"If we want to make our city healthier, I believe we need to get out of our comfort zones and see the world from the perspective of the neighborhoods"

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Voices of Health Equity in Chicago
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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, August 2, 2017
Interview by Amber Miller and Sarah Wozniak

Background: Steven K. Rothschild, MD, is a family physician, educator and researcher in the Departments of Preventive Medicine and Family Medicine at Rush University. In addition to a 30-year clinical career focused on providing primary medical care to the medically underserved, he is an established researcher focusing on health services research, chronic illness self-management, and community- and team-based approaches to addressing health disparities. We talked with Steve about this work and his perspective on health equity in Chicago.

Amber: Can you tell us a little bit about who you are and what you do?

Steven: So my background is as a Family Physician. I graduated from the University of Michigan Medical School in 1980, which was the early days of family medicine. The department at the University of Michigan was just established two years before and most academic medical centers did not have Family Medicine, but there were a lot of people in my class who were committed to Primary Care and Family Medicine in particular. Why I had chosen family medicine has always been a little bit of a mystery to me. I knew fairly early on when choosing to go to medical school that I wanted to be a family doctor, but I can't say I had a family doctor growing up or I knew someone who was, but there was sort of a commitment to service, and primary care in particular made sense. I think I hindsight, I correctly diagnosed myself with Attention Deficit Disorder, and knew I couldn't limit myself to one specific area, I found everything interesting and I still continue to find everything and how they connect in systems ways to be interesting. So I couldn't necessary limit myself to the liver or heart or a certain age group or gender.

After that, I went to the county hospital in Cleveland, Cleveland Metropolitan General Hospital, to do my residency and I chose it for several reasons. I actually had always assumed I was going to go to Chicago to do my residency at Cook County Hospital. That had been plan, and then when I came to interview, County was at the time was under threat of being closed permanently. The chair for the Department of Family Medicine had just had his second heart attack and he was out. They had forgotten I was coming and they found a second-year resident to tour me and he said, "Whatever you do, don't come here". Needless to say, that did not leave a very good impression.

Then, I went to Cleveland where it was a brand new state-of-the-art facility. Not only were they doing great Family Medicine work, but they were really strongly tied to the west side community in Cleveland, which was a multi-ethnic community. We had both a family therapist and a half-time anthropologist as part of our faculty who trained us, you know, in- *how do you do community assessment? How you do family therapy will vulnerable populations?* And so, you know, I was already aimed in that direction but that element of my training really solidified how I think about patient's social determinants of health -- but we didn't call it "social determinants" at that at the time, but faculty like Drs. Jack Medalie and Tom Mettee emphasized that we understand our patients people in the context of which they live, work, study, and play.

So that was that, I worked in Cleveland for another year at a community health center, one of the earliest federally qualified health centers, the Kenneth Clement Center which is on the east side in a very poor African-American community that had been largely devastated by the riots of the 1960s and never fully recovered. But at the FQHC, one of the projects they did was that they had recognized that a lot of the people who were still in the area were elderly because they didn't have the options to leave. They owned their homes, they didn't have anyone they could move in with, and they were very isolated. So that was really my first experience with Community Health Workers (CHWs), which you know 35 years on is still a big part of my work.

There was a project called, *Golden Age Outreach for Health*, or *Project GoH*, and was spearheaded by a guy named Henry Zeigler who was a public health internist who did most of his work and continues to do most of his work in Sub-Saharan Africa in global development work. But, he was lured back to the States because people were asking him, "What kind of community development work are you doing in the U.S", and he had to say, "I don't think we're doing any" so that what brought in back in the 1980's.

Henry was a big influence on me, along with the faculty in my residency. One of the things he always advocated was asking us "You know, as we think about the work we do, we should always consider what would happen if"- and Reagan was president that the time -- "what if a big Reagan budget cut came through and we closed the center down--.would this community be better as a result? Would this community be somehow healthier as a result of the work we did? Not just because we diagnosed, you know, Mrs. Smith with hypertension or Mr. Jones with diabetes and we got the medicine, but how is the community healthier?", and that's been really a driver for me since then.

Amber: What was your goal in publishing your article Mexican American trial of community health workers: a randomized controlled trial of a community health worker intervention for Mexican Americans with type 2 diabetes mellitus?

Steve: Why did I do the research? So, you know, Cleveland in 1983-84, I'm working with CHWs, and by 1988 I opened up a practice in Pilsen here in Chicago and I was looking for a project to improve the health in the community. So this is going a back a bit from MATCH, but we'll get there…

One of the issues that I saw as a practicing family health physician in Pilsen was that I was seeing a lot of young adults, I was seeing a lot of families, I was seeing a lot of middle-aged people, but wasn't seeing a lot of older adults. Now, Pilsen was a Mexican- American community. It was largely at the time, a lot of first generation immigrants. So, there was part of my logic that said, "there aren't that many older people because older people aren't the ones who immigrate." You know, you don't leave your country and move to a new place when you're 70, unless you're moving in with someone, you're too vulnerable, you do that when your 18, 20, or 25. But, the U.S census said that 4-5% of the community was over that age of 65. And I'm going, 'Well, I'm not seeing 4-5% in my office, I mean, older people tend to use more doctors'.

So, I talked to other doctors in the community and I said, “You seeing old people? Maybe you got them?” and they would say, “Well, I’m not seeing them either.”

So, we did some asking around, we did community surveys and things… For the most part, the seniors told us they were unsure about the U.S healthcare system, they trusted neighbors more than healthcare professionals. They went to their church, they went to people they knew from PTA, etc... So I said, “Oh, this looks like a place where CHWs can make a difference.” So, we established a project called *Pilsen Senior Health Advocates*, I did not publish on it. It was a community service based project and was basically hiring older adults to go out and find other older adults and find out what their health care needs are and help them access services. But, it was more than that. It started with that bridge, that connector model in mind, but it was very clear very quickly that our CHWs could do much, much more. That they were educators, informal therapists at times, they were doing a lot of stuff. It was huge, we had 7 of them originally on this grant and we connected with a lot of seniors.

One of the things think that was most striking was this was the summer of the heat wave, 1995, and there was a huge spike in deaths from heat in Chicago, mostly older adults. Mostly because in many cases, they didn’t have access, they didn’t have social support. One of the things that if you have ever read Klinenberg’s work called *Heatwave*, where he looks back on this, and he compares specifically North Lawndale and South Lawndale or Little Village. In North Lawndale, where you had much more social isolation the death rate was much, much higher. Our Senior Health Advocates, in Pilsen to the east of there, were going into people’s homes and making sure they had fans. We contacted every single one of the people we were working with, which was 180 at the time, and the CHWs made sure- *Do you have water? Do you have a fan? Do you have what you need?* And we didn’t lose anybody. Statistically, it’s not that impressive, we probably wouldn’t have anyway, but it was that a process by which we made sure that this population was connected and attended to. So that was that work.

Then, I moved in my career from being sort of an exclusive clinician/family doctor/teacher, to wanting to add research to my portfolio. And, I started to ask myself why we didn’t have CHWs as part of the community health systems. Anyone who would work with them, and this is the early 2000’s, anyone who would work with them would say, “Oh my God, This is the best thing!” Our CHWs in Pilsen would normally accompany our seniors to doctors’ appointments. Sometimes they would just translate, but more often they would help organize things. They brought all the medications, they explained things, they asked questions because they seniors often times were too shy to do it or too passive. And the physicians would say, “Are you their daughter or their sister? Who are you?” and they would say, “No, I’m a Community Health Worker” they said, “This is great. How do we get more of this?” Because it really transformed that relationship. So we all go, ok this is awesome, this is just great, and yet there are no CHWs. When I looked at the literature, one of the things that was clear was there were a lot of case reports or people doing stuff, but no rigorous trials, no real tests to see, could this work? *Does this model make a difference?*

MATCH came out of that. That sense that we need to show policymakers and payers in the United States that CHWs can be a really effective part of the healthcare workforce. We decided to focus on diabetes because we were seeing the spike in the number of patients with diabetes and we were seeing that especially largely in the Latino community and especially in Mexican-Americans, so that's how we got here. We chose Mexican-Americans specifically for MATCH opposed to all Latinos or other health disparity populations or all health equity populations because we don't know what makes CHWs work. So, the one hypothesis is cultural concordance, that people who have similar values, similar life history, a similar set of experience and beliefs would be more effective in doing this than sending a nurse into a patient's home to do the same kind of work or someone from another community that doesn't know Pilsen or this population. So what we tried to do is match as much as possible.

Sarah: That is a good point, you talked earlier about the idea of trust and sometimes people don't trust health professionals. Sometimes CHWs bridge that gap. They have someone on their side, someone who maybe understand what they doing through, and someone from the community who they can relate to.

Steven: Absolutely. I think that is the case. You know, and some people will describe CHWs as cultural ambassadors. You know, I trust you, and you tell me you trust her, therefore you know by whatever property that is in math (laughter), I trust her because of that chain. And I think a lot of the work initially began within that frame, but at the end of the day it's a lot more than that.

Amber: One thing that stood out to me was when you mentioned CHWs and improving self-efficacy [in their patients]. How important is self-efficacy is when trying to make major life changes because if you have type II diabetes?

Steven: Diabetes and most chronic illness require day-in and day-out attention. The person has to be… I don't want to say 'be empowered, I don't like that. It suggest that those of us in power give power, and that's not a correct model. But they have to, number one, believe that a change is important. Number two, they too have to believe that they can do it, and that's what self-efficacy theory says. Self-efficacy is an important piece of this because ultimately, especially in diabetes, we talk a lot about individual choices, 'I am going to have half my plate filled with vegetable instead of three-quarters filled with pasta or rice or carbohydrates. I have to make a decision to go out for a walk today or exercise as opposed to watching Jerry Springer.'

So self-efficacy is very important. In some ways, it is at the heart of MATCH because what we want to do is really empower our community… I used that again… empower our CHWs with a rigorous evidence-based behavioral intervention, and that really is a big part of this because even now in 2017 as you have more and more CHW projects, more often than not, they are really still relegated to that bridge, that connector role. We often hear to word 'navigator' in currency now. Having that navigator role is great, it's really important, but people from the community are capable of so much more. I think that one of the things we demonstrated was that if we partner with communities, they can take a relatively sophisticated behavioral

intervention and deliver it on their own terms and in their own way, in a way that's more effective than a physician, nurse, PhD, or an MPH.

Sarah: So what would you say was the response from the public when you published this piece?

Steven: It's academic, right? So we talked a lot about it. We did community forum and tried to adapt this in other ways that we will talk about in a moment.

In some communities, the biggest response was probably a big old yawn. Like, "Yeah we know that, why do you academics and universities think we're so stupid?" you know? "Of course we know we can do these things, that's what we keep trying to tell you", and I think that's really the truth -- communities have knowledge, assets, wisdom.

So in our relationship with communities, whether we're DePaul, Rush, or University of Illinois, we should not be coming in as "we're from the university, we have the answers to help you poor people", but rather we should be asking "how can we partner together, how do we draw on your strengths and help you have things that you don't have access to?" Communities don't have access to money and policy makers and rigorous research methods, so how do we integrate what they're already good at with what we as academics are good at -- integrating the resources that the community has with the resources that universities have.

So in some ways like I said, big yawn from the community. It's still hard though. One of our next steps was that we partnered with the Puerto Rican Cultural Center in Humboldt Park and we tried to apply some of the lessons from MATCH and apply them to a community-wide area. We took a 100 block area of Humboldt Park to the east of the actual park, in which the late Steve Whitman, from Sinai Urban Health Institute, had done a door-to-door survey. In his door-to-door survey, they found that 22 percent of Puerto Ricans reported that they had been told by a physician they had diabetes. Spectacularly high number: at that time, the highest numbers seen nationwide outside of the Native American community, were about 11-14%. And here in Humboldt Park, more than 1 out of 5 adults are saying, "Yeah, a physician has told me I have diabetes." Not counting gestational diabetes, so not taking the pregnant people into account. And, this was a fairly young community, making the rate even more staggering.

So what we set out to do was to replicate MATCH a little bit and create a community-wide social campaign. Not using a randomized control trial like MATCH, but just to see if we can engage the community in this organizing. And it was a mixed impact study. We were able to do some things that helped strengthen the community- we created a Community Diabetes Empowerment Center at California and Division. It became sort of a kind of center where people could drop in and exercise, they could attend classes, or they could receive information about diabetes, or a CHW would show them how to do glucose self-monitoring. So people would drop-in, drop-out, ask question and things like that. We had four CHWs that went out to their neighbors that were identified as having diabetes.

I think unfortunately we were overly ambitious. There was a little more push back on the interaction. We didn't have a formal curriculum the way we had with MATCH. So where in MATCH, the median number was about 18 visits over two years. In Block-by-Block in Humboldt Park, we typically got three to four visits over a nine month period, it didn't change anyone's A1c (a measure of diabetes control) at all. That goes to show in part, these lifestyle changes really are a big lift and it takes a really high impact intervention. We had hoped by doing this through community engagement, a community wide campaign awareness of diabetes and what was needed might have greater impact. So we wouldn't need 18-36 visits, we would only need four or five, but we didn't achieve that. So it really does speak to long term, one-on-one interactions, even as we work in communities.

Amber: What do you think are some of the obstacles when dealing with community health in Chicago?

Steven: In some ways we are, we can say underpowered. What's that saying? "Don't bring a knife to a gunfight." We are vastly overpowered. We are overpowered by the fast food industry. If I'm telling somebody, "Here is how you cook a healthy meal for your family", and you just been working a long day or a second shift and you just picked up the kids from school and hopefully you got to daycare in time before you get charged extra, you're racing home and the kids are screaming in the back seat and you know if you go home and you cook vegetables, a) you're going to have to fight them to get them to eat it and, b) it's going to be an hour before you put food on the able, and oh look, there's McDonald's and for 99 cents I can get these kids to shut up. We're going to lose that fight, you know?...Doctors and public health educators can say "Hey, this is healthier for your kids!" and the parents are going to respond "I know, but I'm just trying to survive here." Or: "You're trying to tell me that you want me to exercise and go out and walk more but the sidewalk outside my house has got a crack, my neighbor broke her leg there last week and if I get to the park it's likely I'll step on a needle or be shot by a gang that's meeting there. My neighborhood isn't serviced well by the CTA, in order for me to get to work I have to take two buses and an "L" and it's an hour each way. When I get home it's dark and when I get up in the morning it's dark when I leave."

In addition to those fundamental infrastructure barriers, you've got the hopelessness and helplessness that the environment can create as well. You know, one of the things physicians hear sometimes, when encouraging patients to take their medicines for chronic conditions like hypertension or diabetes is "I know that if I don't take this medication I might have a heart attack or stroke by the time I'm 50, but I don't know that many people who live to 50, so I don't figure I'll live that long anyway." So there is also a fatalism there, born of structural inequality and barriers to health.

So these are all things that require attention. We need to attend to the built environment and we need to look at the food deserts to say, "Where does somebody go to get healthy food in this community and how do we have that accessible? How do we educate them so they know what to do with the vegetable? How do we create safe spaces to engage with their families and community member?" It's a lot of work. When you look at studies like MATCH or Block-by-

Block, we were looking at one little tiny part of the health system aspect of the forces affecting peoples' lives. We can't transform communities like that, there's just too much else going on. So, we have to build partnerships, we have to engage public and private sectors, we have to include education and housing and food services and the healthcare industry, and we have to work to bring everyone to the table.

Sarah: Another part you wrote was, "Widespread acceptance of Community Health Workers as an important part of health care teams to enhance patient outcomes is long overdue and should be considered a priority by policy makers seeking to reduce health disparities." So why do you think it is not a priority for some?

Steven: It's somewhat a new concept, even though we've been doing it for decades. Maybe those of us who are advocates of CHWs haven't done a good enough job of describing who they are and what they do. "So if anybody can be a CHW and do whatever, how do we certify that?" "How do we bill for that? How do we pay for it?" "Why should we do it? Does it really make a difference?" For academic experts, this approach doesn't make intuitive sense, because they believe that we need more specialists, not more community people. So when we advocate for trusting community people with their lives and with their neighborhood, it runs counter to an academic or policy culture that says "you have to have letters after your name, you have to be a professional."

As advocates though, we still need to define what is essential to a CHW. One of the strengths of MATCH was a lot of research, we had a protocol. We said "These are the people we're going to recruit to be CHWs. This is what they're going to look like. This is how they're going to be trained. This is how we're all going to monitor what they do, this is what they deliver in the home." Very narrowly defined, you know, in terms of the scope of a community health worker.

When I was in Pilsen, our Pilsen CHWs advocated for safety policies for the residents of a senior citizen building and were able to get changes because the seniors were terrified by the building they lived in. In MATCH, we were not doing policy, were not doing those things, were not changing the community, you are just one-on-one coaching. So we had to shrink the role down so that it was definable and testable and that's a necessity of research, right? Did our community work also do some advocacy on the side? Probably, but we didn't measure that. From a policy maker stand point, I need to know what I'm paying for. How do we do that? So the onus is on those of us who are advocates for creating a model that says, "Here's what you get, and here's what they should be doing, and this is how you can tell they're doing it" and go from there. At least within the healthcare delivery system, that level of specific definition is critical to getting wide adoption of a CHW workforce.

Amber: Are you optimistic about the future of Chicago and the use of Community Health Workers?

Steve: Politically, I consider myself to be a progressive and progressives are always optimistic. We always have to believe that we can envision a better community, a better world, and

working with others we can make that. I think Chicago is going in the right direction in many ways, but there are also risks.

We have a terrific public health department that has made the health of the community a measureable activity. We're now engaged in Healthy Chicago 2.0, which is all focused, -if we look at the Healthy Chicago objectives-, on social determinants and questions like: How do we make streets in communities safe? How do we reduce teen pregnancy? How do we prevent smoking? All traditional public health agendas but being addressed in some really innovative way. And that's a real catalyst for change. I'm a big fan of Dr. Julie Morita, the commissioner, and her department.

We now have people across the city who are engaged with their communities in terms of health and hospital systems and what they're doing, like what Rush is doing with you all at DePaul, but also with community members in the West Side Total Health Collaborative. On the public policy front, all non-profit hospitals are now required under the law to have a community health improvement plan and they have to measure it and they have to show that it's better today than it was 5 years and how it will be better in 5 years. So it's the right alignment of public policy, governance of institutions like hospitals, public sectors, and a commitment really to make the city more livable and doing it in an equitable way.

Now there's also an enormous risk, because what happens as a community becomes more livable and attractive, we see displacement. You may not know this, but where DePaul sits in Lincoln Park, used to be a low income and working class Puerto Rican community, it was what used to be called a quote-unquote "bad neighborhood". It's hard to walk around Lincoln Park today and think that that was the case and not that long ago, we're talking about 35-40 years ago. We therefore need to ask, as we work to make the west side healthier and cleaner, more pedestrian friendly, more bike friendly: What are the adverse impacts of that? Are we pushing people out?

We can look at the Bloomingdale Trail - the 606 - and look at property around there that has now gone up in value, so the taxes are higher so people have to move or people get bought out, they move out, and the community is disrupted. We see this in Pilsen. We see there are concerns about the new bike trail that will go in at 26th Street. Is this how gentrification comes to communities of color? This is a challenge we haven't fully figured out yet. How do we make communities better for the people who live there without pushing them out? I think one of the geniuses in our city, Jose Lopez, a sociologist in Humboldt Park, has really been at the forefront of thinking about this issue and the role of culture in communities. If you drive down Division, you'll see the two Puerto Rican flags. They're 30ft tall metal structures that look like the Puerto Rican flag. Jose always says they're the biggest Puerto Rican flags in the world and I have no reason to doubt him. It's the line in the sand that says "This is our community and that's important", that's one way to do it. But, how do we preserve communities for their residents? That's the big problem because otherwise we will look back in 10 years and say, "oh, we reduced morbidity and mortality, good for us". Except that the risk is that we didn't really lower morbidity and mortality, we didn't lower premature death, we just moved poor health

conditions to Cicero or Chicago Heights, or someplace out of the city and now we're not counting it in Chicago's public health statistics anymore. That's not public health, that's gentrification, and that's the risk for this work that are engaged in. That's what we have to be really conscious of all the time.

Sarah: Lastly, do you have any advice for students who any read this interview orr anyone is interested going into the field of health equity.

Steven: Yeah, don't read this. Go out and see a movie (laughter).

Number one, be a good listener. Listen to the communities, what are they telling you? What are they asking of us? Don't come in with the solution, come in with the willingness to partner. Also, if you're committed to this work, you have to share resources, you can't hoard them. A lot of you will work in university settings where we all feel underfunded and we have to bring in our own funding, or in the public sector where everything is consistently underfunded. So you can't say "I can't afford to share funds because I can't afford to make my payroll as it is", you have to share. You have to be there as a partner and treat community members, nonprofits, churches, and schools as equal partners who are as smart as you are -- they just know different stuff than what you know.

You have to be in it for the long haul. These aren't changes you are going to make in a five year study or a one year study, it's a commitment. It takes several years before people even trust you or believe what you're telling them. The other pieces is to open yourself up to the incredible richness and joy and fun of this work.

Now joy may seem like an odd word when we are talking about life and death issues of people impacted by diabetes, amputation, dialysis, gunshots, strokes, you know all these things are serious. But if you go into community equity, you have to look at the people around you and they have to become more than just the subjects of a study. They have to become more than just people we are trying to help; they have to become our friends and colleagues, and we in turn have to become a part of their world, not the other way around. That's why I think we are often doing it wrong in healthcare, when we spend a lot of time trying to develop ways for people to navigate our world, to attract patients into our hospitals like Rush or Northwestern or whatever. I think the answer is that the medical community must step outside of our hospitals and learn to navigate the communities we want to serve. How do we bring what we have that's of value into a community in a way that says, "This is what we can do and we're here because you've told us you need this and we want to be a part of that effort for community health. We believe it is as important for us to be part of that change, to be a part a making this neighborhood healthier, as it is for you as a resident"? If we want to make our city healthier, I believe we need to get out of our comfort zones and see the world from the perspective of the neighborhoods.