"Equity is a problem of very significant disparities in opportunity…"

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Voices of Health Equity in Chicago
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CENTER FOR COMMUNITY HEALTH EQUITY

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Center for Community Health Equity
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Voices of Health Equity in Chicago
Our *Voices of Health Equity* project collects the stories of people who have made health equity a central concern in their work. We are interviewing academics, clinicians, public health advocates, community organizers, and others to better understand how different disciplines and professions could work together to eliminate avoidable, unnecessary and unfair health disparities.

Wednesday, September 13th 2017
Interview by Amber Miller

Background: Stacy Tessler Lindau, MD, MAPP, focuses on patient care, research, education and advocacy related to the health of women, aging and urban populations. Dr. Lindau is the director of the Program in Integrative Sexual Medicine (PRISM), a program that provides care for and studies female sexual function in the context of aging and common illnesses. Most of Dr. Lindau's patients have sexual health concerns caused by cancer or its treatment. Dr. Lindau is also the director of the South Side Health and Vitality Studies (SSHVS) at the University of Chicago. SSHVS works to create and spread knowledge that people and communities can use to sustain excellent health and vitality. The Studies include MAPSCorps, the Feed1st and CommunityRx. CommunityRx, supported in part by a 2012 Healthcare Innovation Award from the Centers for Medicare and Medicaid, leverages health information technologies to link people and places to improve individual health and grow community vitality.

Amber: Can you talk a little bit about who you are and how you got to where you are today?

Stacy: I am a practicing physician. This is the hat I wear with the greatest sense of responsibility and pride. In addition to that, I am a physician scientist and professor at the University of Chicago. What gets me out of bed in the morning is the idea of engineering solutions to injustice. I believe - and the people who work with me believe - that we can engineer solutions to injustice best by working together with people who live the injustice and know it best. This belief is the kinetic energy behind my life's work in Chicago, especially my work on issues of health equity.

I came to the University of Chicago in 2000 for a fellowship with the Robert Wood Johnson Foundation Clinical Scholars Program. I came here after my residency in OBGYN at Northwestern because I was particularly interested in utilizing my medical skills and my growing scientific skills to serve an African-American community.

I didn't set out to be a physician, I set out to be a teacher. I was a college student at the University of Michigan where I studied political science and secondary education. I meant to be a social studies teacher.

Amber: Wow, that is a big change.

Stacy: Yes, it is. But it has come full circle.

After I graduated Michigan, I went to New York City looking for a teaching job and found there was a hiring freeze in the public sector. I had a public service internship between my freshman and sophomore year in college at the U.S Chamber of Commerce. They had a television division called Biznet news. So when I graduated college, I had some experience working there and I had some television production experience as a high school student. When I graduated college, the television experience on my resume landed me an interview and, ultimately, a job at the Wall Street Journal where they also had a television division. So very much outside of my plan, my first job out of college was on Wall Street working for Dow Jones and Company as an entry-level person in television production.

My educational experiences were social science, education, and this experience in the business and media worlds. While working at the Wall Street Journal TV, I came to discover that really I craved science. Wall Street has a lot of numbers, and numbers drive every conversation – literally, we stared at

the ticker all day long. I'm sure I doubted my intellect at the time and thought, 'maybe these are numbers I just can't understand,' but there was another part of me that felt like there was a real lack of depth with these numbers. And these numbers were the "evidence-base" people were using to make decisions about how to spend and invest their money. That's where I discovered an appetite for evidence.

At the time, I started volunteering at a local hospital because it was the one place that was open 24/7/365, and where I could fit volunteerism around my busy job. I discovered there, to my surprise, that medicine was a job where I could teach, where I could learn the rigors of science, where I was expected to think critically about evidence and contribute to the evidence base, and a place where I could use my natural inclination to care for others.

So I went back to school for post-baccalaureate premedical studies and then I went to medical school. After my residency training at Northwestern, I came to the University of Chicago for the Clinical Scholars program and I also studied public policy at the Harris School. I gravitated to the interface where the social sciences and biomedical sciences meet.

So today, 17 years into my career as a professor, my work involves high school students, my work involves understanding at a very basic level what are the social structures that can be leveraged for better health. My work understands, through close working relationships with the communities we serve, the importance of jobs for people's health. So, maybe my path was destined to be or today I am just drawing on all these different life and learning experiences to have my best impact on the world.

Amber: Did anyone influence you to get into medicine? Or did you have any mentors?

Stacy: I have had many, many influences over time. It turns out I am from a family of doctors, I even worked in my father's medical practice for many years.

Amber: In what field of medicine does your father practice?

Stacy: My father was a dermatologist. At one time my grandma, my cousin and I all worked for my father together. So I sort of thought of it as the family business, rather than a stepping stone to a career in medicine. But he brought so much joy to caring for people. He is retired now, but he is a person who is really loved by his patients and I am sure that exposure to his grace as a physician and his patients' appreciation for him influenced me heavily. Until later and after college, I never consciously considered medicine as a career for me. That wasn't because I didn't admire my dad, to the contrary. There are a number of reasons why I didn't consider medicine as a path for me. I never considered myself a future scientist until I was in the working world.

Other people who have influenced include Cathy Cohen who is a political science professor here at the University of Chicago. She was a graduate student in political science at the University of Michigan when I was an undergraduate. She and I shared the same advisor and she became a mentor for me as I wrote my BA thesis on non-electoral political participation in Detroit. She is someone who really inspired me early on and whom I'm fortunate to have as a colleague today.

There are many passionate advocates for health equity in Chicago who have inspired me. The late Dr. Steve Whitman is not somebody I knew well, but his intense concern for fairness in our city and the scope and pace of his work was a really important inspiration to me. Dr. Mardge Cohen, a physician

activist (now in Boston) spent many years here in Chicago caring for people with HIV. I worked with Mardge early in my career and I really admire her fearlessness, her sense of justice, her ability to solve big problems. Dr. Pat Garcia is an OBGYN at Northwestern University was one of my influential and beloved teachers and mentors when I was a resident there. I am attracted to people who bring intensity and seriousness to their work, and who are not afraid to push the bounds by asking hard questions. Dr. Harlan Krumholz, a world-class cardiologist and physician scientist at Yale has been one of my most important mentors. Dr. Marshall Chin is an internist here at the University of Chicago and has been a treasured mentor for mine since I was a Clinical Scholar. Dr. Babs Waldman, the medical director of Community Health is someone who I came to know a little later in my career, but is a tremendous leader in serving people in Chicago who don't have health insurance. She has also committed a big part of her life to the health of people in Haiti and the Dominican Republic. I am only naming a few of the people who have inspired and taught and supported me.

Amber: It sounds like you have had a lot of influences who have helped shaped how you ended up here.

Stacy: Definitely. And in the last couple of years, my research has led me to become an entrepreneur. This new experience comes from a large innovation award that supported my community-focused research. There were a number of factors that influenced my venture down this path, but I was particularly inspired by a group of good-hearted Chicago business people – mostly people in the information and digital technology world. Brian Fitzpatrick ("Fitz") and Zach Kaplan are two entrepreneurs who created ORD Camp. It's an annual January weekend event in Chicago that involves a 48-hour sort of lock-in at Google Chicago offices. They invite a wide diversity of people who work at the intersection of doing something good for the world, think creatively and who are creators of something. Around the time of the innovation award, I was invited to this ORD camp. It was the first time I had really been exposed to this kind of entrepreneurial energy in Chicago. That exposure inspired me - it gave me confidence and a peer group to think about how I can bring my health equity work out of the lab and into the real world in a sustainable manner.

Amber: I find it so interesting that you went from wanting to become a teacher, to working in media, then into medicine, and now creating your own companies. It's not so linear, but it's fascinating how all of these stages in life lead you here.

Stacy: There was a formative experience early in my life. I mentioned my grandma, and there's a picture behind you of my grandparents in their five and dime store in Detroit.

Amber: Is Detroit where you are originally from?

Stacy: Yes, I am from Detroit. I was born in Detroit in 1968, and if you know the history, that was a really critical period in Detroit. People came to Detroit in the last century, Black and White, because it was a land of industrial opportunity. All kinds of people came. It was a tremendous melting pot. I was born in this flash point period where tensions between white and Black people were flaring. Of course, I was too young to know what was happening in my city, but I do believe that – and there is growing evidence to support how - factors outside our body get under our skin and influence our physiology. Our resilience to disease, our susceptibility to disease, and I think when we talk about racism, when we talk about health, when we talk about health equity, we have to think about how racism has differentially affected the health of Black and African-American people in our country. My early life experiences drive me to seek to understand how the ills of racism. I am especially concerned about racism directed at

African-American people. Racism in the place where I was born and where I lived my first two decades of life, has influenced my life's work and commitments.

So, my grandparents had a five and dime store in downtown Detroit - which was very close to where those 1968 uprisings occurred. My grandpa had passed away before I was born, and the store was my grandma's livelihood. She was the operator of the store and her store was one of the businesses that burnt to the ground in the conflict. That experience obviously affected my family's experience of the racial tensions in our city. My grandma's relationship to her store and the people who worked for her lasted well beyond the store.

The equal rights amendment and the civil rights movement were daily conversations at the dinner table in my family. The fact that my dad was a dermatologist - an expert on skin - I'm sure also influenced me. I just had this very early - and I think I've come to realize as I've gotten older - this deep feeling about the injustice that the color of a person's skin has anything to do with their ability to contribute to the world, their access to anything in the world, their rights, their dignity. I was just so offended early on by those concepts, and I have really consciously made the decision that I wanted my life's work to contribute to reparations between white and Black people in our country. I believe in reparations. I believe the work I do is about saying slavery is a deep wrong. The inequities we see today, I believe, are a direct extension of our country's history of enslaving Back people. I cannot erase that history. I feel like I owe it - that in my life's work I must try to heal those lasting ills in our society.

Amber: That's an interesting perspective you have. Especially when you mention your dad being a dermatologist and realizing that the color of his patient's skin determines their place in this country and produces health inequities.

It's also fascinating that you got into studying food insecurities within the hospital. Can you talk a little more about your work on that end, and how someone's food insecurities can lead to physiological illnesses, such as depression?

Stacy: I'm trained as an Obstetrician Gynecologist. Nowhere in my medical school or residency was training hunger ever a topic we studied. Neither was literacy - which was an early area of my research. Neither was sexual function, which you would think somewhere in Ob/Gyn training would be addressed. But what interests me most is to identify factors that influence health, correctable factors that influence health, that are both obvious and overlooked by others.

Ralph Ellison, the great American novelist, wrote a book called *Invisible Man*. He gave me a word to describe what intrigues me most as a scientist. Most of most of biomedical science is about the pursuit of the invisible. It's about what we don't see because of the physical limitation of ours eyes. So what do we do? We create microscopes and MRI machines and powerful tools to extend or overcome the physical limitations of our eyes. Most of biomedical research is about seeing the invisible. Ralph Ellison, in the prologue to a later edition of the *Invisible Man* - I'm fortunate I just happened to pick up that edition - used the word, *unvisible*. He didn't go on to explicitly define what he meant by it, but when I read the word, I got goose bumps. This was the word I was looking for. So it's not what we don't see because of the physical limitations of our eyes, I'm interested in what we don't see because of our biases. It's what we choose not to see because it doesn't occur to us if we are not hungry, to think about hunger as a correctable factor affecting a person's health. It doesn't occur to use if we can read, to think about how low literacy might affect a person's health. It's what we don't see because we feel

uncomfortable looking down there - like a woman's sexuality, her sexual function and how it affects her health. So my life's pursuit as a scientist is to see the unvisible.

The issue of hunger came to my attention around 2007-2008 via a colleague and a chaplain at our children's hospital. I was working as a research leader with the Urban Health Initiative at the University of Chicago Medicine. UHI had been started by the former dean of our medical school, Jim Madara, now president of the American Medical Association, and Mrs. Michelle Obama, who was a vice president of our medical center at the time. They started the Urban Health initiative around 2005, with the idea that we, as a medical center, may want to rethink how we relate to the people in the communities we serve. And Mrs. Obama, from what I understand, brought an asset-based philosophy to this Urban Health initiative. The team who worked for her passed on the idea to me that our approach, fundamentally, ought to be to understand the assets of the communities we serve, and to work together to leverage these assets to build toward better health and vitality in the region.

I joined the Urban Health Initiative in 2008 after she left for another job. I learned this idea of asset-based community development both from her team of people who were still at the medical center, but also from the community members who came to the table to collaborate with us. An asset-based approach to better health and vitality in the region was uniting and one that made sense to the community, and it made sense to the scientists and leaders at the University. An asset-based approach means we don't just build a new building, we don't just say 'evidence-shows this will works,' it says, 'let's see what's working in this community, and let's understand it and build on it.'

So as we were getting this work started in the broader community, the chaplain at our children's hospital became aware that parents and caregivers with a child in the hospital were struggling to take care of their child because they were hungry. She saw families ask a medical student or a nurse for a sandwich or money, or she saw crumpled up candy bar wrappers, and she really worried from a spiritual perspective that people who were hungry couldn't give the support to their children that was needed. So the chaplain came to my colleague, Dr. Doriane Miller who shared these observations with me. I think the asset-based approached we were taking to solving problems in the surrounding community also made sense for how we might tackle this problem of hunger inside our own hospital walls.

I happened to be going to give a medical school lecture – literally, physically walking to give the lecture on the topic of health disparities – when Dr. Miller raised to me this problem of hunger in our children's hospital, and I was moved by it. I thought hunger in this children's hospital has to be a remediable problem. I brought this sort-of as a case-study to these new medical students who had just arrived on our campus. I said, "If you really want to make a difference, why don't you work with us to help solve the problem of people going hungry in our children's hospital." Students came forward and said they wanted to help, and within a very short period, we reached out to the Greater Chicago Food Depository, a great community asset based on the South Side of Chicago. We shared with them our problem and collaborated on a solution to address this hunger problem.

The paper that you're referencing is called, *Feed First, Ask Questions Later*. The title reminds us that sometimes scientists must act as humanitarians first, and scientists later. What a scientist would say is, "Let's do a needs assessment study to make sure the chaplain really has a good understanding of this problem." Well, we decided to just believe the chaplain and implement a solution and then do the needs assessment study. Sure, by implementing our solution, the prevalence of hunger in the hospital, or the measured need, might have been a little lower than if we had measured the need first. But scientists are smart enough to find a way to overcome this kind of barrier. And it turns out that nearly

half the people in our study were food insecure, even after we implemented the solution. So this is a conservative estimate. That's the story of how we became aware of the hunger problem and what we did about it. It really influenced how I think about my science: when is it necessary to act first and ask questions later?

I will give you an interesting side story of the study title *Feed First, Ask Questions Later*. So you probably remember recognize it as reference to *"Shoot First, Ask Questions Later*," a phrase most people associate with the Wild West. I was naïve to the origin of that phrase, *Shoot First, Ask Questions Later,* but I was asked to give a lecture on this topic for our ethics center at a conference a year ago. I studied the origins of that phrase, and I was horrified to learn it came from one of the first people to be convicted of Nazi war crimes. This Nazi who told his people to shoot first - if you think it's a Jew, then shoot - and I will not fault you for killing someone you suspected to be a Jew. Albeit unwittingly, we have taken back that phrase and we have used it to advance a humanitarian point that scientists should consider.

But I share this story with you, both about Ralph Ellison and his work with this historical reference, because I think to do important science, we need to ground our science in the humanities, in history, and in literature. It can speak to more people, and our science - as much as we would like to think it is objective - it is always rooted in humanity.

Amber: What was your goal is publishing this article? And what was the response from others after learning about this food insecurity issue that was going on in the hospital?

Stacy: This piece on hunger - and actually we have another piece coming out in a couple of weeks - I am very proud to say is led by Jennifer Makelarski who is a PhD epidemiologist who has worked in my lab for many years. She is a maternal and child health epidemiologist and a mother, and this issue of hunger in the children's hospital really touched her as well. So she led this paper, along with the forthcoming paper on this topic, and I want to give her credit for that.

This paper asked: "When can a scientist act first as a humanitarian and then as a scientist, and how does taking that approach influence the science?" This paper also established the prevalence of hunger among parents and other caregivers of children in the hospital. It established that the prevalence is very, very high, number one. And number two, Dr. Makelarski helped us to discover how hospitalization itself can trigger food insecurity. It makes sense that once a parent comes into the hospital with the child, the number one concern is the child's health and recovery. Most of us don't want to leave our child's side. What we learned here was that among the people at highest risk for developing food insecurity in the hospital were people who felt that their child would not be OK if they left.

Amber: Do you think that this concept also brings up the idea of lack of trust some parents may have for medical professionals? Do you think the parent(s) may be fearful of what would happen to their child if they left the hospitals for a few minutes to get something to eat?

Stacy: I think the issue of trust is something I have come to understand to be much more complicated than I would have thought, based on my training in health inequities and health disparities, and I know my view on this issue is colored by a very unique circumstance. That is, as my work started to focus more on the health and vitality of the population we serve here on the South Side of Chicago, the first African-American president of the United States was elected from this community. This was a very unique circumstance. It could not be replicated, obviously, this circumstance only happened here at this

one point in time. Based on my experiences, not my science necessarily, but my experience working with leaders and residents on the South Side of Chicago - most of whom are African American - was that there was a real 'Obama Effect' influencing our work. In other words, people we serve in this community know the story of the Tuskegee studies and the horrible exploitation of Black people by those experiments. The story of Henrietta Lacks was published as a best-selling book at the same time as we were starting our work here. The history of exploitation of Black people by American scientists is real. It is palpable. It is not reconciled. And yet, I think the very specific and unique hope and inspiration created by the election of Barack Obama to the presidency enabled people from his community here on the South Side of Chicago to sit around a table together and work together to use the tools of science to promote health and vitality in a way that was unlikely to have happened before. I think there was an opportunity, at this point in history, to figure out how we can work together by joining the expertise of the lived experience with the tools of science to improve health and vitality in this region.

I guess in addition to those examples I just gave, it's really important to say research from the University of Chicago, Nobel Prize winning research, has contributed knowledge that has influenced the fields of economics and sociology world-wide. Some of that important work has been done with participants from our communities. There was very little tradition or practice, if any, of translating that research back to the betterment of our local communities. There is a stark contrast between the success of the research and the suffering in the community where the research has been done. This observation would resonate in many university towns, not just here in Hyde Park. If we look at our peer institutions around the world, there would similarly be a tradition of research on people, not with people, and research that may have made the world a more enlightened place, but did not alleviate the suffering locally.

People knew this when they decided to come to the table with me and others here at the University of Chicago in 2008. Then in 2009, the economy tanked and people here were hit very, very hard. And, still, in spite of that history, there was a willingness to work together toward a better future.

So yes, trust issues are prevalent, and more complicated than just, "I don't trust you because of the history of exploitation" or "I don't trust you because of the color of your skin." High socio-economic status people, white-skinned people, brown-skinned people, including doctors – we all struggle with trust in our doctor. We struggle with the idea of leaving the bedside of a sick child in the hospital. In some ways, these trust issues are universally human and they are complicated. But when we add hunger to the problem, we have to recognize that hunger deprives the brain of energy. And so, people who are really hungry because they cannot afford enough food to eat and stressed because their child is ill and uncertain about how to keep their job and care for their family in the face of hunger and illness are operating on basic instinct to protect themselves and their child. How does trust work in that moment? How does a hungry parent with a seriously ill child trust people who look different, whose power and status is different, who expect them to make important decisions and understand complex medical issues when hunger is the prevailing sensation?

Another thing I want to point out is hunger is very stigmatizing, especially for parents of a sick child. So what if a social worker recognizes there is not enough food in the home, and say a social worker interprets that to mean neglect of the child. A parent who can't feed herself or her children sufficiently may be worried her child will be removed from her custody. So a parent is not really in a position to say, "I'm hungry, I don't have enough to eat" because she may worry the child could be looked at as a neglected child. This is what I mean about complicated layers of trust.

Amber: What do you think are some of the biggest obstacles to addressing health equity in Chicago?

Stacy: What I take away is, fundamentally, that equity is a problem of very significant disparities in opportunity. Institutional and structural racism are the manifestation of policies that segregate based on the color of skin. To me, these forms of racism are the most mutable factors driving costly health inequities in our society.

In the last six months of our nation's history – at least the history I've lived through - I am starting to hear people in positions of power say the word 'racism' and acknowledge the unlevel playing field under our feet. I think this is a mutable problem. I think that policies can be changed.

Amber: Given that, are you optimistic or pessimistic about the future of health equity in Chicago? How do you see things unfolding in the next 10 years?

Stacy: Chicago really is my city now that I've lived here longer than I lived in Detroit or anywhere else. The tale of two cities always comes to mind, but I think it's even more nuanced than that. Chicago is really a place - on the one hand - of 'yes' and beauty and resources and a beautiful and unique built environment. These factors, plus our architecture and many aspects of our history at the crossroads of our nation give me a very positive feeling. There is real beauty in opportunity and innovation here that does make me feel proud and optimistic. But there is also a great big 'no' side, and the 'no' is that starting from life *in utero*, there is a very big portion of our population, maybe even half, where the answer is 'no': *No* you won't have a gym in your school. *No* you're not eligible for position. *No* you can't have a good night's sleep or affordable fresh food. Those toxic, cumulative *no's* are the legacy of structural factors – including man-made laws and policies - that drive racial and socioeconomic segregation and downstream inequities in this city and in many other U.S. cities.

Am I optimistic? I am, by nature optimistic. So I will have to say yes, I see a future with less inequity, but I am very concerned. I feel enormous distress about violence in our society, and my impotence in the face of solving this problem. I believe I'm part of the problem, and I am really stumped on what I can personally do - other than try to spread kindness as much as I can in all of my interactions - to turn that problem around. The stress and fear make it harder to be kind, which makes me very sad.

I'm concerned about the 'caring community' in Chicago. What I mean by the 'caring community' is all of the people who have committed our lives to, let's say, '*serve and protect'* – the police motto. Why am I concerned? I believe that most of us in the caring community – I will include doctors, nurses, fire fighters, EMS, police, social workers, community health workers, pharmacists, dentists, foot doctors, eye doctors, physical therapists and more - the caring community comprises of big portion of the workforce of our city. I believe we have a city of people with big hearts and with inclination toward generosity, but I'm concerned about the moral distress and the burnout. I am concerned that those of us in the caring community are spending more and more time struggling with poor quality information and technologies, whose structure and function are designed mainly for businesses purposes than for making lives better. I am concerned that there is some dysfunction in the caring community. That under the guise of caring, serving, or protecting, some people are so broken that their actions are not caring. They are harmful. They are even lethal. We have to really acknowledge this fact and correct course. This is the force that counters my optimism.

Amber: Lastly, do you have any advice for students who may be going on to pursue a profession in the community health field?

Stacy: Anyone who enters this field, is by definition, privileged and empowered. We've had the privilege of education, we've had the privilege of enough physical and mental health so we could qualify to care for others. With privilege, comes obligation. My feeling is, each of us in the caring community - whether scholars or practitioners, doctors or community health workers – we must take a high level of ownership over the well-being of not just the individuals with whom we come face-to-face to serve, but all of the residents of our community and ourselves. Some of us feel higher or lower on the hierarchy of things, and there are power structures and inequitable policies in the caring community too, but I feel that the privilege of becoming a member of this community must come with serious obligation. We don't just go to work 9 to 5 then ignore an injured or suffering person on the way home because our day is done. When we enter the caring community, it's a life choice, not a 9 to 5 job. So, either you are up for it because this commitment calls you, it fuels you, it brings out the best in your, or you're not. And if you're not up for being a Good Samaritan when you leave work, or once the paper is published, then my view is you may be better off in a different profession. And that's ok. We all have our jobs to do.