schervier Short-



Seymour Geffner hand feeds his wife Blossom her lunch and dinner, seven days a week, at Schervier Nursing Care Center. (Photo by Nadine K. Baker)

Term Rehabilitation, Burke at Schervier Cardio/Pulmonary Sub-Acute Care, Schervier Respite Care, the Schervier Center for Alzheimer's and Dementia Care; Schervier Home Care, and the Schervier Apartments. Information about Schervier and Bon Secours New York Health System may be obtained at [www.scherviercares.org](http://www.scherviercares.org) or 718-884-5100.

Nadine K. Baker was a graduate student in the Health Advocacy Program at Sarah Lawrence; she was director of public relations and marketing, Bon Secours New York Health System, Riverdale, N.Y. from March 2005 to March 2010.

## Working as an Emergency Department Post-Discharge Patient Representative

By Megan Donovan

Anyone reading this knows how difficult it can be for a patient to access what he or she need in our complicated health care system. Take that difficulty, add on a serious illness, mix in the chaos that can sometimes result from a visit to the Emergency Department (ED), and then try to navigate the labyrinth of requirements for insurance, specialists and expedited medical appointments.

Stuck? Many patients are, yet medical care providers who work in a busy ED don't have the time or resources to serve as navigators for patients. The aim of my new role as post-discharge patient representative for the ED at St. Luke's Hospital in Bethlehem, Pennsylvania is to help patients seen in our ED become "unstuck" (or, preferably, prevent them from becoming stuck in the first place!) after they are discharged. This position was created in 2010 by ED leadership in response to a growing sense that patients who were discharged from the ED were facing an increasing number of obstacles in pursuing needed health care.

St. Luke's is a not-for-profit hospital nestled in Fountain Hill, a neighborhood of Bethlehem that now primarily houses an aging population and many former employees of the failed Bethlehem Steel Company, as well as a growing Hispanic population. The Bethlehem ED meets the needs of about 75,000 patients a year and is a Level 1 Trauma center, treating over 2,000 traumas each year.

As the liaison for patients who are discharged from the ED, I have a variety of tasks. One of my primary roles is serving as a patient navigator. I function as a link between the ED and patients with urgent health needs that are not acute enough to warrant admission. This allows the staff to confidently discharge patients in need of particular follow-up with specialists or testing, knowing that I will help the patient complete follow-up as recommended. There are already procedures in place for many of the follow-up

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recommendations, but my position acts as a safety net to ensure no one falls through the cracks when they are referred to Orthopedics to cast a fracture or to Cardiology for a stress test.

*“...patients who were discharged from the ED were facing an increasing number of obstacles in pursuing needed health care.”*

The post-discharge management of a patient positive for deep venous thrombosis (DVT) provides an example of this safety net. In the ED we prescribed the blood-thinner Coumadin, gave the patient an order for lab work and told her to follow up with her family doctor who could manage her anticoagulant dosage based on those results. The patient had told our ED doctor that she had a primary care physician to follow up with; however when I called the patient to ensure that she had indeed done the required follow-up, it came to light that she had been formally discharged from her last doctor's office and could not find a doctor to see her within a reasonable time frame. After many phone calls and some coercion I was able to get her an expedited appointment in our medical clinic (the same one that had discharged her as a result of several no-show appointments) to ensure that her Coumadin dosage was appropriate, avoiding a potentially fatal situation.

In this same vein I help patients find primary care physicians, other specialists, options for insurance or medical assistance, or affordable medications, and handle their other requests. (This aspect of my job will be especially challenging in the coming months after 42,000 Pennsylvanians lose their state-subsidized health insurance, Adult Basic. See <http://pahealthaccess.org/> for more information.) Keeping these patients within the St. Luke's Hospital network smoothes the transition of their care from office to office. It doesn't hurt the bottom line, either.

I began collecting data on some of the obstacles that patients face after leaving our ED, and armed with that data the ED di-

rector addressed those departments that were the hardest for our patients to navigate. Several useful procedural modifications have taken place since then. For example, I found that our orthopedic patients were having trouble getting through to the orthopedic specialists, and often times would be seen in the ED two or more times for pain control before their first orthopedic appointment. In working with the orthopedic specialists we identified the source of the miscommunication. Patients with fractures are now called within hours of their visit in order to schedule an appointment, so the patient needn't spend hours or days repeatedly trying to get through to someone at the orthopedist's office. Not only do these small adaptations improve health outcomes for patients, they also are positive from a customer service perspective.

Another of my roles is to be a patient satisfier by being the go-to person for questions from patients about the department. It's an improvement over patients calling the ED directly with a variety of questions, as the person answering the phone may not be able to give the matter the time or attention needed. In addition, calling patients after they have been discharged offers an opportunity for service recovery, if necessary. I assess patient satisfaction and report the satisfaction data to the ED directors on a weekly basis, giving the directors an opportunity to address any negative trends in customer service in real time. Under this umbrella I also take patient complaints, as well as encourage patients to return the customer service surveys they may receive in the mail.

The most gratifying aspect of my job is the interaction I have with patients. I have enjoyed educating them on the strategic aspects of being one's own advocate and helping them find health care options for their particular situations. It feels good to watch a patient who at one time used the ED as a primary care office find herself newly insured and managing chronic conditions with a family doctor. Above all else, it is in my interactions with patients where I feel my degree from Sarah Lawrence College comes through the most.

*Megan Donovan is a graduate of the Health Advocacy Program.*

## States Prepare to Implement Health Policy Changes by 2014

By Brenda Shipley

The Patient Protection and Affordable Care Act (PPACA) was signed into law on March 23, 2010, was voted to be repealed by the Republican-controlled House of Representatives on January 19, 2011 and was found to be unconstitutional by a Republican-seated federal judge in the state of Florida on January 31, 2011. Just three days later, however, the National Academy for State Health Policy (NASHP) held a briefing in Washington, DC that showed no signs of states slowing their progress toward implementing PPACA policy and technology changes by 2014.

The focus of the briefing was on maximizing enrollment of the uninsured in state-sponsored insurance programs like Medicaid, CHIP and the newly created insurance exchanges borne out of the

*“The level of collaboration is stunning...”*

PPACA. States have been drowned in paper enrollment applications and burdened by complex eligibility rules for decades. Until now, they have lacked financial resources to both improve their technology and improve the experience of the uninsured who endure the stigma and frustration of having to show up in person at

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## POINT OF VIEW

### Health Care Reform One Year Later

By Pamela Willrodt

A full year has passed since the Patient Protection and Affordable Care Act (PPACA)—also known as Health Care Reform—was signed into law last March 23. Fortunately (or unfortunately, depending on one's viewpoint) this presents health advocates with a multitude of opportunities. At last count, 28 states were challenging the Act's constitutionality.

The February 2011 Kaiser Health Tracking Poll revealed a statistic that surprised even Drew Altman, PhD, the president and CEO of the Kaiser Family Foundation. The “doozy,” as he referred to it? That 22 percent of Americans believe PPACA has been repealed and is no longer law, and another 26 percent said they didn't know its status. Only 52 percent of Americans believe PPACA is still the law of the land!

*“At last count, 28 states were challenging the Act's constitutionality.”*

Fast forward one month to the March 2011 Kaiser Health Tracking Poll reporting that more than one-half of Americans, another 52 percent, are confused and lack information about the law, specifically about how it will affect them personally.

The key point is that the law will not affect most people in regard to how they will obtain their health insurance. To alleviate angst, we must reinforce the fact that the majority of people will still get insurance through their employer; it is that simple; nothing will change. The employee's cost share for the least expensive coverage offered can be no more than 9.5 percent of household income. For a household income of \$30,000, this means that the premium will be under \$2,850; anything above that cost is defined as unaffordable by PPACA and the employer will pay a penalty.

The current estimates are that the health law will expand coverage to 32 million more Americans in 2014. Currently an all-time high of 50.7 million individuals, or 16.7 percent of the population, are uninsured. Coverage will be gained through expanded Medicaid, which will cover about 16 to 18 million individuals under age 65 with income up to 133 percent of the Federal Poverty Level (FPL), and insurance exchanges with appropriate government subsidies, which are expected to provide coverage to about 16 million individuals and families with income at 133 to 400 percent of the FPL. Medicaid and the Exchanges will provide health insurance that is stable, secure and, most importantly, affordable.

But how affordable will this new insurance actually be? Let's look at two scenarios, one for a family of four and one for a single person, with both estimated for a higher cost of living area. According to the data prepared by the U.S. Census Bureau from the 2006 American Community Survey (ACS), the estimated median income for a four-person family living in the United States is

\$70,354 for fiscal federal year 2009; the estimated median income for a single person is \$36,284 for the same period. Based on the Health Reform Subsidy Calculator found at <http://healthreform.kff.org/SubsidyCalculator.aspx>, health insurance cost and any tax credits (also known as subsidies) are based on age and income. Varying levels of coverage will be available, known as bronze, silver, gold, or platinum (i.e., benefits that are actuarially equivalent to 60, 70, 80 or 90 percent, respectively, of the full actuarial benefits provided under the plan).

The figures below are based on 2016 estimates for the silver plan:

Family of Four – Income \$70,354			
Age	Unsubsidized health insurance premium 2014	Actual payment	Government tax credit
20	9,139	6,684	2,456
30	10,108	6,684	3,425
40	12,130	6,684	5,446
50	16,858	6,684	10,174
60	24,042	6,684	17,259
Single Person – Income \$36,284			
20	3,391	3,391	0
30	3,440	3,440	0
40	4,500	3,447	1,053
50	6,978	3,447	3,531
60	10,172	3,447	6,725

What becomes clear is that this family of four, no matter the age of the oldest family member, would pay no more than \$6,684 per year (\$557/month); for a single person, the premium is less than \$3,500 per year (\$287.25/month)—9.5 percent of median family income in either case. The maximum out-of-pocket expenses for the family (not including the premium amount) would be \$8,333; for the single person, \$4,167. Current data/projections from the Commonwealth Fund show that health insurance costs consumed about 19 percent of family income in 2010 and are expected to reach 22 percent in 2015. Maximum premiums at only 9.5 percent of income are a true bargain.

In spite of continued Republican opposition to the law and efforts to defund it, and in spite of deliberate misinformation campaigns, many have already been helped. Medicare recipients are already receiving free preventive care and wellness checkups, as well as assistance with prescription costs associated with the doughnut hole. Families are able to keep their adult children on their health

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## FACULTY NEWS

### Publications by HAP Faculty Members:

*Patients as Policy Actors*, edited and with an introduction by Beatrix Hoffman, Nancy Tomes, Rachel Grob and Mark Schlesinger, Rutgers University Press, 2011. *Patients as Policy Actors*, a volume faculty member Rachel Grob (HAP '92) co-edited with three colleagues, addresses a number of questions central to health advocacy. What roles do patients and consumers play in shaping health care policy, and how are these roles mediated by other actors? What enables patients to effectively gain leverage for policy change, and what impedes them? What criteria should be used to measure the success of advocacy? *Patients as Policy Actors* concludes with an epilogue Rachel co-authored that outlines principles for integrating patient perspectives into a pluralistic conception of policy-making. She and her co-authors are publishing these

with the intention of sparking a robust conversation with others interested in making policymaking more responsive, and Rachel hopes to hear from some of you as you read and respond to this new work. She can be reached at rgrob@slc.edu.

*Handbook of Program Evaluation for Social Work and Health Professionals*, by Michael J. Smith, Oxford University Press, 2009. The *Handbook* includes examples of all types of evaluation studies, with many examples from coursework done by students in the Health Advocacy Program. The book presents examples of both quantitative and qualitative analysis, linking current perspectives in social work and health practice to evaluation concepts.

*States Prepare to Implement Health Policy...continued from page 8*

a welfare office, simply to enroll in an insurance plan. With the federal government picking up 90 percent of the tab for technology retooling, only one state—Alaska—is sitting on the sidelines.

Beth Osthimer, Director of Medicaid and Health Reform for the NY State Department of Health, describes her state's break-neck speed implementation efforts as, "building the plane as we fly." Mike Fogarty, CEO of the Oklahoma Health Care Authority, has turned the long-held perception that "these people can't use computers" on its head by reporting a 91 percent success rate in the move from paper to online enrollment in his state sponsored insurance programs. The sense of urgency—"2014 is tomorrow—is palpable.

As a way of mitigating the risk of failure by states to implement PPACA-mandated policy change, the Department of Health & Human Services' Center for Consumer Information and Insur-

ance Oversight has created an Office of Health Insurance Exchanges. According to Joel Ario, Director of the Office, "This is a sea change in terms of how the Feds approach building State systems." Indeed, the level of collaboration is stunning as the collective objective is not to recreate the wheel fifty times, or forty-nine times, as the case may be. Together, states are sharing ideas to streamline a laundry list of eligibility and enrollment guidelines for the uninsured, including policies regarding continuous eligibility, fingerprinting, asset tests and verification of status.

In spite of all the political efforts to stop PPACA in its tracks at the national level, the states at the NASHP briefing have thus far not experienced any efforts at the state level to sabotage their game plans of scoring a few points for the uninsured.

*Brenda Shipley is a first-year student in the Health Advocacy Program. She attended the February NASHP briefing in Washington D.C.*

*Health Care Reform One Year Later...continued from page 9*

plans to age 26, even if they are not in school or living at home. Small businesses are receiving tax credits that assist them in offering employer-based health insurance to employees.

*"How affordable will this new insurance actually be?"*

As health advocates, we must become and stay informed on the basics of PPACA. If an individual or family is covered through an employer, no change will be necessary. If income is less than 133 percent of the FPL, Medicaid will provide coverage beginning in

2014. If income falls between 133 and 400 percent of the FPL, affordable insurance can be purchased through an Exchange. Anyone who has an income greater than 400 percent of the FPL will need to purchase private insurance, if not otherwise covered.

The Kaiser Family Foundation website is a great place to become and stay informed. Calculate your own family's insurance costs under PPACA and compare them to your current plan or those available in your area ([www.healthcare.gov](http://www.healthcare.gov)). Do the math; make up your mind. Then use whatever tools are at your disposal to clarify the individual mandate whenever and however you can. Perhaps an Op-Ed piece of your own would be a good place to start.

*Pamela Willrodt is a student in the Health Advocacy Program.*

### Ageism in the Job Market: Tips to Overcome Prejudice and Maximize Opportunities



*Dede Bartlett, speaking to HAP students and alumnae.*

Lecturer and career coach Dede Bartlett addressed HAP students and alumnae on April 14. She spoke about the "new normal" in the job market, where all age groups now compete for the same jobs and power is no longer always in the hands of older workers. An older worker may report to someone much younger. Learning to work well with every generation has become an essential skill.

Ms. Bartlett offered an overview of general characteristics of younger demographic groups. Generation X—those born between 1961 and 1979—was the first technologically savvy generation. Generation Y—those born between 1980 and 1995—grew up with technology. Both generations tend to be informal in their speech, manners and dress. They're challenging and curious, comfortable working in teams. It's important for older workers to be able to function well as part of the team and to have basic technological competency, as it is now expected of all workers.

Today's tight job market demands creative thinking, particularly by older applicants. Networking is essential. According to Ms. Bartlett, "every contact is important in getting a job." Personal contacts can be the door openers for career change. She suggested creating a personal Board of Directors—a group of trusted advisors to talk with periodically about career goals.

Suggestions were provided for revamping resumes and projecting confidence and energy in interviews, essential in countering any negative attitudes about older workers. Older applicants are often viewed as having a lack of flexibility, lack of energy, poor technical skills and an inability to adapt to new situations. Ms. Bartlett suggested structuring answers to open-ended interview questions in ways that dispel these stereotypes. Mention active pursuits to demonstrate energy. Describe volunteer work and community involvement to demonstrate ability to be a team player and willingness to "give back." Relate stories that show flexibility and successful adaptation to change. The goal is to present your age as an asset, as it has helped you in developing the skills to find solutions to problems, both personal and professional.

## Upcoming Events

### New York Academy of Medicine: Healthcare Is Going Digital: What It Means for You

June 2, 2011

Presented by the NYAM Special Interest Group on Informatics. Developments in Health IT, with particular concern for how they affect individuals, whether healthy or sick. Attendance is free. To register, go to [www.nyam.org/events](http://www.nyam.org/events)

### Intensive Bioethics Course 37

June 6-10, 2011

A week-long academic program in bioethics designed for health care practitioners, policymakers and clinical researchers. The course addresses the day's most challenging topics in health care ethics in a setting that allows for sustained dialogue through lectures and small discussion groups with a distinguished faculty. The course will be held at Georgetown University in Washington, DC. Tuition fee is \$1,700. For more information, go to <http://kennedyinstitute.georgetown.edu>

### Aid and International Development Forum

June 8-9, 2011

A global event dedicated to the effective delivery of humanitarian aid and development solutions. It will bring together decision makers from UN, governments, NGOs and aid agencies involved in the delivery of humanitarian aid relief to conflict and disaster situations as well as international development to countries across the globe. Event will be held in Washington, DC.

Registration is free. For more information, see [www.aidforumonline.org](http://www.aidforumonline.org)

### 16th Annual Jarvie Colloquium: Aging Cohorts in Perilous Times: Disparities, Opportunities and Strategies

June 10, 2011

The annual colloquium is a one-day, issue-focused conference that provides a continuing education opportunity for social workers and administrators working with older adults. This year's plenary and workshop sessions will address multiple strategies for empowering older adults in these financially and emotionally challenging times. Registration fee is \$50; discounted registration fee of \$25 for students and those 65 or older. To register, go to [www.jarvie.org/colloquium16](http://www.jarvie.org/colloquium16)