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HEALTH ADVOCACY BULLETIN

The Journal of the Health Advocacy Program at Sarah Lawrence College

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Letter from the Director

By Vicki Breitbart

Focus on Sexual Health

In 1980, when I worked in a shelter for domestic abuse survivors, sexual violence was starting to be more fully investigated and understood. The relationship between sexual violence and health outcomes has since been clearly documented: a 2002 study found greater substance abuse, unhealthy weight control, and higher rates of suicidal ideation and attempts among survivors of intimate partner violence and sexual assault.¹ It's a widespread problem: a 2004 paper stated that "physical and sexual dating violence are normative."² Almost 80% of the women studied had experienced sexual violence

between age fourteen and the fourth year of college. I was an investigator in a 2006 study in which only 9% of 645 women between age fifteen and twenty-four said they had experienced sexual "abuse" in their lifetimes, but when we described sexual violence in behavioral terms, the percentage rose to 29%. For 17%, it was their first disclosure.³

In recent years the focus has shifted to college campuses. Dramatic cases of universities hiding sexual assault have inspired heightened scrutiny of policies and practices. With 5,000 forcible sex offenses on college and university campuses in

2012, 80 to 90% by known assailants and only 5% reported, the issue is finally getting some of the attention it deserves.⁴

A number of federal laws prescribe sanctions for lack of programs to meet the needs of survivors at colleges and universities receiving federal funds. Title IX of the Education Amendments of 1972, prohibiting discrimination on the basis of sex, requires a rigorous response to sexual violence. The Clery Act of 1990 added strict regulations for reporting crimes and warning students about sexual assaults. The Campus Sexual Violence Elimination Act, part of the 2013 reauthorization of the Violence Against Women Act, increased emphasis on primary prevention and awareness programs. These laws require a system for reporting, reviewing, and handling campus sexual assault complaints regardless of police in-

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¹ Jacquelyn Campbell et al., "Intimate Partner Violence And Physical Health Consequences," *Archives of Internal Medicine*, 162, no. 10 (2002): 1157-1163. doi: 10.1001/archinte.162.10.1157.

² Jacquelyn W. White and Paige Hall Smith, "A Longitudinal Perspective on Physical And Sexual Intimate Partner Violence against Women," in *Violence Against Women and Family Violence: Developments in Research, Practice, and Policy*, ed. Bonnie Fisher, (US Department of Justice, 2004), NCJ 199708.

³ M.S. Zeitler, et al., "Attitudes about Intimate Partner Violence Screening among An Ethnically Diverse Sample of Young Women," *Journal of Adolescent Health*, 39, no.1 (2006): 119.e1-8.

⁴ "Whoopi Goldberg Says, 'Enough Is Enough. Stop Sexual Assault on College Campuses,'" New York State, Accessed March 23, 2015, <https://www.ny.gov/whoopi-goldberg-says-enough-enough-stop-sexual-assault-college-campuses>.

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GRADUATE PROGRAMS

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volvement.⁵ The White House Task Force to Protect Students from Sexual Assault issued a report in April 2014 providing a comprehensive set of recommendations about policy language, investigative and disciplinary procedures, and the need for colleges and universities to take the issue seriously.⁶

States have come up with various solutions to the problems of sexual assault on campus. Colorado, Wisconsin, and seven other states have policies allowing guns on campus, though some have specific restrictions.⁷ New York has gone a different route. This year, the New York State Department of Health initiated a campaign that highlights the need for colleges and universities to create policies and procedures that provide services and support for survivors. The State University of New York now

requires affirmative consent (“yes, means yes”) for each sexual act;⁸ proposed legislation would extend this policy to all colleges in the state, public and private.⁹ In March of this year, New York State established a Campus Sex Assault phone number (1-844-845-7269) for reporting incidents.

In recent years, the Department of Education’s Office of Civil Rights has responded to many individual student complaints against institutions by investigating their compliance with Title IX. There are currently 97 such investigations underway in 94 colleges and universities, including Sarah Lawrence.¹⁰ In order to address our students’ concerns and questions, Sarah Lawrence has formed a Sexual Assault Task Force that is diligently working to be responsive to students and ensure that our policies meet their needs, including an affirmative consent policy.

A review of effective interventions on college campuses prepared for the White House Task Force has made it clear that policies alone or even one-shot educational programs are not sufficient.¹¹ The authors support more comprehensive campus-based primary prevention strategies and recommend some specific programs, including some that have worked with younger students. As advocates, we need to be part of the process of addressing sexual violence and so honor a long history of anti-sexual assault work.

Letter from the Editor

By Jean Kahler

As this edition of the Bulletin — my first as editor — goes to press, I’m struck by the range of issues covered in these articles. Health advocacy is a field characterized by its extraordinary breadth, from patient advocacy to policy and law to education.

Health advocacy means creating better solutions for individuals dealing with illness and aging, like the new Portable Assisted Living Services program Amy Lifson writes about and the healing power of personal writing with Visible Ink, a partnership with Memorial Sloan Kettering. It means helping patients take full advantage of existing programs, as Shade Grahling describes in her contribution to our ongoing series on the implementation of the Affordable Care Act, and lobbying for improved laws and policies, as when members of the HAP community testified in support of a truly universal health care act in New York State. HAP believes advocacy should be grounded in an understanding of the history of health, a view clearly shared by the conferences and events inviting our students to present their discoveries and insights.

The varied work of our faculty, students, and alumni bears out value of health advocacy, but even as advocates carry our knowledge and passion for health to the wider world, Vicki Breitbart’s letter about sexual assault on college campuses reminds us that we cannot be complacent at home.

⁵ Jean Reynolds, “Sexual Assault on College and University Campuses,” *Law Enforcement Today* (July 17, 2013), <http://www.lawenforcementtoday.com/2014/07/17/sexual-assault-on-college-and-university-campuses/>.

⁶ White House Task Force to Protect Students From Sexual Assault (US), *Not alone: the first report of the White House Task Force to Protect Students From Sexual Assault* (2014), <http://purl.fdlp.gov/GPO/gpo48344>.

⁷ Alan Schwartz, “A Bid for Guns on Campuses to Deter Rape,” *New York Times*, February 18, 2015.

⁸ Ariel Kaminer, “Cuomo Orders SUNY to Overhaul Its Sexual Assault Rules,” *New York Times*, October 2, 2014.

⁹ “2015 Opportunity Agenda: Ensuring Justice in Perception And Reality,” New York State, January 17, 2015, <http://www.governor.ny.gov/news/2015-opportunity-agenda-ensuring-justice-perception-and-reality>.

¹⁰ Tyler Kingkade, “Barnard College Joins List of 94 Colleges Under Investigations,” *Huffington Post*, January 7, 2015, http://www.huffingtonpost.com/2015/01/07/barnard-college-title-ix-investigations_n_6432596.html.

¹¹ Division of Violence Prevention, Centers for Disease Control and Prevention, *Preventing Sexual Violence on College Campuses: Lessons from Research and Practice* (2014), <https://www.notalone.gov/assets/evidence-based-strategies-for-the-prevention-of-sv-perpetration.pdf>.

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REPORTS FROM THE FIELD

Portable Assisted Living Services: Aging in Place in New Jersey

By Amy Lifson

How can people with limited financial resources get long-term help with tasks such as showering, dressing, and toileting? In Northern New Jersey, where I live and work, assisted living facilities cost an average of almost \$80,000 per year, nursing homes (which provide a higher level of care) are close to \$112,000 per year for a shared room, and home health aides average \$20 per hour.¹

Many people mistakenly believe that Medicare will pay for long-term care (LTC), but Medicare’s role in LTC is very limited, accounting for only 5% of all LTC expenses nationally. Medicaid is the government program that most often pays for LTC. However, regulations regarding eligibility for Medicaid coverage for LTC vary from state to state in terms of services covered.² New Jersey has a Medicaid program that will pay for eligible seniors to live and be cared for in assisted living facilities; however, many New Jersey assisted living facilities don’t accept Medicaid and/or restrict the number of Medicaid residents. The result is that there are very few “Medicaid beds” for seniors in New Jersey assisted living facilities. Nursing homes are typically more flexible with Medicaid policies, resulting in many on Medicaid entering nursing homes even if they don’t require such a high level of care.

Soon after graduating from HAP, I began working at Bright Side Manor, a non-profit assisted living home. Bright Side is the only assisted living residence in Bergen County and one of the few in New Jersey that don’t restrict Medicaid beds; it has a sliding fee structure for people ineligible for Medicaid. I became interested in Bright Side because

of its dedication to providing affordable long-term care and its broader vision to affordably address issues relating to helping seniors live safe and healthful lives. Bright Side Manor’s umbrella organization, Senior Housing Services (formerly Geriatric Services), recognized that most people can’t afford the high cost of the average assisted living facility and prefer to stay in their own homes for as long as possible. In response, Senior Housing Services began an Assisted Living Program (ALP) in February 2015, licensed to provide assisted living services in independent subsidized senior housing buildings, allowing residents a way to “age in place” as their care needs increase.

Since April 2014, as Program Director of Portable Assisted Living Services (PALS), I have helped develop and launch our new ALP, the first in Bergen County and one of only 15 licensed in New Jersey. ALPs offer the same services provided in assisted living residences, including help with personal care, ongoing health monitoring, medication administration/management, nursing services, coordination of health care, housekeeping, laundry, meal preparation, and help accessing transportation. The key difference between ALPs and assisted living facilities is that people continue to live in their own private apartments while assisted living services are brought to them. The ALP model of care is similar to how care is delivered in assisted living residences, with help provided on an as-needed basis instead of an aide providing care for a specific block of time, as with home health aides. Support is provided seven days a week, with an RN on site or on call at all times.

NJ’s Medicaid program pays for ALPs for people who are both financially and clinically eligible. For those who don’t qualify for Medicaid, ALPs are much more affordable than typical assisted living residences. The cost structure of ALPs saves the Medicaid program a significant amount, compared to the high costs associated with assisted living facilities and nursing homes.

For many reasons, it has been a challenge to get PALS up and running, despite widespread agreement that this type of program is needed. Since ALPs are licensed by the New Jersey Department of Health, there was a very lengthy licensing process and rigorous staffing, safety, and care requirements. The Medicaid approval process for PALS applicants has become more complicated and time consuming due to the recent change in New Jersey to managed care organizations (MCOs) coordinating Medicaid. Since this is the first ALP in Bergen County and one of the first in New Jersey, it has been a challenge to make potential enrollees and their families, referral sources, and especially the MCO care managers responsible for approving Medicaid applicants aware of the program. PALS is also dependent on its relationship with building managers, who may prefer that aging tenants move out and into long-term care facilities. PALS is currently funded by grants but will eventually need to be self-sustaining; we’re both hopeful and excited as we begin providing services.

Amy Lifson is a 2012 graduate of the Health Advocacy Program.

¹ “Long-term Care Calculator,” AARP, accessed February 15, 2015, http://assets.aarp.org/external_sites/caregiving/options/your_options_calculator.html.

² “What You Should Know About Long-Term Care,” New Jersey Department of Banking and Insurance, accessed January 11, 2015, http://www.state.nj.us/dobi/ins_ombudsman/lcguide.htm.

Transforming the Illness Experience through Writing: Visible Ink/MSK

By Debbie Finn

Patients navigating the medical world of cancer diagnosis and treatment often find their existence focused on illness and the hopeful path to improved health. Rarely does that path include the healing therapy of expressive writing. Through the Memorial Sloan Kettering Cancer Center (MSK) partnership with Visible Ink, patients are given the opportunity to explore this medium as an adjunct therapy.

Narrative writing as a therapeutic tool has the power to transform the illness experience. The rise of narrative medicine over the past 25 years reflects the benefits to physical and mental health of writing about traumatic or stressful events.¹ Visible Ink allows patients the opportunity to express themselves individually with the support of an experienced writing mentor. Narrative writing promotes creativity, stress reduction, and personal empowerment. New workshop opportunities

to share one's writing in blog format and other writing genres increase the benefits through shared experience. Through this creative expression, a sense of stability can be restored.

The writing experience itself can be valuable and meaningful. Arthur Frank, a sociologist on the forefront of the consideration of medical narrative as a mechanism to link body, illness, and the written word, contends that our stories dictate how we shape ourselves. As disease interrupts life, illness means living with this perpetual interruption. How we interpret that illness, and tell the story of illness, is at the core of the focus on illness narratives.²

The interpretation of the illness experience has been traditionally neglected in modern medicine. The recognition of narrative in the medical culture signifies a shift from fixing an illness to healing a patient. Constructing a story allows one to organize thoughts in such a way that an emotional response is more manageable. The design of the narrative helps to give coherence to the events and nature of illness and suffering. "The plot lines, core metaphors, and rhetorical devices that structure the illness narrative are drawn from cultural and personal models for arranging experience in meaningful ways and for effectively communicating those meanings. Over the long course of a chronic disorder, these model texts shape and even create experience."³

The importance of storytelling and listening to stories is being recognized within

medical schools, universities, and hospitals. "Medicine practiced with these skills of recognizing, absorbing, interpreting, and being moved by the stories of illness," is the definition of narrative medicine proposed by Rita Charon.⁴ At Columbia University's Masters Program in Narrative Medicine, Charon is building a new framework for medicine, understanding the ways in which narrative can enhance traditional medical care. Patients can discover a way to reflect upon illness, disease, and the emotions that accompany them.

Visible Ink/MSK has embarked on a path to utilize this power of expressive writing with their patient population. Thanks to MSK's large number of cancer patients Visible Ink has a tremendous range of outreach, allowing them to engage participants in a depth and breadth of narrative programming. I have introduced a new workshop format to their existing program that will be instrumental in reaching a broader range of patients in new, approachable ways. Many who might never have felt comfortable within an individualized independent writing structure may consider joining a group in a workshop. This program extension has the potential to reach many more patients, with diverse interests, and to extend the power of expressive writing well beyond Visible Ink's current participant base.

Debbie Finn will graduate from the Health Advocacy Program in 2015.

¹ James W. Pennebaker and Sandra Klihr Beall, "Confronting A Traumatic Event: Toward An Understanding of Inhibition And Disease," *Journal of Abnormal Psychiatry* 95, no. 3 (1986): 274-281.

² Arthur W. Frank, *The Wounded Storyteller*, (Chicago: University of Chicago Press, 1995).

³ Arthur Kleinman, *The Illness Narratives: Suffering, Healing, And the Human Condition*, (New York: Basic Books, 1988).

⁴ Rita Charon, *Narrative Medicine: Honoring the Stories of Illness*, (New York: Oxford University Press, 2006).

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POINT OF VIEW

Saving Lives through Policy Advocacy: The Sepsis Alliance

By Thomas Heymann

At a time when debates over health care have reached an unproductive stalemate, advocates are presented with an opportunity to push state and federal governments to step up to their leadership roles, starting with improvements in the treatment of sepsis.

Sometimes called blood poisoning by the general public, sepsis, the body's often-deadly response to infection, is a medical emergency. Costing more than 250,000 lives each year in the United States, sepsis is the third leading cause of death in the country. It is also the leading driver of cost in U.S. hospitals, at more than \$20 billion every year. Addressing sepsis, the most frequent cause of death in hospitals, with 80% of cases entering through emergency departments, requires increased awareness and education to accelerate prompt and effective treatment. Early recognition and treatment is the key to improved outcomes, yet fewer than half of American adults have ever heard of sepsis, and many hospitals do not yet have sepsis protocols in place.

What makes sepsis special, however, is not its high cost in terms of lives lost and health care expense. Sepsis represents an unusual opportunity for immediate health care improvement because, in most cases, it is a preventable and treatable disease. We do not need to wait for research to bring us a cure to make a significant impact in saving lives. With appropriate awareness, prevention, and treatment, we can save lives now, improve the welfare of survivors now, and save significant health care dollars now, all at the same time. How is that for a win-win-win?

Examining a recent New York State initiative and the role that advocacy played in its development, we can envision how other states and the federal government can be encouraged to save lives and money on a national scale. Here is a case in point; at the urging of two parents from New York City who lost their 12-year-old son to sepsis, Governor Andrew Cuomo enacted Rory's Regulations, requiring New York State hospitals to adopt protocols for early identification, treatment, and reporting of sepsis cases. Hospitals operating within the state are now required to develop and deploy sepsis reduction protocols and to maintain statistical collection systems. Although it took a tragic loss to implement this effort, the state of New York should be applauded for setting an example for the rest of the country.

Now New York State's approach needs to be implemented nationwide. Toward that goal — and pushed by advocates across the country — the Senate Health, Education, Labor and Pensions Committee, chaired by Senator Tom Harkin, held the first special hearing on healthcare-acquired infections and sepsis late last year. At the hearing, Senate members were surprised by the statistics presented on infections and sepsis, and they were moved by the emotional stories of loss that were shared. The hearing room overflowed with the faces of sepsis stakeholders: survivors, families of the lost, advocates, students, providers, industry representatives, and media.

At the same time, advocacy organizations like Sepsis Alliance have brought together volunteers and advocates to organize community awareness events across

the country. Sepsis Alliance, a public charity founded by a father who lost his healthy 23-year-old daughter to sepsis, also provides awareness and education materials to tens of thousands of individuals and to hospitals and health care providers across the country. The Sepsis Alliance website receives more than 80,000 visits each month from interested parties who want to learn more about sepsis, many of whom want to work to change the course of this disease.

We don't have to wait for a cure to prevent hundreds of thousands of deaths and save millions from the pain and suffering of sepsis recovery. In fact, as indicated by the New York State protocols, and evidenced by the changes made by some forward-thinking hospital systems, sepsis can be prevented and treated successfully with good old-fashioned clinical rigor, saving 50% or more of the lives that would have otherwise been lost.

Our state and federal governments now have the opportunity to lead in this area. By requiring hospitals to adopt sepsis protocols, we can overtake what might be the most preventable cause of death on earth. We cannot afford to lose any more 12-year-olds while the rest of the country waits for action on sepsis prevention and treatment. We must task state governments and our federal leaders to act. Every 20 seconds, one of us develops sepsis, and every 2 minutes, someone dies. Maybe someone we know.

Thomas Heymann is Executive Director of Sepsis Alliance. For more information, please visit: <http://www.sepsisalliance.org>

Navigating Health Insurance: The ACA And Zufall Health

By Shade Grahling

The second year of open enrollment for the Affordable Care Act (ACA) came to an end on February 15th (or so we thought before the announcement of the special enrollment period from March 15th to April 30th). This term certainly went more smoothly than the inaugural season in 2014. Healthcare.gov had fewer glitches and problems, the operators were better trained, and most in-person assistants had a much better understanding of the process, including the details of immigration statuses, insurance plans, provider networks, and tax scenarios.

At Zufall Health, a network of community health centers in northern and central New Jersey, we had four staff and a team of eight AmeriCorps Community Health-Corps® members who became Certified Application Counselors (CACs) to provide in-person assistance to consumers applying for insurance through the Marketplace or directly with NJ FamilyCare, New Jersey's expanded Medicaid program. This team assisted 2,120 individuals and filed 414 applications, leading to approximately 340 enrollments. We also helped file appeals of eligibility results and exemptions from the individual responsibility payment, a.k.a., "the fine."

In 2014, Zufall Health cared for approximately 26,000 patients, of which 57 percent were uninsured. Some of these individuals are undocumented immigrants and are thus not eligible for insurance coverage through the Marketplace or Medicaid. Additionally, we have patients who reside legally in the United States but have been in the country for less than five years, the bar for Medicaid eligibility. Although these individuals and families may have been eli-

gible for a tax subsidy to purchase private insurance through the Marketplace, for some the plans remained unaffordable. Our CAC staff spent a lot of time educating our patients and community members about how insurance works — what is a premium, what is a deductible, how does a co-pay vs. a co-insurance work? Many of these concepts are very different from how health insurance works in the patients' home countries; it took time to help them to begin to understand a system that is not widely understood even by those who have had private health insurance in the US. We talked about why someone would want insurance and how it could protect them from a financial crisis, since the majority of personal bankruptcies in this country are caused by medical bills, and how having insurance could improve access to care. Additionally, we spent time learning about the needs of these consumers — what chronic health conditions they may have, what medications they take, how often they visit their doctors, and with which insurance programs their providers participate — all in an effort to try to help them select the most appropriate plans for their needs.

We had not anticipated the amount of case management that our CACs would eventually do with these families or the relationships and trust that would be built from an appointment to enroll in health insurance. Each individual or family had a story to share with us as we filled out the healthcare.gov application, and thus we talked to them about their families, incomes, and health needs. We would hear about job losses, age discrimination in job searches, divorces, babies born, fami-

lies split by immigration status, domestic violence, cancer diagnoses, and searches for doctors who would accept Medicaid. I kept a box of tissues on my desk for people who cried from joy when they were found eligible for Medicaid and now felt able to schedule a doctor's appointment for the first time in years, who now didn't have to choose between buying food for their families or going to the doctor, who could stop running up credit card debt to pay for their prescriptions. We saw these reactions even from individuals who walked through our doors opposed to "Obamacare."

These meetings also allowed us to share the story of Zufall Health and our mission to provide primary medical and dental services for anyone, regardless of immigration status, insurance coverage, or ability to pay. They allowed us to dispel some myths about Zufall as a "clinic" only for people who can't go anywhere else. We shared the quality of our staff and the enabling services that we offer in an environment of cultural humility we hope becomes the patient's medical home.

The Affordable Care Act rollout has not been without its bumps along the way and provides a fascinating case to examine how a written policy works when implemented in the "real world." As a health advocate, the most satisfying aspect of my work with the ACA has been empowering our patients and other consumers to navigate the confusing world of health insurance in order to improve their access to care and, I hope, their own health outcomes.

Shade Grahling is a 2013 graduate of the Health Advocacy Program.

Taking a Stand for Universal Health Care in New York State

On December 16, 2014, members of the Health Advocacy Program joined more than 80 other organizations and individuals to provide testimony to the New York State Assembly Standing Committee on Health in support of the New York Health Act. This public hearing was one of six held around the state in order to give elected officials feedback on the law and suggestions for how it might be strengthened. Vicki Breitbart led a group of HAP alumni, current students, and faculty in drafting the public testimony, which presented a multifaceted argument in favor of the creation of single payer health coverage in New York State. In HAP style, personal narratives were woven into a discussion of the ethical and economic failures of our current for-profit multi-payer health care system; an excerpt appears below.

Gloria Escobar-Chaparro (HAP '10, Fieldwork Coordinator), Alice Herb (Ethics of Advocacy faculty) and Susan Greenberg (HAP '11) attended the hearing, which lasted more than six hours. Participants included more than 30 medical providers describing the burdensome paperwork requirements imposed on their practices by insurance companies, which often create barriers to providing timely and appropriate care to patients as well as financial burdens on their businesses. Numerous unions and political and community based organizations large and small testified, as did many individuals whose stories of navigating our health care system make one realize how limited the terms tragic and heartbreaking are in describing the lived experiences of

many New Yorkers. Not all of the testimony was in favor of the bill; there were a handful of organizations lobbying against its passage. Overall, the testimony presented spoke clearly and loudly that in New York our residents and medical providers both need and want a single payer health plan.

The Affordable Care Act has done a lot in New York State to improve care, and many more New York residents have much needed insurance than ever before. Yet we are seeing that for many, out of pocket expenses have increased under ACA. We are still left with critical gaps. The system is still burdened with high administrative costs and a very bureaucratic system that remains uncoordinated and largely irrational in its execution. The system still remains one that profits insurance companies and not necessarily the individuals they serve. The system is still fragmented, costly, and not accountable to the public. While we have seen the overall cost of health care in this country declining, individuals' contributions to their health care are climbing.

The health care system still remains largely employer driven. A recent article in *Modern Healthcare* by Bob Herman states "high deductibles, stagnant wages choke affordability of employee's health insurance." Employers are still the largest provider of health insurance, and while there are some provisions in ACA to contain yearly raises in premiums, employer-funded family insurance "rose 73% from 2003 to 2013 and for individual plans 60%". The same ar-

ticle points out that "median income only climbed 16% in the same time period."¹

As we understand it, New York residents now receiving state and federally supported care would not lose what they have. Residents who benefit from Veteran's Health would still be able to receive these services. Overall, Medicare and the VA system in New York State seem to work well, but a single payer system needs to avoid problems that still exist in these programs. There are long waits and too few providers, many of whom are moving away from these systems because of low wages and inadequate reimbursement for services. New York State will need to support fair, reasonable and geographically adjusted payments for health care providers so that serving New York Health patients would be an honor and not a drain on their livelihood.

The new legislation would also encourage the further coordination of care. Under a single system, communications between providers and specialists could be vastly improved. One system could eliminate costly duplication of services and lack of coordination of care. In addition, a single payer system would increase accountability of health care to the public and not insurance companies.

New York has missed the opportunity to be the first state in the nation to adopt universal health care, however, we must be the next to adopt this legislation if we are to provide the kind of health care that is our right.

¹ Bob Herman, "High Deductibles, Stagnant Wages Choke Affordability of Employees' Health Insurance," *Modern Healthcare*, December 9, 2014, <http://www.modernhealthcare.com/article/20141209/NEWS/312099936>.

NEW YORK ACADEMY OF MEDICINE HISTORY NIGHT



Devon Santoro, Natalie Taylor and Jane Himmel

Current students Jane Himmel, Devon Santoro, and Natalie Taylor were invited to present work they began in HAP's History of Health Care in the US course at **The New York Academy of Medicine's "History of Medicine Night: 19th and 20th Century Stories,"** on May 6th, 2015.

Abstracts of their papers follow.

More information about the event can be found at: <http://www.nyam.org/events/2015/2015-05-06.html>

Medical School Discrimination: Advocacy in A Postwar World

Jane Himmel

The post-World War II period was a robust one for attacks on discrimination in higher education. Blacks and Jews in particular moved towards an assertive position in claiming their rights in society rather than continuing to accommodate prejudicial structures and attitudes. While the defeat of Fascism, the emergence of the Cold War, and the issuance of Presidential Reports on Civil Rights and Higher Education helped focus the nation's attention on injustice in America, sentiment was insufficient: educational barriers needed to be broken down on a state-by-state basis. Affected communities took charge of their own advocacy efforts, using tools of mass communication, data collection, litigation, lobbying, conferences and intergroup relations.

In medical schools, admissions practices had long been used to shape a profession that was white and native-born. Segregated schools kept blacks confined to underfunded and overcrowded facilities, while quotas restricted Jewish applicants. Even as evidence mounted showing the results of these policies, the governing bodies of the AMA and AAMC chose not to show leadership in addressing these concerns and responded tepidly to outreach by NMA leaders.

Ten years after the war ended, Jewish applicants had greater success than blacks in medical school admissions, not only because of the concentration of Jewish applicants in northern schools. The effects of segregated education impacted the ability of blacks to present competitive test scores, and rather than adjust for racial barriers, medical schools used these results to continue admissions restrictions.

Puffing and Passing Legislation: The History of Marijuana And Its Place in Society

Devon Santoro

This paper explores the historical complexities of medical marijuana in the United States and the political and social elements that led to the Marihuana Tax Act of 1937. Through the investigation of texts, newspaper articles, and video, I have gathered evidence of interrelated social and political issues as well as stakeholders that defined how marijuana would eventually come to be understood in the medical and legal worlds. I give a brief overview of how marijuana was used medically and recreationally for over 12,000 years all over the world, up through its appearance and use in the US. Marijuana use became severely restricted in the US by the Federal Narcotics Bureau and its head commissioner, Harry Anslinger, between 1906 and 1937, despite its earlier recognition as a scientifically researched cure-all. I argue that marijuana was taxed, regulated, and criminalized to a point where it was not worth risking medical professionalism to prescribe. Other drugs, such as cocaine and opiates, went through a similar and interrelated legal history, however each drug garnered different outcomes of legality. My argument comes through the lens of Michael Foucault's docile bodies theory, which also serves as a lens through how women's narcotic use has been perceived. Marijuana's legal history in the US has been largely overlooked at the federal level and needs to have a place in the debate in favor of more research for medical marijuana.

A description of Natalie Taylor's paper, "The Unequal Burden of Censorship: Classism in the Wake of the Comstock Law," appears in the article describing *Worn Out: Motherwork in The Age of Austerity*.

Worn Out: Motherwork in The Age of Austerity

Indira Case and Natalie Taylor, current HAP students, presented at the 17th Annual Women's History Conference at SLC, *Worn Out: Motherwork in The Age of Austerity*, held March 6th and 7th. Their panel, "Redefining Motherhood Through Community and Activism: Two Historical Examples of How the Work of Women Shaped America's Health," wove together two historical moments that had great impact on how motherhood was perceived, governed and defined. Case and Taylor explored motherhood both through the traditional lenses of birthing and raising children and also from the perspective of women as mothers to their communities. Both examined major movements in American history that shifted women's abilities to care for their bodies, their families, and their communities, shedding light on the fortitude of women in times of turmoil and the response of women to oppression.

Taylor's presentation, "The Unequal Burden of Censorship: Classism in the Wake of the Comstock Law," focused on the historical context and aftermath of the enactment of the Comstock Law in 1873, and the classist ramifications of its implementation. This law was built to censor obscenities sent via the mail. It included for the first time legislation making it illegal to send contraceptive devices and information about contraception. Taylor discussed contraceptive methods and devices available (and popular) despite the law and how their use varied in different social classes.

Several factors led to the law being disproportionately oppressive to poor women, including the expense of contraceptives, lack of access to doctors and information on reproduction, issues of literacy and language barriers, and lack of privacy afforded to them. She considered the burden of censorship and the relationship between power, knowledge, and access.

Case's presentation looked at how the Black Panther Party implemented various services to gain social justice and empower blacks within the community. Although Black Panther Party leadership was primarily male, many of the services, such as the free breakfast programs and the health clinics, were run and organized by women. Women's activism often relates to motherhood/caretaking roles; Case discussed how women came to occupy leadership roles within the party in part via community caretaking.



Indira Case and Natalie Taylor

HAP e-Network Survey Results

By Gloria Escobar-Chaparro, 2010

In January the Health Advocacy Program distributed a survey by email to alumni and current students. Thank you to all who participated. You provided a great deal of helpful information. The goals of the survey were to gain feedback on ways we can build a stronger network among the HAP community using LinkedIn and to gauge interest in this initiative. The survey was sent to approximately 200 alumni and 30 current students. There was a 30% (n: 60) alumni response rate, and a 73% (n: 22) response rate from current students.

The survey showed that many alumni and current students use LinkedIn, and that many who are not already members of the

HAP LinkedIn group are interested in joining. Survey participants shared their views on how the HAP LinkedIn group might be improved, in addition to suggesting areas that they would like the Health Advocacy Program to focus on. From the comments received, several common desires for the group emerged:

- The ability to network is a high priority. Survey respondents indicated that they wanted opportunities to network with alumni, current students and with others in the field, in person as well remotely.
- Staying connected is also important for alumni and students. This means ex-

changing information about the field of health advocacy, including sharing articles on pressing or timely related issues, relevant work and personal experiences, and events of interest. A few mentioned that they would like opportunities for dialogues about some of these topics. Providing links to members' blogs, websites, and publications was suggested.

- Locating professional resources, including job leads, employment-related information, ongoing assistance with resumes, and ways to receive advice, matters to many alumni.

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FACULTY INTRODUCTIONS AND UPDATES

HAP is pleased to welcome to our faculty Katherine Moos and Jean Kahler.

Katherine Moos, BA, Sarah Lawrence College. MA (Economics), New School for Social Research. PhD expected 2017 (Economics), New School for Social Research. Recipient of the Eberstadt Prize Fellowship (2014-2017). Research focuses on macroeconomics and political economy with particular interests in: the political economy of the welfare state, theories of economic policy, labor relations, poverty, and inequality. Prior to beginning work on her PhD, Katherine worked for a number of non-profit advocacy organizations focused on domestic poverty and hunger in research, policy analysis, and public affairs positions. In 2007-2008, Katherine was named a Bill Emerson National Hunger Fellow. She recently published "Stabilization Policy — Phillips before the Phillips Curve" in *Global and Local Economic Review*, with K. Vela Velupillai. SLC 2015-

Jean Kahler, BA, Smith College. MFA (Nonfiction Creative Writing), Sarah Lawrence College. Teaches composition, creative writing, and literature in SUNY and CUNY systems. Professional writing work for CDC- and NIH-funded public health and social work research projects, including pediatric preventative dental care outreach, and HIV-related interventions for couples, women on parole and in alternative to incarceration programs, and patients of clinics in the townships of Capetown, South Africa. Her work includes *The End of New York*, a collaborative exploration of southern Staten Island with photographer Jessica Rowe (Furnace Press 2010), and "Our Radical Traditional Families: Online Support for Queer Motherwork," presented at the 17th Annual Women's History Conference at Sarah Lawrence. SLC 2011-

Alice Herb formed a consortium of 6 medical schools to examine the extent of unethical or untoward behavior experienced by medical students, in connection with the publication of "Ethical Dilemmas in Clerkship Rotations" in the November 2013 issue of *Academic Medicine*. The consortium is in the process of gathering a focus group of medical students to whom

they will administer a survey/questionnaire they created and from whom they will gather more detailed information. The goal is to conduct a national survey. Alice has been Co-Chair of the Committee on Ethics in the Provision of Care of the Health Law Section of the NYS Bar Association for the past year and a half.

Sayantani DasGupta's recent publications include "The space that difference makes: On marginality, social justice and the future of the health humanities," to be published in the *Journal of Medical Humanities*, "Bringing home the health humanities: Narrative humility, structural competency and engaged pedagogy," to be published in *Academic Medicine*, as well as numerous other print, online, and blog articles. For more, see: <http://sayantanidasgupta.info/>.

Karen Porter was appointed by Governor Andrew Cuomo to serve on the New York State Task Force on Life and the Law. In her role as Director, Center for Health, Science and Public Policy and Associate Professor of Clinical Law, Brooklyn Law School Karen also moderated a panel on Disability as a Legal Construct, held on February 20, 2015.

Lois Uttley gave two presentations at the American Public Health Association annual meeting in November 2014: "Using State Hospital Oversight Laws to Protect Reproductive Health Care" and "Model Policies for Women-Friendly State Health Marketplaces." In February 2015, Lois was the lead author on comments submitted to the New York State Department of Health from the LGBT Task Force of Health Care for All NY urging improvements to a proposed regulation lifting restrictions on Medicaid coverage of medically-necessary transgender health care.

Heidi Weiss (HAP '08) presented at the "Working Along the Margins: Social Work and Palliative Care with At-Risk Populations" conference held on March 3, 2015 at Memorial Sloan Kettering Cancer Center in association with NYU Silver School of Social Work. Heidi's breakout session was titled "Building an Understanding of End of Life Care for the Intellectually Disabled/Developmentally Disabled Population." Heidi is also working as a palliative medicine social worker at WestMed Medical Group in Westchester, New York.

Healing Gotham: New York City's Public Health Policies for The Twenty-First Century

HAP faculty member Bruce F. Berg has recently published a book with Johns Hopkins University Press examining public health policy in NYC: *Healing Gotham: New York City's Public Health Policies for The Twenty-First Century*. The book examines five contemporary threats to public health in NYC — childhood lead poisoning, childhood asthma, HIV/AIDS, obesity, and West Nile virus — and argues that forces such as race and ethnicity, New York City's relationship to the state and federal government, the promotion of economic development, and the availability of knowledge related to preventing, treating, and managing illness all contribute to effective public health policy making.

For more, see: <https://jhupbooks.press.jhu.edu/content/healing-gotham>



HAP STUDENT AND ALUMNI UPDATES

Debbie Finn '16 is a Harris Kramer Educational and Therapeutic Consultant, with a focus on children and adolescents with special learning needs. Debbie seeks to match students with schools and programs that offer a "culture of support" — social pragmatics, executive functioning, and/or specific instruction in the application of learning strategies. In visiting hundreds of specialized schools nationally, Debbie assesses their academic, social and residential curriculum to meet the needs of students with academic, cognitive, social or neuro-atypical profiles.

Ariel Hidalgo '14 is a Physician Liaison with Weill Cornell Imaging at New York Presbyterian. Her department recently began a Pediatric Imaging Program designed to lower the need for sedation in children undergoing MRI exams. They partnered with Siemens and Marvel to create a one-of-a-kind program, which includes an educational video component, a caped t-shirt with shorts in place of a gown, a specialized comic book, and a plush toy. The program was promoted on local cable channel NY1.

Additional information can be found at http://marvel.com/news/kidsparents/23554/siemens_and_marvel_team_up_again_for_the_new_mriamahero_campaign

Helen Hovdesven '92 is now Chair of the Patient Family Advisory Council of the Memory Center at Johns Hopkins Hospital and is working to enlarge the Council. Helen continues her volunteer work at Johns Hopkins with the Dementia/Alzheimer's population and recently recorded a podcast on Brain Donation, which can be found at http://www.hopkinsmedicine.org/psychiatry/specialty_areas/memory_center/patient_family_resources/podcasts/podcasts_Hovdesven.html

Farrah Schwartz '03 is working in the field of Patient and Family Education, advocating solutions to mitigate low health literacy in a hospital environment. Farrah has published several papers in journals such as *Hypothesis* (2010) and *Healthcare Quarterly* (2010). A recent blog post on health literacy in Canada (2013) can be found here:

<http://healthydebate.ca/opinions/a-small-step-towards-a-health-literate-canada>

Jessica Donaldson Stein '12 is a Patient Oncology Navigator at the Hollings Cancer Center at the Medical University of South Carolina, in Charleston. In her role, she coordinates care for all recently diagnosed Neuro-Oncology patients and guides them and their families through the treatment process. She is happy to be working with patients and their families again.

Rebecca Szer '16 coauthored an article published in the peer reviewed journal *Psychology*, and online in the November 2014 edition of *SciRes*. The article, titled "Conscientiousness Moderates the Influence of a Help-Eliciting Prime on Prosocial Behavior" describes a research study that looked at how an individual's measure of Conscientiousness determined their willingness to help or to offer assistance to another in a conditional situation. The article can be found at: <http://dx.doi.org/10.4236/psych.2014.517198>

HAP e-Network...cont'd from page 9

Several respondents cited a need for HAP to direct attention on issues around aging, specifically the need for eldercare advocates, limited housing options for individuals as they age in place, and legal issues around elder abuse. In addition, a few respondents shared perspectives on broadening the focus of the Health Advocacy Program, and suggested its communications be more national, rather than focused on the East Coast.

What are the next steps? The HAP LinkedIn Group priority will be identifying ways to focus on the three commonly shared themes of the survey responses. A volunteer group of alumni and current students who have expressed interest in participating in this initiative will begin expanding and refreshing the HAP LinkedIn network with Gloria Escobar-Chaparro over the next few months.

Eighty-seven percent of alumni and 100% of current students who completed the survey responded "Yes" when asked if they would be willing to be contacted by other

HAP alumni or current students to talk about their professional experiences. So, if you've not already done so or you are a new member, please update your LinkedIn profile with professional areas of interest, places of employment, fieldwork/internship experiences and capstone project (if applicable). If you are a HAP graduate and not currently a member of the HAP LinkedIn group, please request to join. (Current students will receive separate instructions on next steps.)

Look for future updates and news to be posted on the HAP LinkedIn Group itself.