In my decades as a health care advocate helping clients through the maze of hospital and treatment services, I have had intimate knowledge of preventive, diagnostic, curative, palliative and end of life care. Yet only recently, completely by accident, did I come across the entire field of rehabilitative medicine, literally by accident.

I was hit by an ambulette on February 10, 2014. Had this not happened, I probably would have never gained an intimate understanding of rehabilitative medicine, a valuable aspect of our health care system. I know several people who praise the effectiveness of rehabilitation medicine and have had my own experience with outpatient physical therapy, but I had no knowledge of what quality comprehensive inpatient rehabilitation medicine entailed.

Although my accident took place close to our local hospital, I was taken to Lutheran Hospital, a designated level 1 trauma center in Brooklyn, NY. Level 1 trauma centers are comprehensive regional resources capable of providing total care for every aspect of injury — from prevention through rehabilitation. A recent study reported in Kaiser Health News showed that extended travel to a trauma center can be life threatening. For many reasons, I was lucky a trauma center was relatively close to the site of my accident.

In the hospital I was assigned a trauma doctor, an internist, a cardiologist and a neurologist. Typical of hospital care, there was little coordination between the different services, and in order not to get unnecessary tests and medications, I had to rigorously advocate for myself. Additionally, I had to advocate strongly for the type of rehabilitation care that was best for my recovery. Yet, once I was transferred to the Lutheran Sub-Acute Rehabilitation Center, located in the very same medical system’s hospital, I entered a whole special world of medicine with a distinctive difference in care. In the rehabilitation center, my attending physician was board-certified in physical medicine and rehabilitation: a physiatrist. A physiatrist is a nerve, muscle, bone and brain expert who diagnoses and treats injuries or illnesses affecting movement. The physiatrist approach to patient

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1 Rabin, RC. Injured Who Lived Near Closed Trauma Centers More Likely To Die. Kaiser Health News. 3/13/14

continued on page 2
care looks at the whole person and all systems, not just one symptom or condition.  

The term ‘physiatry’ was coined by Dr. Frank H. Krusen in 1938 and accepted by the American Medical Association in 1946. The field grew notably during World War II to accommodate the large number of injured soldiers. Today, there are over 6,700 physiatrists practicing in the United States; a relatively low number when compared to other disciplines. For example, there are 62,000 pediatricians in the American Academy of Pediatrics. Rehabilitation medicine is not a rotation in medical school and students must seek out this lesser known discipline. Yet, the comprehensive approach to the patient by physiatrists can clearly benefit all sectors of health care.

As would be expected, my rehabilitative care included physical and occupational therapy. But, the unexpected and most striking aspect of my program was its focus on holistic care. Acupuncture was provided on request, and I was assessed by a speech pathologist who could also work on areas of cognition, comprehension, focus and attention issues related to trauma. We decided this therapy was to be part of my essential care.

The major concern of this medical field is to help the person function optimally within the limitations imposed by a disabling impairment or disease process; in my case a crash. By definition rehabilitation is based on team work and collaboration among health care professionals. When done well it is essentially person-centered; optimizing quality of life. Though relatively comprehensive, my rehabilitation program was not without some gaps. There were other aspects of palliative care that would have been helpful and there was a significant lack of attention to the psychological and emotional aspects of trauma.

The Lutheran Rehabilitation Center acknowledges that these aspects of care need to be integrated into the treatment plan, and is taking steps to include them in the program.

Overall, I feel my experience with the trauma center and their rehabilitative medicine program was a unique experience in health care. Thanks to the immediate response to my injuries by a highly skilled team of professionals who collaborated throughout all aspects of my treatment and the inclusion of my family in my care, I am well on my way to returning to work. I have broadened my own personal and professional knowledge, and hope that we can continue to advocate for rehabilitative medicine's comprehensive approach — especially when implemented in the kind of safe caring environment I experienced at the Lutheran Rehabilitation Center.

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3 http://www.hss.edu/what-is-physiatry.asp
Laura Weil graduated from the Health Advocacy Program in 1994. As a student, faculty member and Director, Laura Weil had a tremendous and positive impact on the Program. Her career continues to unfold and provides an example of how the field of Health Advocacy is evolving. Laura met with Gloria Escobar-Chaparro on March 10, 2014.

GE-C: Laura, you have spent much of your life as a health advocate. How did your career begin?

Like most people in this field, I was initially drawn to it because of a personal experience. Most folks who are interested in becoming patient or health advocates have some fairly uncomfortable health care experience that leads them to want to make some positive change in the system. My experience was that my mother had a particularly tough death and it didn’t need to be so tough. It’s just the way health care professionals manage people who are ill without wanting to recognize that the illness might be terminal and without knowing how to ease the passage toward death and give up on a cure. That’s just something most clinicians find particularly difficult, but it’s hard on patients.

GE-C: How have you seen the Health Advocacy Program evolve?

One of the roles that I played as a staff member in the Program is someone with experience in the clinical sector. With my retirement, and that of other faculty recently, I hope the Program does not lose this perspective. I think one of the most important things that the Program has evolved toward is a broad spectrum concept of health advocacy, where you look at all the things that allow people to live healthy lives, all the barriers to living healthy lives, to receiving care, to being able to sustain the healing process that might have begun with medical care. It’s really important that we look at health from a zoomed out perspective, but that is of course a public health perspective and we are not a public health program. What differentiates us from public health is that we keep the patient at the center of our focus, not losing sight of the individual when we employ that macro lens.

GE-C: You started your career working at the individual level, but now you are at the zoomed out level.

I was a particularly focused student in terms of career objectives, I knew I wanted to work in a clinical environment in hospitals and I did all my fieldwork in hospitals. I was hired by a hospital before I had my degree. Even though I only had hospital experience, I ended up doing things that were a surprise to me. I did not expect to be offered the opportunity to be Director of the Health Advocacy Program.

I think the work I do now with the United States Nuclear Regulatory Commission (NRC) is more aligned to my patient advocacy role than the work I did in the academic world. I’m back working with clinicians — nuclear medicine physicians, nuclear pharmacists, radiation oncologists and other health care providers who use medical isotopes — and I’ve gone back to my original career goal of representing patients.

GE-C: Can you describe your work with the NRC?

The NRC is an agency of the Department of Energy and is responsible for the use and licensing of nuclear or radioactive materials for civilian use in the United States. Most of that use is in nuclear reactors for power, but a small subset is for medical treatment and diagnostic purposes. My work includes looking at how the government regulates the use of that material, how it addresses its misuse, how radioactive material is transported, how it is licensed, who gets to use it, under what conditions, and how to protect the public. But what’s particularly nice for me is that I get contact with patients, they are the constituency that I represent. The nuclear cardiologist on the committee, for example, is representing nuclear cardiologists in the United States. I’m representing patients. My title is Patient’s Rights Advocate. It’s my job to talk to patients about their experiences and about regulations that the NRC is putting into place to manage the isotopes that they use for their medical care. Are the regulations sensible from a patient’s perspective? Do they feel safe? Do they feel their families are safe from second-hand exposure to radioactive material used in treatment? Do they have access to the specialized use of medical isotopes? Are there barriers to access to new technologies?

GE-C: How has the field of Health Advocacy changed?

That’s a hard question. Hospitals now take patient satisfaction very seriously so the original role of the health advocate in the clinical environment has changed. Originally it was to convince hospital and health care management that they needed patients to be happy. That’s pretty well established now. Patients still are not happy but there is a recognition that they ought to be. It’s not just the convenience of the clinicians that’s paramount in the way that health care services are designed, but also the comfort and the dignity of the patient. And because patient satisfaction has become so much a part of the bottom line in the way that health care is funded, if you want to work in patient satisfaction you better make sure that you know about data collection and analysis, how measurement and satisfaction scores and metrics are used to define pay for performance so that you can be effective in selling the value of your ideas and innovations for better patient experiences while working in an institution.

GE-C: Where would you like to see the field go?

I’d sure like to see us have a single payer plan. I’d like to see more people working to give us a rational health care system, to reign in the costs of the way we do business. And, to be kinder to patients as they approach the end of life.

Gloria Escobar-Chaparro, HAP 2010. HAP Faculty, Fieldwork Coordinator. Consultant and grant writer for Mossville Environmental Action Now (MEAN).
Among the Clean and Green cohort at the Urban League of Essex County, David Williams may hold the record for one of the longest stays in prison — 30 years for his affiliation with the Black Panther Party in the 1970s. Mr. Williams was released from a New Jersey Prison several months after his 66th birthday, and we met when he came in to enroll in health insurance coverage under the Affordable Care Act. Mr. Williams didn’t know at the time that he was entitled to what is also known as Obamacare, nor was he aware of his entitlement to Medicare. He is one of many formerly incarcerated who are not aware that they are eligible for health insurance coverage.

The only way for an inmate of New Jersey’s jails or prisons to sign up for insurance coverage under the Affordable Care Act is to make a formal request. But how can you ask for something you know nothing about?

Stories like Mr. Williams’ emerged each time I went to the Urban League of Essex County and the New Jersey Institute for Social Justice (both in Newark, New Jersey) to enroll formerly incarcerated individuals participating or who had participated in the organizations’ pre-apprenticeship workforce programs. For many, the criminal justice system’s revolving door could stop spinning. The Affordable Care Act can be the new tool to fight recidivism.

Consider that approximately 95 percent of the inmates released from New Jersey state prisons and jails return to their respective communities. With such a high number of inmates returning to their original community, three vital questions should be asked on the part of the criminal justice system and the community health system: (1) what are the health care needs of these individuals; (2) what role can health and access to health care services play in affecting their success in transitioning back into communities; and (3) who is held accountable for making sure this uninsured population becomes insured. Inmates represent a large population that is disproportionately burdened with problems of physical health, mental illness, and substance abuse. Returning citizens face a number of hurdles when trying to access necessary health care services because they are either uninsured or underinsured.

These issues are especially acute in Newark, New Jersey, where approximately 1,700 individuals return to Newark from state prison annually; and 1,400 individuals are released from the local jails every month. When returning from prison or jail the citizens are bringing a host of health and social needs that ought to be addressed before release. Despite the impact of reentry affecting Newark every day, the residents are largely unaware of the returning citizens’ health needs, and the challenges they bring to the community that are not being addressed. Inmates and returning citizens who are victims of the criminal justice system have neither public nor private insurance.

This year, the Affordable Care Act provides a historic opportunity to address one of the key barriers to care for returning citizens, which is lack of health insurance. Currently, it has been estimated that 70-90% of returning citizens are uninsured. Since the implementation of the Affordable Care Act and expansion of Medicaid in 25 states, 6-7 million returning citizens qualify for Medicaid. Since Governor Chris Christie expanded Medicaid in New Jersey, services important to returning citizens such as substance abuse treatment, prevention services, and wellness programs are available. Because of this, the lives of many will be and have been significantly impacted in a positive way.

Some taxpayers may ask why should I pay for prisoners and the formerly incarcerated to be covered under the Affordable Care Act, and particularly Medicaid? First, what many taxpayers do not realize is that inmates in jails and prisons are not entitled to health insurance unless they are hospitalized for over 24 hours at a community hospital outside the jail or prison. Medicaid, by law, cannot pay for health care provided in a public institution such as prison or jail. This is known as “Medicaid exclusion.” Misinformation and confusion arises because even though the federal government will not pay for care while an individual is incarcerated, inmates are eligible for Medicaid coverage if they need health care services outside of prison or jail — at the expense of the federal government.

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1 Newark’s Transitional Jobs Program that gives participants a chance to learn basic job skills as well as marketable skills in landscaping and light construction.
2 Pseudonym
6 The number has increased.
The Affordable Care Act has the potential to change the criminal justice system, and significantly improve public safety outcomes. If the formerly incarcerated receive the best mental health and/or substance abuse services immediately after release, the likelihood that they will relapse or return to prison or jail can potentially decrease. Second, it can greatly improve community public health outcomes. If there is immediate and increased follow-up treatment for communicable diseases, it is less likely to affect the communities in which they live. Third, the Affordable Care Act can potentially reduce spending on corrections by doing a series of things such as increase the number of treatment programs, and comprehensive discharge planning for inmates, to name two. Lastly, there will be a significant increase in health care savings if prevention and treatment services are used and this can reduce the number of emergency room visits and hospitalizations.

Taxpayers ask, “Will the formerly incarcerated enroll? Once individuals obtain health insurance, will they utilize services?” Based on my experience helping to enroll returning citizens, and in speaking with them about their health concerns, the answer is, “Yes, they will.” How can the community help this already marginalized group? My solution is to welcome them back into society, and change our attitudes so that we do not continue to marginalize the formally incarcerated. Things do not change overnight; change occurs over time. We have a long way to go; however, I hope that communities come to understand that they will benefit if the reentry population has more access to health care and treatment.

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On November 8, 2013, HAP Faculty Rebecca O. Johnson lead a small Health Advocacy team to Mississippi to volunteer at Southern Echo, a community-organizing group that has focused for many years on leadership development and education in the Mississippi Delta. Southern Echo’s leaders wanted to learn more about the Affordable Care Act (ACA), Medicaid and Medicare and how they could help their Delta resident constituents sign up for health care. Over four days the Health Advocacy team — Rebecca, Nazsa Baker, Kay Bellor (students) and Gloria Escobar-Chaparro (faculty) conducted workshops and supported community leaders as they assisted the residents’ efforts to enroll in the health insurance marketplace. In this article, Kay and Nazsa answer questions about their experience.

Why did you want to volunteer in Mississippi?

Nazsa: When Professor Johnson presented the opportunity to do some Affordable Care Act and Medicare volunteer work in the Mississippi Delta, I was extremely excited. First, because I'd just completed a summer internship at the Center for Medicare Advocacy in Washington, D.C., so anything dealing with Medicare was fresh in my mind. Secondly, I wanted to visit the Deep South, and immerse myself in Southern culture.

Kay: My interest in the implementation of the ACA was one of the driving factors that led me to come to the Sarah Lawrence Health Advocacy Program. When the Supreme Court struck down the Medicaid expansion part of the ACA, I started to think about advocacy in the states that decided not to expand. So when Professor Rebecca Johnson mentioned she was looking for volunteers to go to Mississippi to help with community education and ACA sign up, I jumped at the chance.

What was it like volunteering in the Mississippi Delta?

Kay: Volunteering was an inspiring experience. Leroy Johnson, the director of Southern Echo, had campaigned for Medicaid expansion and believed that the denial of Medicaid to Mississippi’s poor is a huge justice issue. It was wonderful to be welcomed in the cities of Jackson, Duran, and Lexington, and get the chance to work with Mr. Johnson and others.

Nazsa: It was amazing volunteering in the Delta. It was a very welcoming environment. They say Southerners have the best hospitality and what I heard was true.

What challenges did you experience?

Nazsa: We experienced technical difficulties that forced us to use paper applications, but one of the most difficult challenges I faced was trying to not get emotional. I say this because so many families in the Delta could have benefited from the Medicaid expansion. I found it hard to explain to these individuals and families that they were too poor to be eligible for a tax subsidy (their income was below 100% of the Federal Poverty Level) but not poor enough to qualify for Medicaid in Mississippi. I just couldn’t stop saying to myself, “What is wrong with Mississippi? Do they not want individuals and families to have access to health care?”

Kay: As Nazsa mentioned, when we went to Mississippi, Healthcare.Gov was still not functioning. As a result, we really did not know how hard or easy it would be to try to sign people up. The folks in Mississippi were fantastic and had all the logistics set up for training, and two sign-up events. Despite the website malfunctions, we assisted over 35 individuals with applications. Another big discouraging challenge was the fact that many of the people who came for information were not eligible for help. There is a great need in Mississippi and other places for health care access. It’s unconscionable that the state legislature and governor have blocked this access by refusing to expand Medicaid.

Can you share a story that stood out to you when working with the community?

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A CA Outreach…cont’d from page 6

Kay: We did training the first day, and then just were present while Southern Echo community leaders helped people with signing up. Watching Ms. Betty and Ms. Dianne, from Southern Echo, at work was a privilege. Also, it was amazing to see Nazsa assisting Medicare beneficiaries. She was able to provide real help to people who thought there was no aid available to them.

Nazsa: I was helping an older African American woman obtain another Medicare card, since she’d lost hers, and she began telling me how the local pharmacist was charging her $17 for her medication. I just couldn’t wrap my head around how a pharmacist would overcharge a Medicare beneficiary who should only be charged around $7-$10 for medication. After hearing this story, I made sure to print out a temporary Medicare card, and write down the true costs of her prescriptions.

**How is the Delta different than where you are from in regards to health care and signing up for health care?**

Nazsa: New Jersey expanded Medicaid, even though we have a sorry federal exchange. Unlike Mississippi, New Jersey received the lowest amount of money per capita for outreach, so it is not surprising that individuals and families are not signing up or are only just finding out about enrollment.

Kay: The situation is completely different in New York, I would say. New York expanded Medicaid and had a fairly good state exchange and website going from the start. So people in New York did not hit the same snags as did so many people in other states. I’m hopeful that there will be organizing and campaigns planned in Mississippi to help sway the legislature in the elections coming up in 2015. The people of Mississippi deserve better.

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**Experience as a Customer Service Representative at Montefiore Medical Center’s Emergency Department**

By Angela Canagasaby – HAP 2014

Montefiore Medical Center (MMC) provided me with the opportunity to roll up my sleeves and interact with patients, families and health care professionals. The reason I use the phrase “Roll up my sleeves” is because I encountered some situations that were easily dealt with by an exchange of a few words, and then some situations that required actual legwork which took a month or so to obtain the most satisfying solution for the patient and family. Interning as a Customer Service Representative (CSR) at MMC provided me with much more than I expected.

After shadowing a few CSRs at the Moses and Einstein campuses, I began to understand and get the feel for both environments. Though both hospitals abide by the same rules and regulations, they explicitly had their own set of needs. This helped with the realization that situations are not just black and white and I had to prepare myself for the more commonly occurring in-between grey incidents.

After I was given permission to independently venture into the Emergency Department, I was able to converse one-on-one with patients — from the simplest to the most complex concerns. Some of the duties required me to provide patients with blankets, food trays and to reposition them in their beds. Initially, I was skeptical, “Is this what I signed up for? This isn’t what I want to do.” As days went on, I realized that those small gestures of kindness helped build a more satisfying relationship with the patient, and actually made me more aware of not only the patient’s concerns, but also their health and safety in the hospital. As a CSR, I was constantly the second set of eyes, and an extra helping hand in order to run the ED as smoothly as possible.

I had to always remind myself that I am representing the patient/family. And though there maybe situations where it is obvious that circumstance is not in the favor of the patient, I had to learn to communicate that to them in a demeanor that was nonjudgmental, calm and respectful. There were times where patients were aggrivated with the hospital processes and verbally expressed that frustration, and sometimes it was difficult for me to remain calm. Luckily enough, the course work, especially Models of Advocacy: Theory and Practice I & II, really prepared me for situations such as this. I always had to step back and look at the whole picture prior to making any judgment or decision based only on the current situation. I had to talk to myself, step-by-step, trying to figure out why an individual felt the way they did. Having learned that health is connected to the environment, social phenomenon, and economical stance really set the foundation for me to view things without a barricade.

After the completion of my internship, I was offered employment at MMC for the summer as a CSR during the evenings. Being the only CSR present during that shift at Moses campus, all the concerns were referred to me. I gained a lot of experience dealing with various situations.

If you like working directly with patients and staff, I highly recommend MMC, as you will learn to handle issues varying in complexity, and it will definitely prepare you to gain the confidence to speak to multiple individuals in a hierarchical system. I enjoyed interning at such a wonderful hospital, and being part of a supportive team.
On February 10th the Health Advocacy Program and Brooklyn Law School co-sponsored Sick and Tired of Being Sick and Tired: Leveraging Law to Facilitate Citizen Epidemiology, a roundtable discussion which focused on how communities organize to protect against industrial environmental health hazards. The panelists analyzed the role of “citizen epidemiology” in the advancement of environmental health justice.

Each panelist examined a case study of a public health crisis that began when community residents noticed prevalent health problems in their community, and the complete lack of government involvement in resolving the problem.

There was often an initial belief by the communities that they just needed to get the right information to the right officials and their problems would be addressed. Not only did they not find this to be the case, but oftentimes the communities’ concerns were obtusely addressed or flatly denied by government and industry. For instance, the residents of Mossville, Louisiana were told by representatives of the local industrial facilities that “The cost to lower fugitive emissions would be economically infeasible”; and the residents of the town of Toms River, New Jersey were informed by government officials that it was “…not possible to conduct studies to determine possible causes” of the childhood leukemia clusters they were experiencing.

Environmental attorney Monique Harden reminded us that there is no law in the United States that guarantees people the right to health. This makes getting the attention of the officiating bodies, before there is a full-blown crisis or catastrophe, particularly challenging. NYU Professor and author Dan Fagin illustrated the innumerable barriers that communities face when confronted with an inordinate amount of environmental toxins, such as access to information and power structures, is where opportunities for health advocates lie.

Panelist Ogonnaya Dotson Newman, with the organization WEACT, articulated a need for bridge builders, and translators among the groups working toward environmental health justice, noting “We’re all using different language to say the same thing.”

All who spoke agreed that it’s not enough to pacify communities on a case-by-case basis after an incident occurs. Instead, attention should be also focused on addressing the systemic problems or correcting the faulty policies that allow industries to continue colonizing communities which lack the political resources to resist. As Mossville Environmental Action Now President Dorothy Felix stated, “The ultimate goal is to become empowered so that communities can stand up and say, ‘no industry in this area’.”
Dr. Sally Ricketts, Medical Director for Behavioral Health Integration and Rehabilitation Management, Montefiore Medical Center CMO (Care Management Organization); conducted a workshop on Motivational Interviewing (MI) for HAP students on February 19th. The workshop outlined the framework and strategies used by MI to help people change behaviors, with the goal of improving their health. MI is defined as a "directive, client-centered counseling style to elicit behavior change by helping clients to explore and resolve ambivalence." The following summary is based on Dr. Rickett's presentation.

The traditional approach health care professionals take to encourage patients to make behavioral changes for health improvement is to persuade or confront the patient. The "expert" outlines for the person the specific health benefits the change will bring, instructs the patient what must be done and how best to accomplish the goal. It is a one sided interaction: health care professional leading, patient receiving. Numerous studies demonstrate the natural tendency of the recipient to this approach is ambivalence to change. If he/she is not an active participant and self-motivated it is unlikely behaviors will be modified.

MI takes the opposite approach to the traditional. MI collaborates with the patient to understand their goals, evoke their values and understand their reasons for change. The medical professional provides acceptance and compassion for the challenges such changes bring. This approach, done effectively, strengthens the "clients' motivation for and participation in behavior change." The acronym OARS describes the framework for the MI approach — Open Ended Questions; Affirmations using genuine statements of support; Reflections, mirroring back what the person has stated; and Summarizing, synthesizing what the client has said and their plan for change.

Dr. Ricketts, provided an example of the difference between a persuasive/confrontational approach and MI. A persuasive approach, for a patient with a recent heart attack, would include a lecture about the health hazards associated with smoking and a directive to quit. If the client is ambivalent about stopping the habit, this approach provides little opportunity for dialogue or support.

In contrast, MI would start a discussion with open ended questions: "What are your health goals after experiencing the heart attack?" The person may start with, "I don't want to quit smoking." An appropriate MI response could be "You're willing to accept the health risks of smoking at this time. What steps are you willing to take now? Why do you want to make this change (or changes)? How might you go about this plan in order to be successful? What are the 3 best reasons for changing your behavior? On a scale of 1-10 how important is it for you to make this change?" The practitioner then summarizes and reflects back what the person said. Then asks, not tells the client, "So what do you think you will do?" Then, asks the client to commit to the changes.

For health advocates the MI framework respects the patient’s autonomy, strengthening the opportunity for improved health through effective and lasting behavioral changes.

More information can be found at motivationalinterviewing.org, or by reading William Miller's book Motivational Interviewing, Third Edition: Helping People Change (Applications of Motivational Interviewing).

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**CALL to ACTION**

Did you know that a change to Facebook’s algorithm for how posts are seen has the potential to negatively impact smaller non-profits, specifically patient advocacy groups who do not have the budget to purchase paid ads on Facebook? This could potentially mean that posts will be seen by less than 1% of a page’s followers. To learn more and/or to sign a petition to stop Facebook from doing this visit: https://www.change.org/petitions/keep-facebook-free-for-non-profits.

Leslie Rott is currently a first year HAP student and Global Healthy Living Foundation intern.
A Diagnosis of Philanthropy: Carnegie and Rockefeller and the Medical Profession

By Katia Sokoloff – HAP 2016

“We don’t want to put bandages on weeping wounds. Philanthropy is about trying to solve problems at their root causes.”
— Andrew Carnegie (in a letter to Rockefeller)

Abstract

Through exploring the evolving interests of Andrew Carnegie and John D. Rockefeller during the Progressive Era, this paper unearths how these philanthropists, and their advisors, facilitated and funded the writing of the infamous Flexner Report in 1910. The report, also called Bulletin Number Four, exposed the inadequacies of medical schools and catalyzed dramatic education reforms. However, the Flexner Report was not the effort of its author, Abraham Flexner, alone. As this paper reveals, the report was born out of a unique time in history and was commissioned and supported by the wealthiest, most educated, and most influential men of the late 19th and early 20th centuries. The key players in this history were: Andrew Carnegie, Henry Pritchett, John D. Rockefeller Dr., Frederick T. Gates, John D. Rockefeller Jr., Simon Flexner, Abraham Flexner, and the American Medical Association (AMA) headed by Arthur Dean Bevan. In describing the backgrounds of the major players in this drama and their relationships, the paper demonstrates how they, their money, their interests, and their mindsets interacted to make them true catalysts for medical education reform.

One Student’s Journey to Professional Presentation and Publication

By Katia Sokoloff

When I started the History of Health Care conference paper for Professor Rebecca O. Johnson, I had no idea that just a few months later I would be presenting on History Night at the New York Academy of Medicine. As it turned out, the very process of researching and writing the paper was the best preparation for my first professional lecture.

It is common to start a paper by asking a question that you would like to find the answer to. It is also common that the question you start with changes drastically during your first few trips to the library. That’s how it was for me, at least. I started my research by asking questions about early American medical publications: “What did they look like; did peers review them; did they contain studies or opinions”? I began to narrow the timeline, keeping in the back of my mind there might be some dramatic articles on the subject of medical education in journals immediately after the 1910 Flexner Report, which fundamentally changed how medical schools operate by revealing the inadequacies and incongruities across all 150 medical colleges across the United States and Canada. I quickly expanded my search to publications intended for mass consumption. Reading about the Flexner Report in history books opened my eyes to just how important it was for the fields of medicine and education; only in reading the public’s reactions in newspapers and magazines did I begin to realize its impact on an entire nation.

As I learned how important the report was nationally, my conference paper questions changed to: “Who was Abraham Flexner; who published the report; who were its benefactors and influencers?” These questions ultimately led me to research John D. Rockefeller and Andrew Carnegie and their role in medical philanthropy. My research evolved further as I uncovered relationships between these powerful men and medicine.

As Professor Johnson tells her students, “The finished paper in History of Health Care should resemble a very polished draft... continued on page 11
One Student’s Journey...cont’d from page 10

of a larger piece of work; only scratching the surface of the topic” — difficult to believe when you first start, but so true. Sure enough, by December, I had an enormous paper that really did feel like the start of something big. When I was encouraged to submit an abstract to the New York Academy of Medicine, it felt like a great opportunity to keep going forward with my work.

Once selected to present, I began preparing for my lecture. I made outlines and practiced in front of a mirror. Ultimately, I found it helpful to reread my paper and notes many times. I was selected to present alongside doctors, which was intimidating at first, however, I reminded myself that all of the work I had done in this subject made me an authority on it and in that sense, I was a peer to the other medical historians on stage.

I chose to present my story logically, instead of chronologically, using a single PowerPoint slide as a map for audience members to reference. My goal was to have the audience leave the lecture hall feeling a new sense of curiosity and interest in the Flexner Report. At the beginning of the talk, I told the audience that this was my hope and by question-and-answer time, I felt confident I had stirred people’s imaginations.

Following my presentation, I spoke with attendees with whom I made some great connections. It was incredible to stand among peers and receive encouragement and advice — advice which I have decided to take. My paper continues to grow and I am currently working on submitting it for publication with the continued encouragement of Professor Johnson as well as a few new-found friends from the New York Academy of Medicine.

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**Negro Health Week: A People Claims Its Health**

By Rebecca O. Johnson

**Abstract**

Before the idea of health disparities were conceptualized, W.E.B. DuBois had documented the effects disproportionate access to the guarantors of wellness — adequate nutrition, access to the nascent services that constituted American medicine at the time, and attention to maternal and child health — had on the African-American community (The Philadelphia Negro, 1897, p. 160).

This paper will describe one of the earliest nationally organized community health movements, Negro Health Week. Negro Health Week was an annual, eight-day event, beginning in 1915 and ending in 1951. It was conceptualized by the leadership of an only recently, and briefly, freed people who recognized that the nation was not prepared to address the ongoing problems of disenfranchisement, dispossession and discrimination. African-American physicians, nurses, and intellectuals recognized with mounting concern the desperately poor health of African-Americans, urban and rural, North and South, that The Philadelphia Negro triggered, and his succeeding work, The Health and Physique of the Negro American (1906), which informed the proceedings of the Eleventh Conference for the Study of the Negro Problems. The predecessor of Negro Health Week, a local event held in Virgin-

ia in 1913 called Negro Health Improvement Week, was a direct result of the Eleventh Conference. The national movement would be the culmination of a six-year effort by Booker T. Washington, and the last one he would accomplish before his death in 1915.

While others have considered Negro Health Week in the context of its implications for the development of public health practices, this paper will focus on the larger context of political and community organization that Negro Health Week, as a part of the National Negro Health Movement, initiated and how its increasingly close alignment with the US Public Health Service (USPHS) resulted in a decrease in relevance to the self-identified needs of the African-American community. Conditions as disparate as racial violence, structural unemployment, and discriminatory vaccination campaigns (Chicago Defender, 1927) required a response in the form of increasing levels of community activism, creation of health services, and political advocacy.

The USPHS assumed control of National Negro Health Week in 1930. The USPHS approach was more agency, and less community focused. I will show that the USPHS operated from the unexamined, everyday racial prejudice of the time. They chose not to see health as one of a constellation of structural inequities that resulted in “Negro Problems” but rather saw Negroes as the problem. The National Negro Health Movement resulted in a steady increase in African-American life expectancy and reduction in infant and maternal mortality. These gains were lost after 1930 for several reasons, the Great Depression, infant and maternal health issues associated with the Great Migration, but I will show that the failure of the USPHS to focus on structural inequities and focus on pathologizing the Negro body contributed significantly to the loss of improved health outcomes. The USPHS would call an end the National Negro Health Movement in 1950 because “the nation was moving toward integration.”

Rebecca O. Johnson, MS, MFA, HAP faculty member. Founder and executive director of Cooperative Economics for Women, Boston, Massachusetts. Recent published works include: Lonesome Refugees (Callaloo, 2007); We Want To Be At The Table: Helping Environmental Groups Rebuild After Katrina (Environmental Support Center, 2006); The History of Charity (Grassroots Fundraising Journal Conference, 2006); New Moon Over Roxbury, Ecofeminism and the Sacred, Carol Adams, ed. (Continuum, 1993). SLC, 2007
Sculpting a Sexed Society: The Rise of Medicine and the Surgical Eradication of Intersexuality

By Marissa B. Nargi – HAP 2016

Abstract
The breadth of research on the history of the medical management of intersexuality in the United States cites the 1950’s as a pivotal moment during which the surgical management of infants with ambiguous genitalia began. This paper explores the technological and professional changes activated within the medical profession at the turn of the twentieth century that led to the growing role of physicians as moderators of the social order and managers of gender adherence.

In the 1990’s intersex activists revealed that invasive surgical procedures including clitoridectomy, vaginoplasty and phalloplasty, were performed on many of them as infants and children depriving them of their personal autonomy and physical integrity through adulthood. While the medical profession has since reconsidered the approach in performing genital surgery on infants and children, intersexuality remains recognized as a range of medical ‘conditions,’ now widely labeled Disorders of Sexual Development (DSD’s). Intersex activists advise against premature surgical procedures, but bodies that fall outside of the gendered sex binary are under medical surveillance and potential procedural regulation. Medical intervention continues to be carried out at the individual discretion of physicians and parents.

This paper sets various texts on the history of intersexuality against the wider historical backdrop outlining the development of the medical profession during the early twentieth century. The work concludes that while medical protocol incited physicians to surgically ‘correct’ infants with ambiguous genitalia in the 1950’s, “normalizing” surgery was often carried out with no expectation for medical benefit but instead to protect the most crucial ideas about sex as gender and sex as an act that govern the American family and identity.

Processed to Perfection: Milk and American Idealism, 1880-1930

By Deb Jones – HAP 2015

Abstract
Cow’s milk was destined to become America’s “perfect food.” It can be seen as a metaphor for an emerging national character whose hallmarks were social and cultural superiority. Religion and medicine helped lay the groundwork for milk’s evolution.

The newly-independent colonies eschewed Calvinism during the Second Great Awakening (1790 to 1840) and established uniquely American religious denominations that emphasized self-determination toward achieving God’s grace. Legions of middle- and upper-class white women, drawn by the Awakening’s imperative to reform social ills, stepped out of their home-centered roles. Yet, they were still expected to fulfill those roles. One consequence of the tension between the two was a decline in maternal breastfeeding.

There are numerous socio-historical theories regarding the decline, but it also coincided with changes within the medical profession. Physicians established sovereignty in gynecology and obstetrics, effectively marginalizing midwifery by the early 19th century, advised mothers on alternatives to breastfeeding. In the competition between wet nursing and “artificial” feeding, milk won even as doctors were split on the benefits and risks of both. Milk was preferable to wet nurses drawn largely from poor native-born and immigrant classes, considered vectors of both undesirable behavioral traits and germs.

But, the milk supply was dangerously unsanitary. In the late 19th and early 20th centuries, U.S. infant mortality stood at 30% in some urban areas. There was plenty of finger-pointing as to cause, but immigrant’s lack of hygiene and dirty milk were at the top of the list. Milk consumption plummeted.

Two camps emerged in the clean milk movement, both with proponents among physicians: certify clean raw milk, or pasteurize it. Certified milk was safe but costly, therefore, out of reach for low-income families. Pasteurization changed the composition of milk but it was still deemed safe, when properly stored. The costs of pasteurization favored large producers but made the milk affordable. Most states had pasteurization statutes by 1917.

Once the safety of milk was established, its rise became a matter of image-correction. The U.S. Department of Agriculture and others mounted a vigorous campaign to increase consumption. Milk would be marketed to the whole family as essential to good health. It was safe, nutritious, readily available and affordable: it was, indeed, the perfect food.

Milk’s perfectibility — through the agency of science — fit well with the eugenicist thinking of the same period (1920s), which touted human perfectibility. Both public education and public health were used to promote milk, giving it the imprimatur of institutions that held social authority. But there is also what historian Paul Starr calls “cultural authority” arising from embedding ideas into a societal norm. Milk was given a berth in the collective psyche, achieving not just safety but status as a metaphor for an American national character.
CONFERENCES

The final presenter at the Women’s Health Symposium at the New York MetaCenter, Susun Weed made an unrivalled impression. The daylong event was devoted to integrative and alternative medicine and featured expert speakers in the fields of homeopathy, midwifery and naturopathy. Weed began her lecture by singing unreservedly, immediately capturing the attention and affection of her audience with her energy, ferocity and acumen. She spoke candidly about menopause and her unflinching opposition to the medical profession’s pervasive prescription of bioidentical hormones for aging women. She revealed the historical evolutionary necessity of this human transition and used audience participation to debunk common menopausal myths. Employing her critique of heroic and scientific medicine, she emphasized each tradition’s inclination to fix bodies that have been deemed defective.

Weed is a renowned American herbalist, and practitioner of the ancient Wise Woman tradition of healing. She has authored five books in a Wise Woman Herbal series, championing “common, abundant, wild plants, or weeds” who she lovingly refers to as, “green allies”. Her texts apply her original concept of complementary medicine to breast health, menopause, child bearing and male and female reproductive organs.

Weed, through her writing, lectures, and mentorship, makes an overwhelming case for the reimagining of health care as a nourishing, rather than punishing, endeavor. She points to various herbs for their disremembered sustaining and healing qualities and advocates their infusion, generating beverages with infinite benefits. She prompts us to evaluate our fearful perceptions of disease, and command our ability and responsibility to engage in individualized and truly preventative measures. She reminds us that despite dependence on modern medicine we have the innate capacity to know and support our bodies, prompting each of us to listen to our inner wise woman.

Weed assures us that drugs and surgery do have a place, but promises that they needn’t always be step one. She invites us to embrace chaos, illustrating that ‘dynamic disequilibrium’ is life, and life is never static. She warns us to freeze our fruit, cook our vegetables, reject the allure of restrictive diets and give our bodies the sustenance necessary to enhance cellular regeneration. She is a source of the most essential natural knowledge and an overwhelmingly inspiring force, reintroducing us with her wisdom to ourselves and our environment. She believes that ‘herbal medicine is people’s medicine,’ echoing a primal philosophy which, if remembered, could ultimately progress our current sensibilities and wellbeing.

The Case for Palliative Care

The Westchester/NYS Southern Region Collaborative for Palliative Care recently held its 6th Annual Interdisciplinary and Interfaith Conference about Palliative and End of Life Care in April. Well attended, the Conference attracted the participation of leaders in the palliative care field from every conceivable discipline. The Conference theme was The Art and Science of Palliative Care: Where Medicine, Market and Meaning Meet. The keynote speech on the second day was delivered by Dr. Sean Morrison on the imperative of making palliative care meet standards of an evidence-based practice, in order to argue for its expansion. While many of us have intense personal experiences that collectively offer compelling anecdotal evidence about the need for and efficacy of palliative care, it requires rigorous research for the unconverted to be won over.

From excellent research studies, we know patients who receive palliative care report a higher quality of life, less depression, fewer burdensome treatments, and, based on at least one study, live longer. Families also report better quality of life, suffer from fewer symptoms of trauma and are able to grieve appropriately. However, in the world of U.S. health care, quality results are not enough to create change. To that end, extensive research has been done on the costs of unnecessary treatments, particularly of patients near the end of life. In one study noted by Dr. Morrison, patients in the last 18 months of life, with advanced dementia, were given intravenous therapies (34%), ended up in hospitals (17%), 10% landed in the ED (10%), or had feeding tubes placed (8%). Only 22% were referred to hospice and many only in their final days. These interventions create enormous cost — by some accounts, one-third of all health care expenses are incurred in the last two years of life. As reported by Lisa Morgan, communications officer for the Center to Advance Palliative Care, public aware-
The Case for Palliative...cont’d from page 13

The awareness of palliative care is not high (84% have no idea what it is). Yet, when people are educated about palliative care, the overwhelming response is that everyone should know it is an option. Hospitals should provide it and Medicare pay for it.

The challenges to effect change are many, not least of which is that people do not like to talk about death and dying. Physicians, untrained in the basics of palliative care and who do not recognize it as a specialty, still dominate the conversation with patients about treatment options. Research dollars do not flow freely and insurance — public and private — are inconsistent in their coverage of palliative care. Palliative care is about a team of doctors, nurses, social workers and spiritual advisors providing specialized medical care to the seriously ill. Its focus is on quality of life for the patient and family — in alignment with the patient’s treatment goals. The Conference showcased encouraging examples of palliative care in action — not only in hospital settings but increasingly through outpatient services. Yet, despite the crowded Conference auditorium, there are still more people outside those walls who know nothing about palliative care; an excellent opportunity for health advocates to provide information.

MEDIA REVIEWS:

NEW BOOK ANNOUNCEMENT

Globalization and Transnational Surrogacy in India: Outsourcing Life
Editors: Sayantani DasGupta and Shamita Das Dasgupta

In the twenty-first century, parenthood is no longer achieved only through gestation, adoption, or traditional surrogacy, but also via assisted reproductive technologies (ARTs). In the globalized world economy, where the movement and transfer of people and commodities are increasing to serve the interests of capitalism, gamete donation and surrogate birth can traverse innumerable geographic, socioeconomic, racialized, and political borderlands. Reproduction itself can be outsourced. This interdisciplinary collection of essays assuages the dearth of knowledge and addresses significant issues in transnational commercial gestational surrogacy as it takes shape in a peculiar relation between the West and India.


Elizabeth Bailey, HAP 2014, has been elected to the Board of Directors of the National Association of Health Advocacy Consultants (NAHAC). Elizabeth also recently organized and moderated four educational teleconferences for NAHAC that covered topics including the aging in place and village movements, ethical issues relevant to clinical trials and patient/provider communications, how advocates can help expand and support patient end of life decision making and Katy Butler’s memoir Knocking on Heaven’s Door: the Path to a Better Way of Death.

Nicole A. Barrios, HAP 2011, began her career at NYU Langone Medical Center in August of 2011 as a Patient Advocate. Nicole is currently a Specialist in the Patient Relations Department focused on the Emergency Department and Pediatrics. Her days are spent managing grievances and writing letters, proactively rounding on patients and helping patients and family members navigate the Hospital Center.

Louise Becker, HAP 2011, is creating and writing support programs for lupus and MS patients at a health care advertising agency, HAVAS, in Chelsea, New York City.

Louise Anlyan Harris, HAP 2012, continues the work on Behavioral and Psychological Intervention in Epilepsy Patients started as part of her HAP Capstone Project. Louise assisted as a volunteer in preparing grant extension requests at Yale University School of Medicine for a Multicenter Study of Epilepsy Surgery evaluating outcome at greater than 10 years to gather more data in terms of surgical outcome, quality of life, AED burden, death and psychiatric comorbidities to better counsel and advise patients on epilepsy surgery. Funding was provided through PCORI, a patient centered research institute mainly focusing on outcomes of diseases to allow patients to make informed decisions about their health. Obtaining IRB approval and recruiting subjects took almost a year. The research for the MOSES Program at Yale University School of Medicine Epilepsy Program is almost ready to begin, with Louise as a volunteer trainer for the first trials that will hopefully start this spring. Louise is also volunteering with other epilepsy families to get medical marijuana legalized in New York State. She is a grant writer for San Miguel Academy of Newburgh, a tuition-free school in Newburgh, New York.

Helen Hovdesven, HAP 1992, is actively volunteering as the Chair of the Patient-Family Advisory Council of the Memory Center at Johns Hopkins, and as an Advisory Board Member of the Department of Psychiatry and Behavioral Sciences also at Johns Hopkins. Helen loves working with patients and families with Dementia/Alzheimer’s and their physicians! Helen completed a series of I-Pod casts, from diagnosis to death. The podcasts can be found on the John Hopkins Department of Psychiatry website at: http://www.hopkinsmedicine.org/psychiatry/specialty_areas/memory_center/patient_family_resources/podcasts/.

Betsy Klampert, HAP 2012, has been named Interim Executive Director for the Center for Aging in Place (www.centerforaginginplace.org), a nonprofit organization that enables and supports grassroots community organizations in Westchester working to help seniors stay in their own communities for as long as possible. Betsy is an attorney focusing on the areas of elder law, health law and health advocacy. Betsy is also currently a member of the Elder Abuse Committee of the New York State Bar Association’s Elder Law Section, and sits on NYSBA’s Health Law Section. She is a member of the National Association of Elder Law Attorneys (NAELA) and is incoming co-chair of the Elder Law Committee of the Westchester County Bar Association.

Linda Koebner, HAP 2012, has been elected to the Board of Directors of the National Association of Health Advocacy Consultants (NAHAC). She is also a Patient Representative at Westchester Medical Center and maintains her private practice. Linda is editor of the Health Advocacy Bulletin.

Amy Lifson, HAP 2012, is part of the management team at Bright Side Manor, an affordable non-profit assisted living home in Teaneck, NJ, where her responsibilities include quality assurance, admissions, community outreach and marketing. She is also developing a program that will bring affordable assisted living services into subsidized senior housing, allowing seniors to age in place.

Linda Ricci, HAP 2015, published a blog article “Volunteers Confront Health Care Injustice on MLK Day” on the Health Care for All New York website. You can read the article about the volunteer enrollment work she is doing with Get Covered NY at: http://hcfany.org/volunteers-confront-health-care-injustice-on-mlk-day/.

Leslie Rott, HAP anticipated 2015, article “You’re So Short!”. The Stigma (and Disability) of Being a Short Woman” was published in Research in Social Science and Disability, Volume 7, Disability and Intersecting Statuses, Edited by Sharon Barnartt and Barbara Altman. Emerald Publishing Group. Leslie was also recently interviewed about her work on the website Support For The Short (http://supporttheshort.org/).

Pam Willrodt, HAP 2012, is completing the second semester of her Ph.D. in Applied Demography. Pam finds her studies to be the perfect fit and tool for Health Advocacy, and she is up to her ears in data, and loving it. Pam is working with vulnerable populations, i.e., SES (poverty, education, etc.) and aging, specifically looking at the 50-65 group with her research focused on trying to understand what the recession, unemployment, and underemployment means for health. She is currently analyzing the differences between individuals in the target age group born and continuously residing in the US versus individuals born outside the US but currently residing here looking at years in the US relating to health and beginning to think of the cohort analysis of this age group area for her dissertation.

Leslie Rott