

HEALTH ADVOCACY BULLETIN

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Letter from the Director

By Vicki Breitbart

A Matter of Life and Death

Many of us are well aware of how the present healthcare system can make the final days of life an unnecessarily painful and devastating experience for our loved ones, and for ourselves. About a quarter of all Medicare spending is for the last year of life.¹ Yet, the great cost of this care has left many human needs unmet.

People in this country are living longer and those with a terminal illness need to have a say about what treatment, if any, they want and how they spend their final days, or even months and years. Person-centered, family-oriented end-of-life care requires compassionate communication

and shared decision-making. It requires attention to the right to self-determination about pain and symptom management, and a close look at the ethics and efficacy of continued routine medical interventions. For this vision to become a reality we will need significant changes in how and where our society provides care; we will need to ensure that the terminally ill are cared for in environments that value personal autonomy and comfort, in addition to safety, which has traditionally been the main concern for the elderly and dying.

A new and poignantly written book by Atul Gawande, *Being Mortal: Medicine and*

what matters in the end, relates story after story of people, including Gawande's father, lost in a system of medical care designed to provide tests and procedures no matter how futile, and at what cost.² Gawande shows us that the end-of-life can be a lonely experience especially when our final wishes are denied. He not only calls for a dignified death for the terminally ill, but for "living now" where people's final days continue to be meaningful, and where they can keep "shaping the story of their life".³

As the need is growing for more compassionate care and better communication with patients and their families about end-of-life decision-making, the healthcare providers' roles are changing. Many are not adequately prepared to deal with these types of conversations and generally lack the awareness of how cultural backgrounds, experiences, and expectations affect these end-of-life discussions and the decision-making process. Training programs have emerged for those who provide care in the final stages of life, but they neglect the vast numbers of these providers who are being called upon to help patients and their families navigate this difficult journey. HAP can play an effective role in these educational efforts as many of our alumni do.

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¹ Hogan C. Lunney J, Gabel J & Lynn J. Medicare Beneficiaries' Costs of Care In The Last Year Of Life. Health Affairs. Health Aff July 2001 vol. 20 no. 4 188-195.

² Gawande A. (2014) *Being Mortal: Medicine and what matters in the end*. New York: Henry Holt and Company

³ *Ibid.* p. 147

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"...the end-of-life can be a lonely experience especially when our final wishes are denied."

Healthcare providers at all levels need to be prepared for these roles, but they also need to be fairly compensated. In October 2013, federal legislation was passed that for the first time will guarantee home care workers (which can include "authorized" family members), those who provide many direct services at end-of-life, federal minimum wage and overtime protections.⁴ Payment for "advance care planning" is also slowly becoming a reality. States like Colorado and Oregon have begun to reimburse providers to have end-of-life conversations with Medicaid patients. The AMA recently created codes for payment of end-of-life conversations and submitted them to Medicare which is a positive sign that these changes will occur soon.⁵

The Institute of Medicine's report on Dying in America, released in September 2014,

highlights many of the changes that will need to take place if we are to enhance the final days of people's lives. The report was issued to improve care and "enhance the quality of life through the end of life."⁶ The report recommends a comprehensive approach that calls for more attention to the individual's and family's needs in the delivery of care, improved clinician-patient communication, additional professional education, greater public education and engagement as well as better policies and payments systems.

In recent months, we have seen a shift in public awareness of these issues and increased media attention on end-of-life. There have been television programs, as well as several related articles on the subject. There is hope that this increased attention will play a part in re-examining how individuals can live well until their end. As Americans are re-examining how we approach death, we as health advocates can play a significant role. As advocates we need to ensure that financial, institutional and policy changes will help make compassionate care the norm, and end-of-life a dignified and meaningful experience. We need to do everything we can to maintain the individual as the focus of his or her own life and death.

⁴ PHI Campaign for Fair Pay. (2013) FLSA Facts. Understanding the revised companionship exemption. www.PHInational.org/fairpay.

⁵ Belluck P. Coverage for end-of-life talks gaining ground. New York Times August 30, 2014.

⁶ Institute of Medicine. Dying in America: Improving Quality and Honoring Individual Preferences Near the End of Life. September 17, 2014

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Calling All HAP Alumni

In early January, please keep your eyes open for a Health Advocacy Program Alumni survey that will be sent by email. The survey will focus on ways we can build a stronger network among the HAP alumni community and to gauge your interest in becoming involved. Please feel free to contact Gloria Escobar-Chaparro (gescobar@sarahlawrence.edu or 914-395-2467) with questions, comments, to make sure HAP has your current email address, or if you would like to receive the survey by mail.

Letter from the Editor

By Linda Koebner

With every article that appeared in my inbox, it became increasingly clear this issue of the Bulletin would showcase health advocate's breath of expertise, interests and knowledge. You will read about a range of topics from a personal ordeal to sweeping policy issues affecting millions. Kirsten Pruzek speaks of her own experience advocating for her father in his quest for a liver donor. She shares with us the burden she encountered, and the lack of support or understanding that is all too prevalent. As in past issues, we continue to follow the evolution and impact of the Affordable Care Act. And, even if we cannot attend, the summaries of workshops and conferences in this issue provide a glimpse of excellent programs. I learned for the first time about Stanford's Medicine X program from Leslie Rott and Monique Harden's ground breaking advocacy through student reports. When you read about the alumni's diverse work and the impact each one has in their field it brings to light what we are experiencing in this growing field. My very best wishes for good health in the New Year.

The Patient Protection and Affordable Care Act (ACA) and Mental Health: How Are Things Looking?

By Jean Anne Cipolla

The ACA goes far towards ensuring that individual and small group health insurance plans, inside and outside of the exchanges, cover mental and physical health equally. Plans cannot put lifetime limits on mental health treatment or on basic care. The ACA forbids an insurer from rejecting, failing to renew or charging a higher premium to an enrollee due to prior illness. Your coverage cannot be dropped if you become sick after you pick a new plan. Let's look at some of the biggest gains and see what the downsides might be.

The ACA requires health insurance plans in the exchanges to cover mental health and substance abuse disorder services, expanding mental health benefits to more than 62 million Americans, the largest extension of mental health coverage in more than a decade.¹ Part of this projected number is based on the state Medicaid expansions. However, depending on which sources you check, nineteen states did not expand their Medicaid programs and four have not decided yet, leaving roughly 6 to 7 million people without this access.²

While the ACA demands parity coverage for physical and mental health, this doesn't guarantee that limits will not be placed on treatment. Insurance companies may still require therapists to obtain "authorizations" after a certain number of sessions. These soft limits, depending on the insurer, will vary.

Prior to this year, the rules for Medicaid eligibility, variable by state, were dependent first on disability and secondarily on income level. After January 2014, in states that have

expanded their Medicaid programs eligibility has been expanded to a minimum of 138% of the Federal Poverty Level (FPL), and includes some single, non-disabled adults. In states where the Medicaid expansion was not approved, disability categories (pregnant women, people receiving Social Security Disability Income) are still qualifying determinants of Medicaid eligibility in combination with low income. Some advocates think that while more mentally ill people will have insurance under Medicaid, due to the increased FPL, they may not be able to get services because there are fewer counselors and behavioral therapists who accept Medicaid as well as private insurance.³

For those people who already have Medicaid coverage, in a state that has expanded Medicaid, and are in recovery with a mental illness, they may choose to go back to work without the threat of not having access to health insurance due to an increase in income. As their income grows and exceeds the Medicaid limits in their state, the health exchanges will provide options for health insurance plans for them outside of Medicaid.

All plans must provide 10 Essential Health Benefits. These include wellness and disease management, prescription drugs, hospitalization, laboratory services, emergency services, maternity and newborn care, children's care (including dental and vision), rehabilitation and habilitation, mental, behavioral health and substance use care and outpatient clinic services.⁴ Each state, however, can determine what falls into those categories, resulting in much

variation in services for those essential health benefits. For example, states may or may not include mental health screening in primary care mental health prevention services, crisis services, along with traditional inpatient and outpatient treatment in the category for mental, behavioral health and substance use care, while another state may only include inpatient and outpatient care.⁵

The ACA provides the ability to keep young adults on their parents' medical insurance up to the age of 26 if the parents' insurance plan provides for dependent coverage. This new rule applies to all plans in the individual market and new employer sponsored plans, offering options for young adults who cannot afford insurance, or those who are still in college and their college plan is not suitable for them. If a young adult goes to school or lives in another state, the parents' health plan may not provide coverage in that state, so consumers need to check their plan carefully prior to selecting this option.⁶

These mental health coverage advances are only beneficial if we educate ourselves when choosing healthcare plans. Glenn Liebman, CEO of the Mental Health Association in New York State wrote an op-ed for the Albany Times-Union on March 12, 2014 on Behavioral Health Benefits entitled "Be an Educated Consumer in Choosing Healthcare." He says there are several questions you MUST ask when selecting a

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¹ MentalHealth. "Health Insurance and Mental Health Services." Accessed October 1, 2014. <http://www.mentalhealth.gov/get-help/health-insurance/>

² PsychCentral. "An Update on How The U.S. Affordable Care Act Impacts Mental Health Care." Accessed October 1, 2014. <http://psychcentral.com/blog/archives/2013/11/01/an-update-on-how-the-u-s-affordable-care-act-impacts-mental-health-care/>

³ McClatchy DC. "Medicaid Expansion is expected to Strain Mental Health Services." Accessed October 1, 2014. <http://www.mcclatchydc.com/2014/02/13/217906/medicaid-expansion-is-expected.html>

⁴ Healthcare.gov. "What does Marketplace insurance cover?" Accessed October 1, 2014. <https://www.healthcare.gov/what-does-marketplace-health-insurance-cover/>

⁵ PsychCentral. "An Update on How The U.S. Affordable Care Act Impacts Mental Health Care." Accessed October 1, 2014. <http://psychcentral.com/blog/archives/2013/11/01/an-update-on-how-the-u-s-affordable-care-act-impacts-mental-health-care/>

⁶ United States Department of Labor. "Young Adults and the Affordable Care Act: Protecting Young Adults and Eliminating Burdens on Businesses and Families" Accessed October 1, 2014. <http://www.dol.gov/ebsa/faqs/faq-dependentcoverage.html>

Voices of Color in Disability Studies: Jason DaSilva's "When I Walk"

By Sayantani DasGupta

The one thing that makes me grimace, that makes my stomach cartwheel, is watching myself walk in a full view mirror. My imagination could never wish away the way I walk...It makes me wonder how my friends walk to Pizza Hut with me, next to me, behind me...What do they think? That I dip and wobble like a cork in water?...Do they wonder what I think? What do I think? —Emiliano Bourges-Chacón "My Body is My Temple"

As the Health Advocacy faculty member who has taught the "Illness and Disability Narratives" course for the last decade or more, I am always on the lookout for stories. Stories which enable people experiencing illness, and people with disabilities, to speak for themselves—to give voice to their own embodied experiences rather than being spoken for by others, particularly the medical establishment.

Although I have my students write their own narratives, and interview individuals about their life narratives, we primarily read published illness and disability narratives in our class, and in doing so, understand our own function as "witnesses" to these stories. Indeed, for future advocates, understanding issues of narrative ethics are paramount. Whose story is it? Do advocates speak about, for, or with their clients? Are individuals experiencing illness/individuals with disabilities understood solely as "patients" or fellow "citizens"? How are narratives shaped by bodies, identities, families, cultures, contexts, and sociopolitics?

There is a major problem with this kind of teaching—teaching other colleagues do across the country in programs called "Narrative Medicine," "Literature and Medicine" and "Medical Humanities." And that problem is diversity of narratives used.

In trying to find stories by and about people of color, young people, working class, and LGBTQ people, I have introduced narratives of various genres to students in the Health Advocacy Program. One such genre is spoken word poetry. Young people experiencing illness or disability may not be publishing traditional memoirs, but they

certainly are speaking articulately about their lives online, as well as in performance spaces, and poetry festivals. One such young man, Emiliano Bourges-Chacón, wrote and performed the above quoted piece "My Body is My Temple," about his life with cerebral palsy; specifically, about 'when he walks.'

I am always on the lookout for more narratives by and about people of color. Recently, I had the privilege of meeting Jason DaSilva, the director of an award winning documentary-memoir called *When I Walk*, that is already winning acclaim at film festivals around the country. Diagnosed at age 25 with a rapidly progressing form of multiple sclerosis, filmmaker DaSilva trained the lens on himself over the last decade. The moving and insightful film covers not only his experience with MS, but meeting his wife Alice, getting married, experiencing a miscarriage, and arduously editing their story while trying to simultaneously live it. In his own words,

Documentarians often want to build trust and acceptance with their subjects. Being that I was the subject of my own film, and that I didn't yet have that acceptance of myself, the filmmaking was arduous at first...As I got worse and worse, reviewing the footage became emotionally difficult and physically draining...Every night after filming and editing, I would have dreams of being able to walk; then I'd wake up unable to move and start the process of filmmaking all over again.

Jason DaSilva didn't just make an award winning film about his life with MS, he used his life's story as an advocacy tool. When he and his wife moved to Brooklyn, DaSilva realized that, as a scooter-user, much of quaint and hip life in Brooklyn was inaccessible to

him. Not only was there a lack of cut curbs, businesses without entry stairs, and accessible bathrooms, but none of the Brooklyn subways stops even had an elevator. So he and his wife created AXS Map (www.axs-map.com), a "crowd-sourced tool for sharing reviews on the wheelchair accessibility of businesses and places." Born from his own experience and frustration, this app aims to share information about physical accessibility broadly, and mobilize both people with and without disabilities to 'map' their local communities.

Not only is Jason DaSilva's a sensitive and compelling new voice of color in disability narratives, but in his multimedia, advocacy approach to his story, he makes clear that the personal is and must be political. Stories of illness and disability are not to be read/viewed and witnessed as tales of triumph, tragedy, or pity. Rather, they are spaces to remember and articulate the story of our own responsibilities to our fellow citizens. In the words of DaSilva, "It's hard to know where our stories are going, as they are being written. That is the mystery of fate."

How can we best prepare future advocates to face the complex world of health care? We can teach them to listen to the voices of those experiencing illness and disability, and from that listening, to act in solidarity for socially just change. Jason DaSilva's is one such important new voice to which we should be listening.

Sayantani DasGupta, MD, MPH teaches at Columbia University's Program in Narrative Medicine and in the Health Advocacy graduate program at Sarah Lawrence College

The Patient Protection...cont'd from page 3

healthcare plan: "Are my doctors and hospital in the plan I want? Will the prescription medications I need be covered? What will the medications cost? Are cost-sharing

supports available to me? What co-pays will I owe? What mental health services will be available to me?" I would add one more question: "Are prior authorizations needed for any mental health services?" All of the answers to these questions provide critical

information in order to assure there will be no limits set on your physical or mental health coverage as envisioned by the ACA.

Jean Anne Cipolla is a 2007 graduate of the Health Advocacy Program.

Caregiver Casualties

By Kirsten Pruzek

I felt isolated and tired. Each day it was more difficult to get out of bed. Sometimes life is just like that. But, as a caregiver to a seriously ill loved one, you have to push yourself for months and months (or years and years) with no break—physical or mental. There is a cost; burn out—and I had it.

In January of 2013, during my final semester in the Health Advocacy Program (HAP), I was evaluated at Mt. Sinai Hospital in New York as a potential living liver donor for my father. In the previous month, my father had asked me if I would donate part of my liver to him. Aside from liver failure from an unknown cause, my father was a robust 72 year-old. “Living liver donation is not a big deal anymore” he said.

I am a single mom and the primary caregiver to a (then) 8-year-old daughter. I was filled with fear and anxiety, but faced with the chance to save my father; what could I do? I was approved as a living liver donor. In March 2013, the week before the scheduled surgery, I was told the surgery was off. Some of my arteries were too small; the surgery wouldn't work. The blow to my father was tremendous. Other blows were to follow. When it became clear how ill my dad was, his partner left him. She wanted no part of caregiving.

Over the course of the next six months, I cared for Dad, and we struggled to find a liver donor for him in New York. We researched transplant centers and decided on Indiana University Hospital in Indianapolis. The transplant center has an excellent reputation for speedy and successful liver transplants. My brother moved him, and my daughter and I moved there to care for him, and to wait. He is still waiting 14 months later.

Love, duty, honor, respect, and/or a sense of obligation leads people to be caregivers. When there is no pay, little or no improvement to the health of the loved one, no respite, and perhaps, as I felt, a feeling of invisibility mixed with shame, it was difficult to admit I might have needs of my own. The associated sense of hopelessness felt like caregiver burnout.

My dad is seriously ill but doggedly moves forward with little complaint from one crisis to another. In Indianapolis my days were spent trying to move fast enough to get him a bowl for his abrupt and unexpected vomiting, maintain constant vigilance for signs of advancing ammonia levels, check dad in or out of the hospital, cook, do laundry (more than usual for reasons I won't explain), run to the pharmacy, jump when alarms went off reminding me to give a medication, an insulin check, a doctor's visit or...

The toll was not only on my dad and me, but my daughter as well. Pulled from home, friends and routine she began to have long meltdowns every night. I was completely sandwiched in. If I cared for one, I would be abandoning the other. I had no one to talk to in Indianapolis, no information about what resources might be available to me, and I was too exhausted to search for organizations to give me guidance.

Our nation has only just begun to formally recognize “patient” centered care. Caregivers are hidden casualties. In 2008 the Centers for Disease Control and Prevention published a study that stated, “The care giving crisis is a public health priority of national concern.¹ According to AARP, “family caregivers of adults with chronic or disabling conditions provided an estimated 40 billion hours of unpaid care with an esti-

mated economic value of 450 billion.”² An AARP Public Policy Institute report shows that “While today there are seven potential caregivers per frail older person, by 2030 there will be just four, and by 2050 fewer than three.³ Depression, anxiety and poor health are some of the additional costs for caregivers. “Without systematic assessment of family caregiver needs, caregiving family members' own health and well-being may be at risk, which may, in turn, jeopardize their ability to continue providing care.”⁴

Now my father also requires a kidney transplant. I want my father to receive the liver and kidney that will extend his life. I also look forward to the time when my family and I can find our way back to a good quality of life. Despite the hardships, I recognize that my experience gave me a gift of unexpected time with my father and a deeper understanding of how to advocate for another caregiver, hopefully before they burn out.

Kirsten Pruzek is a 2013 graduate of the Health Advocacy Program.

National Resources for Caregivers (partial list)

- American Association of Retired Persons (AARP)
- Caregiver Action Network
- Children of Aging Parents (CAPS)
- The National Alliance for Caregiving (NAC)
- National Family Caregivers Association (NFCA)
- National Organization for Empowering Caregivers (NOFEC)

¹ Centers for Disease Control and Prevention and the Kimberly-Clark Corporation. Assuring Healthy Caregivers, A Public Health Approach to Translating Research into Practice: The RE-AIM Framework. Neenah, WI: Kimberly-Clark Corporation; 2008.

² L. Feinberg, S. C. Reinhard, A. Houser, and R. Choula, Valuing the Invaluable: 2011 Update, the Growing Contributions and Costs of Family Caregiving, AARP Public Policy Institute Insight on the Issues 51 (Washington, DC: AARP, June 2011).

³ Seavy D. Investing in Home Care Workers. <http://www.baileypark55.com/index.php/news-and-events/blog/65-investing-in-home-care-workers>

⁴ K. S. Judge et al., “Partners in dementia care: A care coordination intervention for individuals with dementia and their family caregivers,” *The Gerontologist* 51, no. 2 (2011): 261–72.

Exploring the Intersection of Early Learning and Health Policy in Washington State

By Jennifer K. Johal

Washington State has been a leader in many policy innovations, including providing health care insurance coverage for all children. The Children's Alliance (CA), a leading Washington State based non-profit advocacy organization, began the *Cover All Kids* campaign in 2007 and has since made enormous progress toward the goal of universal coverage. It accomplished this by supporting *Apple Health* and *Apple Health for Kids*, which are State funded comprehensive health insurance options.¹ Although Washington State provides access to health insurance coverage for children and families, this is just the first step in ensuring Washington's children are healthy and can thrive academically.

Over the summer, under the Director of Health Policy at CA in Seattle, I began the extensive effort of drafting a policy paper that documented the intersections between early learning and health policies using a race equity lens. I also attended coalition meetings in both the early learning and health sectors. I conducted interviews with key stakeholders and discussed their professional and personal opinions identifying intersections and building bridges between the two groups.

While I consider myself new to the field of health advocacy, my experience working as an assistant teacher in child care programs, analyzing the work of theorists like Jean Piaget and John Dewey, and understanding the importance of dramatic play in children's learning, has taught me that when children are healthy, they learn better than when they are sick.

I also spent time on CA's *Cover All Kids* campaign designed to support the state law that provides affordable health insurance coverage. Compared to 2007, more Washington State children and families now have health insurance, and can go to a doctor for checkups, and get prescription medication without paying out of pocket costs.

However, access to low cost insurance does not yet mean access to quality and affordable health services for all children and families. The Seattle Public Health department data for the Seattle/King County area shows a pattern of poor social outcomes (i.e. adverse childhood experiences, low physical activity, life expectancy, preventable hospitalization, etc) related to the concentration of poor health. The data showed that children who live in the southern region of King County (the most diverse and socioeconomically disadvantaged section of the County) are at the highest risk of poor health outcomes.² This disparity based on race is the reason why CA has developed a race equity policy.

I participated in the policy discussions around developmental screenings, which identify developmental delays in children, and allow for intervention at the earliest age possible. Developmental screenings are covered by both the state *Apple Health for Kids* and Washington State's Early Childhood and Assistance Program (ECEAP) however, this coverage is inadequate. *Apple Health for Kids* only reimburses psychologists for developmental screenings and does not provide coverage for all the follow-up services that might be needed. ECEAP, on the other hand, provides developmental

screenings and support for intervention services. Families and children (from birth to three years of age) living in South King County are eligible for ECEAP.³

I also examined differences in the eligibility requirements for the two programs which effect access to developmental screenings and services. Eligibility for ECEAP is based on the age of the child, and requires the family income to be at or below 110% of the federal poverty line (FPL). Washington State's *Apple Health for Kids* policy provides its population with access to health insurance coverage if family income is lower than 138% of FPL.

Children who live in South King County, who may have health coverage and can afford the services, do not have access to health clinics, and are, therefore, at greater risk of developmental delays and an adverse learning experience. In order to meet the health and early learning needs of children there must be intersections between these two policy areas, which are frequently kept separate.

I gained much knowledge and experience in the field of policy development and program implementation while working with Children's Alliance in Seattle. I have come to understand that policies which are not well thought out can both hurt and help those we advocate for. As a committed advocate for the health and learning of children and their families, it will be my job to develop policy through the work I do with the community, not just for the community.

Jennifer Johal will be a 2015 dual degree student in HAP and Child Development.

Errata

We apologize to the authors for the following errors that were printed in the Spring 2014 edition of the *HAP Bulletin*:

The following names were spelled incorrectly: Nazsa Baker and Gloria Escobar-Chaparro

The correct title of Marissa Nargi's article is: *Sculpting a Sexed Society: The Rise of Medicine and the Eradication of Intersexuality*

The correct title of Marikay Capasso's article is: *Using Motivational Interviewing in Health Care Settings*

¹ "Cover All Kids | Children's Alliance." Cover All Kids | Children's Alliance. July 7, 2014. Accessed September 16, 2014. <http://www.childrensalliance.org/our-current-work/cover-all-kids>.

² Wyesen, Kirsten. "5 Opportunities (and Challenges!) of Community Engagement." A Living Cities. July 24, 2014. Accessed July 9, 2014. <https://www.livingcities.org/blog/653-5-opportunities-and-challenges-of-community-engagement>.

³ Screening Issue Brief. April, 2009. Access July 2014. http://www.doh.wa.gov/Portals/1/Documents/Pubs/970-128_DDScreeningIssueBrief.pdf

Implementing Healthcare Reform One Year Out

By Pam Willrodt

This article provides some Affordable Care Act (ACA) individual enrollment demographics following the Supreme Court ruling to allow states to determine if they would expand their Medicaid coverage. I am covered by the ACA through a Federally-facilitated marketplace aided by subsidies (financial assistance), and will also share a few personal thoughts.

Originally, the ACA was estimated to expand health insurance coverage to 32 million Americans through the national Medicaid expansion and health insurance exchanges; at that time, 50.7 million individuals (15.7% of the population) were uninsured. In the second quarter of 2014, 42 million were still uninsured.¹ The original estimate, based on the supposition that Medicaid would have expanded into every state as well as the District of Columbia, expected the ACA would leave only about 19 million uninsured. To date, 21 states have not moved forward with a Medicaid expansion and two are still open for debate.²

Essentially, the Medicaid expansion was meant to be the coverage vehicle for individuals with the lowest income in this country, setting a national Medicaid eligibility level of 138% of the Federal Poverty Level (FPL). Premium tax credits (subsidies) were then available to assist those with incomes of 138% of the FPL up to 400% of the FPL to purchase their insurance in the Marketplace. For individuals living in states that did not expand Medicaid, many are left with no affordable coverage option. Since the ACA anticipated that those below 138% of the FPL would be covered by Medicaid and set the thresh-

old for subsidies at that level, individuals living below this limit have no options for payment assistance and little disposable income left to pay for insurance. This situation is termed the 'coverage gap'.

Of the 4.8 million uninsured nonelderly adults, 79% live in Southern states (22% in Texas alone), and more than half, 53%, are people of color. According to Kaiser Family Foundation, "Four in ten uninsured Blacks with incomes low enough to qualify for the Medicaid expansion fall into the gap, compared to 24% of uninsured Hispanics and 29% of uninsured Whites" leading to ever widening racial, ethnic, and geographic disparities in health coverage, access, and care.³

Who are the newly insured?

A total of 8,019,763 individuals selected a Marketplace plan; 32% under a State-based Marketplace (SBM), the remainder under a Federally-facilitated Marketplace (FFM). More females chose a plan than males (54% female, 46% male) and 28% of all those who selected a plan were in the 'young-Invincible' group aged 18-34. Individuals in both the SBM and FFM primarily chose a Silver Plan (58% SBM, 69% FFM). As for financial assistance, 82% of the individuals selecting a plan through a SBM and 86% of those selecting a plan through a FFM qualified.⁴

What I learned being on the plan

As for me, I was overwhelmed with over 40 different plan options. I finally chose one that allows me the freedom to see a specialist when I choose, while my co-payments and out-of-pocket expenses stay at a reasonable level. The insurance company I chose was not quite operationally ready for

ACA implementation nor was their network of physicians and medical facilities available for review. I learned, after hours of internet research, advocating for myself, and waiting on hold, that the premium grace period is not the single month as might have been stated, but three months for subsidy-supported premiums. Early in November 2014, I received a packet from my ACA health insurance plan stating that my premium was raised by \$31 per month for the same plan, assuming I continue with the subsidy. When the marketplace opens again on November 15, I can review and evaluate the options again.

Concluding Thoughts

According to the most recent Kaiser Family Foundation Tracking Poll, public opinion on the ACA continues to be more unfavorable than favorable (47% unfavorable, 35% favorable, and 19% don't know/refused).⁵ With the upcoming open-enrollment period and the New Year quickly approaching, the data has been mixed in terms of how premiums may change. In spite of the additional unknowns, i.e., the recent federal court rulings against ACA subsidies in federally-run exchanges (versus the state-run marketplaces), how upcoming small-business implementations will roll-out, and what the future expansions of low-cost, quality health insurance and care will be to those who at this point, still have no options, I, for one, am thrilled to have decent, affordable healthcare insurance coverage for the first time in many years.

Pam Wilrodt is a 2012 graduate of the Health Advocacy Program.

¹ Levy, J. (2014). In U.S., Uninsured Rate Sinks to 13.4% in Second Quarter. Retrieved from <http://www.gallup.com/poll/172403/uninsured-rate-sinks-second-quarter.aspx>

² The Henry J. Kaiser Family Foundation. (2014a). Current Status of State Medicaid Expansion Decisions. Retrieved from <http://kff.org/health-reform/slide/current-status-of-the-medicaid-expansion-decision/>

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CONFERENCES AND EVENTS

4th Annual Margaret Keller Distinguished Lecturer Series Monique Harden, JD – Guest Speaker

From Environmental Injustice to Climate Change: How Health Advocates Can Bridge the Divide Between Human Rights and Environmental Protection

The Margaret Keller Distinguished Lecturer Series was established in 2010 to honor Margaret Keller upon her retirement from the Health Advocacy Program (HAP). Ms. Keller taught Health Law from the inception of HAP in 1981, engaging students in a broad range of legal and policy issues concerning the delivery of health care in the United States.

The Series seeks to highlight the work of individuals who combine advocacy and the law, and this year's guest speaker, Monique Harden, is a supreme example. Ms. Harden is co-founder and attorney for Advocates for Environmental Human Rights (AEHR), a nonprofit, public interest law firm in New Orleans, Louisiana, dedicated to upholding our human right to live in a healthy environment. Through more than 20 years of successful litigation and advocacy Ms. Harden and Nathalie Walker, co-founders of AEHR, have helped communities achieve important environmental justice victories.

We first became familiar with the work of AEHR in 2008 when faculty Rebecca Johnson led a team of students to work with Moss-ville Environmental Action Now (MEAN), a grassroots environmental justice organization that has been fighting for the rights and the health of residents of Mossville since the early 1990's. Ms. Harden and the legal staff of AEHR filed the first ever human rights petition that seeks fundamental change of the United States environmental regulatory system on behalf of residents living in the historic African American community of Mossville, Louisiana. The Inter-American Commission on Human Rights of the Organization of American States recently deemed the petition to be admissible for a review on the merits, marking the first time the Commission has taken jurisdiction over a case of environmental racism in the United States.



Monique Harden in Louisiana.

The following are comments from HAP students, edited as a conversation, about the stimulating and inspiring talk:

Mossville was settled nearly 225 years ago by freed slaves and today has a (primarily) black population. It exists in the midst of 14 oil and chemical refineries; its residents suffer high rates of central nervous system problems, cancer, asthma, and other diseases associated with environmental poisoning. (Deborah Jones, 2015)

The right to racial equality, health and security of home are just a few of the basic human rights that health advocates can work to protect... As Ms. Harden stated, a humane and moral approach to health advocacy is needed in the struggle to defend our right to clean air and safe drinking water as well as to eradicate environmental injustice and environmental racism. (Chloe A. Politis, 2015)

By pointing out the limits of environmental law as the sole means to compel industry to engage in practices that do not put people or the environment at risk, Ms. Harden makes the case for health advocates to step in to bridge the gap between environmental protection and human rights. She frames the argument around a detailed analysis of all of the ways public health is undermined in its practice... (Michelle Weiss, 2016)

For example, those polluting industries affecting the residents of Mossville, LA, are within the letter of the law. The residents have no legal recourse. Ms. Harden used the BP oil spill as an example. Claimants were expected to provide medical proof of causation for their health claims. Victims who breathed in the toxic air of the World Trade Center Towers after they collapsed along with (Vietnam

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Stanford Medicine X 2014

The Intersection of Medicine and Emerging Technologies

By Leslie Rott

Early this September I had the honor of attending the Stanford Medicine X¹ (MedX) conference as an ePatient delegate/scholar. Stanford Medicine X was founded in 2011. The organization's mission is to advance the practice of medicine, improve health, and empower patients to be active participants in their own care. The MedX conference is one of Stanford Medicine X's many programs, and is billed as "The academic conference for everyone." The focus of the conference is on medicine and emerging technology, yet puts ePatients at the center of the experience.

An ePatient is a health consumer who views himself/herself as being in an equal partnership with their doctor. ePatients take to the Internet to find health information for themselves, utilize social media to learn and communicate about their illnesses, and share their patient experiences online. ePatients are considered to be taking part in Health 2.0/Medicine 2.0

or participatory medicine. Health 2.0, in a general sense, is the use of web-based technologies, such as blogs, online communities, and social networking sites by healthcare actors including both doctors and patients, that allows for a more personalized side to healthcare.

It is difficult to put into words what MedX is because it is so different than any other gathering I have ever been to. It is 100% patient-centered, including the way the main room of the conference is organized. The ePatients were the focus of the conference, sitting in special, individual seats at the front of the room, while the other attendees—doctors, academicians, and technology people—sat at round tables filling the rest of the auditorium. Always with the ePatients in mind, a wellness room was available for people to be able to rest and recharge (something I utilized and would love to see more of in other settings).

During the conference I wore both my patient and my advocate hats. As a person with lupus and rheumatoid arthritis, who started a blog a week after my diagnosis in 2008, I definitely consider myself an ePatient. Like many ePatients, when I did not find the information and answers I needed from medical professionals, I felt isolated and alone until I took to the Internet and found other people like myself with whom to share information and experiences.

The conference made me realize there is a difference between being a personal advocate and moving beyond that to be an advocate for others. While one does not need an academic degree to self-advocate—most of us fall into the job of being our own advocate because the healthcare system has failed us in some way—there is more to advocating for others than simply being an advocate for oneself. I learned many important skills that I can apply both to my own self-advocacy and my

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¹ I received a scholarship to attend the conference

Distinguished Lecturer...cont'd from page 8

vet victims of) Agent Orange did not have to provide such proof. Residents of Mossville have three times the average amounts of cancer-causing agents in their blood... (Daphne Kanellopoulos, 2016)

Science can't yet prove that certain chemicals directly cause health defects; there is only an association between health defects and high chemical levels. Therefore, the industrial manufacturers believe they have the right to continue to produce these chemicals. Ms. Harden mentioned but that the industries paid for residents to move, that is not a solution to the broader problem of chemical industries harming people and the environment. The government and the citizens of this nation need to hold these corporations accountable for their destructive decisions... (Indira Case, 2016)

We [health advocates] should be present as an identifiable force before the EPA when it revises regulation (of) polluting and dangerous industries. (Deborah Jones, 2015)

When people think of public health...They do not necessarily think environmental protection and human rights. However, many communities (often those who face racial disparities) are becoming "sacrifice zones" due to destruction of their environment and violation of their human rights... Ms. Harden challenged us to become advocates for our communities through the frameworks of environmental protection and human rights. (Devon Santoro, 2016)

Towns other than Mossville have been leveled in favor of industry...[is] the government protecting industry or people? As health advocates, we must speak for those who cannot speak for themselves... (Leslie Rott, 2015)

In 1970, I went to my first activist march/rally. It was Earth Day. I was just nine years old. I wanted my voice to be heard about the environment... As health advocates...we can make our voices heard by writing politicians, taking part in demonstrations, and boycotting products from companies that do not support the environment. Ms. Harden reminded me of the 9-year-old girl inside of me and moved me to continue to speak against environmental injustice. (Linda Gross, 2016)

Greed is a powerful motivator in ignoring the injustices being inflicted on racial and ethnic minorities... Seeing only the economic gains these companies supposedly bring, politicians have overlooked the importance a clean environment has on the health of individuals. As a result, it is crucial for health advocates to amplify the cries of those whose wellness has been harmfully impacted by corporations to make certain they receive the justice they deserve. (Jocelyn Rivas, 2015)

Digital Health Advocacy Summit

By Sarah Aoanan



Vicki Breitbart and Sarah Aoanan

On October 20th, the Global Healthy Living Foundation www.ghlf.org hosted the Digital Health Advocacy Summit www.dhadvocacy.org (#dhAdv). Leaders in the digital communications space shared helpful insights and best practices for activating memberships, with a focus on engaging policy, regulatory and other stakeholders in the healthcare space. Watch the conversation online www.dhadvocacy.org/summit-videos to learn how to better engage your audience using social media, download the resource guide www.dhadvocacy.org/resources/ developed specifically for healthcare non-profits and also view my interview with HAP Director, Vicki Breitbart. Helping to organize the conference was a big challenge and great opportunity to use the skills I learned from the Health Advocacy Program.

Sarah Aoanan is a 2013 graduate of the Health Advocacy Program and was one of the organizers of the Digital Advocacy Summit.

Announcing a New Dual Degree In Health Advocacy and Social Work

We are excited to announce a new dual degree in Health Advocacy at Sarah Lawrence College and Social Work at NYU Silver School of Social Work. This new program will combine the theoretical knowledge of health advocacy and clinical social work. It will prepare health advocates and social workers for both clinical practice with patients and families in diverse health care settings and for community and policy practice aimed at reducing structural barriers to health such as poverty and racism. Both programs will emphasize the importance of understanding the impact of culture, race and gender on the development of individuals and social systems. For more information please contact Dr. Vicki Breitbart at HAP, 914-395-2602 or at vbreitbart@sarahlawrence.edu

Stanford Medicine X...cont'd from page 9

role as a patient advocate for others, including the need for patience, perseverance, and tenacity.

The highlight of the conference, for me, was the Ignite talks given by a variety of ePatients. The presentations were each only five minutes, but they were dynamic

and inspirational. Through words, music, or media, each ePatient presenter focused on an area of health care they had personal experience with and identified as an area that needs to change. Another high-point was meeting in person people I have built relationships with online.

Anybody interested in this topic should definitely attend the next MedX confer-

ence. The opportunity to attend was for me a truly transformative experience, and one that I will never forget. Stanford Medicine X 2015 will take place September 25-27, 2015.

For more information, visit <http://medicine.stanford.edu/>.

Leslie Rott will be a 2015 graduate of the Health Advocacy Program

HAP STUDENT AND ALUMNI UPDATES

Sarah Mendoza Aoanan, is now a Health Advocacy Fellow at the Global Healthy Living Foundation (GHLF). Sarah's first significant project was to help coordinate GHLF's *Digital Health Advocacy Summit* which was held on October 20th both online and in person in Washington, D.C. Sarah was also a guest blogger for HealthCetera, the Center for Health Media & Policy at Hunter College blog about health & health policy. Sarah's article can be found at <http://centerforhealthmediapolicy.com/2014/10/03/digital-health-advocacy/>

Nazsa Baker, is an investigator for the State of New Jersey, Essex County, Office of the Public Defender, Division of Mental Health Guardianship & Advocacy. In this role, Nazsa conducts investigative interviews with clients to assist in advocacy efforts to ensure clients are not improperly committed to psychiatric hospitals and are gaining access to appropriate health care.

Debbie Finn, currently works at HarrisKramer, an educational consultancy; Debbie serves clients with learning differences and therapeutic needs. Her gratification comes from a family's satisfaction when they know the most promising opportunity for their child has been identified, researched, and meets their goals.

Ashley Gephart, recently joined the BeWell Team at Stanford University as a Wellness Advisor. Ashley's primary responsibilities as a Wellness Advisor are to assist BeWell participants in setting health and wellness goals, as well as connecting participants to helpful campus resources.

Susan Titus Glascoff, was one of six panelists invited to speak at the *Reforming the Legal System Conference*, hosted by St. John's University in New York on October 2, 2014.

Rachel Grob, has received a permanent appointment to the University of Wisconsin-Madison (UW-M) Center for Patient Partnerships (CPP) where Rachel is a clinical associate professor and the director of national initiatives. Rachel is also the first CPP faculty member to receive a formal appointment in the UW-M School of Medicine and Public Health where she

is a Senior Scientist for the Department of Family Medicine.

Ariel Hidalgo, recently joined the Marketing Team at Weill Cornell Imaging at NewYork-Presbyterian. Ariel will work as a Physician Liaison, assisting on all health awareness campaigns, both internally and externally, that the department will focus on.

Elizabeth (Betsy) Henry Klampert, is now the co-chair of the Elder Law Committee of the Westchester County Bar Association.

Amy Lifson, is the Program Director for Portable Assisted Living Services (PALS), a new non-profit program run by the Geriatric Services Group, which also operates Bright Side Manor, an affordable assisted living home in New Jersey. PALS is launching the program in a subsidized independent senior apartment building, with the goal of keeping residents living safely and affordably in their own private apartments for as long as possible. PALS will provide the same types of services offered to residents in NJ assisted living facilities, including help with personal care, medication management/administration, nursing care, coordination of health care, house-keeping, meal preparation and arranging transportation.

Lindsey Prange, is a Wish Coordinator for Make-A-Wish Metro and Western New York. Lindsey assigns wish granting volunteer corps to wishers throughout the five boroughs and Long Island and manages follow-up on wishes that have been assigned and are in progress. Lindsey feels very fortunate to be part of a dedicated team, committed to an outstanding mission.

Kirsten Pruzek, is working on a collaborative venture with Stanley Glick, M.D., Ph.D., Professor Emeritus, Albany Medical Center (lead) and David Hannay, Ph.D., Professor Emeritus, Union College. The team is developing a website, *Growing Old and Wise*, which will be a centralized source of comprehensive information regarding health, retirement, and housing options for seniors in the Capital District, currently in the pre-publication stage.

Sheila Reynertson, recently accepted a position with New Jersey Policy Perspective as a Senior Policy Analyst. In this role, Sheila will be focused on the state budget, tax policy and related economic issues, particularly as they relate to low-and moderate-income people. Sheila also currently serves as President of the Board of Health in Hopewell Borough.

Leslie Rott, has begun working part-time as a Patient Advocate with the Hospital for Special Surgery, New York, NY.

Karen Wexler, has published her first book, "Having My Cake: The Mastery of Mindful Eating." Karen is a patient advocate, writer and actress who has appeared in theatre, film and television. Karen has written for hospital publications and was a presenter at the National Patient Safety Conference in 2013. Karen works as a patient representative at Memorial Sloan Kettering Cancer Center in New York City.

Pam Willrodt, is a Graduate Research Assistant (PhD) working with a principle investigator for the Veterans Administration studying the effects of the Affordable Care Act for the Rural Texas Veteran population. Pam's own work will be on investigating the health literacy of veterans and its effect on health insurance, health access, healthcare, and health.

Congratulations HAP 2014 Graduates

Elizabeth Bailey
Nazsa Baker
Dharshini Canagasaby
Laurel Cates
Megan Fortner
J D'Anne Graham
Ariel Hidalgo
Lauren Luik
Harriet Meekins
Lindsey Prange
Laura Schneider

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