

“...it’s really helpful to have someone on your side.”

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Metropolitan Chicago Breast Cancer Task Force

Voices of Health Equity in Chicago
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CENTER FOR COMMUNITY HEALTH EQUITY



Center for Community Health Equity

The Center for Community Health Equity was founded by DePaul University and Rush University in 2015 with the goal of improving community health outcomes and contributing to the elimination of health inequities 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.

Friday February 23rd, 2018

Interview by Amber Miller and Sarah Wozniak

Background: Ariel J. Thomas is the Health Policy/Advocacy and Research Coordinator for the Metropolitan Chicago Breast Cancer Task Force. She has a background in cancer research and cultural studies. Ariel has a unique perspective as she has contributed to all of the three functional areas of Task Force: navigation, quality consortium and policy & advocacy. Currently, she wears two hats: data coordinator for the Quality Consortium and coordinator for health policy and advocacy initiatives. Ariel works on a range of quality improvement projects, including the Statewide Quality Initiative and Mammography Technologist Train the Trainer Program. Additionally, Ariel is dedicated to developing programs that provide community members the ability to lead advocacy efforts and inform policy priorities, such as the creation of the first ever Task Force Advocacy Council, a leadership program for women seeking to increase their engagement in advocacy. Her work has also included supporting the completion of a multi-county qualitative breast health services assessment for the Susan G. Komen Chicagoland Affiliate. Ariel is particularly interested in understanding how public health policy and urban planning and development impact health in communities of color.

Amber: Can you tell us a little bit about who you are and how you got to be where you are now?

Ariel: I was born and raised on the south side of Chicago. I attended Whitney M. Young Magnet High School and graduated from Howard University in Washington DC, a historically Black university. I didn't major in science or health – I've never considered myself a math or science person – but I was discovering my passions, "*how can I help people the most?*" So I made the determination to work in healthcare. I graduated, moved back to Chicago. I took some classes because I was on a medical school track. I took some of those courses because I wanted to get a little more background and a little more training underneath my belt so I could feel more confident in regard to that path. I went to North Carolina Central University – which is another historically Black university – to get my Masters in Biological Sciences. I did basic science research, cancer, biology, worked in an immunology lab but didn't necessarily see myself working in the lab, though I definitely loved the research component and working with people. So, public health was a good affirmation of all of these things. I had finished my degree, started networking, and I spoke to someone about being more hands on and working within the community, along with the research components and just having a broad array of experiences working in public health that was I was seeking. So, I was pointed in a direction of a former colleague, Kathy Tossas Milligan, past Associate Director of the Quality Consortium at the Task Force. I started volunteering and then became a full-time employee as a navigator.

Amber: What exactly is a navigator here?

Ariel: The Metropolitan Chicago Breast Cancer Taskforce has a team of navigators who will walk women through the process of receiving breast health services, from setting appointments, securing orders from a physician, retrieving past imaging films if need be, or even attending an appointment with a client if they feel unsure or not confident about the process. If something comes back abnormal, walking them through the process and linking them with care. So it's really about removing barriers for women who are trying to access care. And so – as you probably know – there is still a huge racial disparity in terms of mortality in Chicago, and many other cities. The Task Force along with many organizations, including the Chicago Department of Public Health (CDPH), are working to eliminate barriers to access, so it may be the films, or calling to make an appointment. Navigators kind of tie up the loose ends to

make that happen. Of course, the women need to follow through and attend, we are not able to drive them.

Amber: Do the navigators usually call the women over the phone or meet them at their appointments?

Ariel: Much of the work is done over the phone. The navigators do attend appointments if needed. Like I said, when it seems like it is more beneficial for a lady. Some women just need a reminder.

Sarah: It's good to have someone on your side when you are going through something like that.

Ariel: Right. And it's really about promoting self-agency, you know? Women are all at different levels of harnessing self-agency, depending on what's going on in life. So, it's really helpful to have someone on your side. This is a free service and so we can provide no cost mammograms for women who are uninsured or underinsured. CDPH has provided funding to various institutions to do this work – we are one of them. Many hospitals around the city and collar counties donate mammograms or diagnostic services for women. Through that, were able to help undocumented women too, because that's a huge barrier – we will get into that – but basically, eliminating barriers to care is the job of the navigators. I did that for about the first year, and then I transitioned into the Quality Consortium, which is the quality improvement programming component of the Task Force. We have trainings on quality improvement for facilities and technologists, the person performing the positioning of a women and taking the mammogram images. There has been research to show that improvement positioning and compression dictates the quality of the images. Cancer can be missed cancer due to poor imaging. That's something that we do, we've partnered with Advocate Health Care for several years to put on a breast imaging symposium. It brings 200-300 mammogram techs who receive Continued Education Units, which is very valuable.

Sarah: Even on the website, underneath the Task Force logo, it says, "United to end disparity". With what you just explained, it really shows that this Task Force is really working towards that. It's extremely important, especially with breast cancer in minority populations. Just with your work with the navigators, you can see how that is showcased.

Ariel: We are the not only ones with navigators. There are many hospitals across the nation, it's a popular model. But, you're right. It's a collective effort, and there has been a reduction to the disparity, but it's still at about 40% in Chicago for Black Women – people are dying every day.

Another piece is obviously advocacy and inclusion policy to ensure equity and access to health care and ensuring we have a safety net, raising the best quality of care. So this is what we advocate for every day and try to always improve on and get our message out there as much as possible and have our ear to the ground and know what exactly is going on so we can advocate efficiently and effectively. We actually had a policy meeting yesterday to talk about the Illinois Breast and Cervical Cancer Program (IBCCP) which is a state safety net program. A lot of the time the navigator will send the ladies who don't have insurance or are underinsured to access services through the program. The program is usually on the chopping block in terms of funding so it is one of our primary advocacy priorities every year.

People don't know about IBCCP, even providers. So, that's a big problem and we have some work to do in terms of ensuring that the state program that has been "appropriated" the money and its being allocated so folks can use it. And like I said, there is a huge gap in access to care for undocumented

ladies, especially with treatment. We are working to ensure we put as much emphasis on treatment as well as screening.

Amber: Are most of the women you interact with from Chicago?

Ariel: Not all of the women. Some of the women are from the suburbs, we are the Metropolitan Chicago Breast Cancer Taskforce, so while most of the women are from the city, we also serve women who live in the collar counties.

Amber: Are there certain neighborhoods or communities that you're seeing a number of clients from?

Ariel: We are definitely focusing on women of color – African American women, Latino women, and Asian-American as well – but primarily African American and Latino women on the south and west sides of the city, where we see the highest mortality. But, anyone who calls and needs our help, that's who we help.

Amber: Do their doctors refer them to the Task Force?

Ariel: Our outreach is folks who know that we exist and help women who do not have insurance. I'm not sure where we are in awareness of primary care doctors and if they know about IBCCP, and that's a problem. That's why we have a dedicated outreach worker who goes to laundromats, bus stops, barber shops. And, what I'm working on now – the Advocacy Council – is a grassroots leadership program for women who want to get more civically engaged. We are looking to recruit more ladies and we are starting up in a few weeks for this year's round.

One of the points that came up in our last meeting is the persistent lack of awareness about the breast cancer disparity in our community. There are people who are not plugged, and these are the people we want to help disenfranchised populations, folks who are not engaged in the medical system.

I was just talking to a colleague about how there is a lady who refused to get navigated and her breast cancer was highly invasive – like externally you could see she had cancer, that's how far along she was. There's a lot of mistrust in the medical system in the African American community. Fear and misconception, that is what we are fighting. Through the advocacy council – which is grassroots and comprised of ladies who live in communities on the South and West sides – we aim to identify spaces in which a high level of engagement with community members who may not necessarily be connected to the medical system could occur organically.

Amber: Are the women in the council generally past patients or women's health advocates?

Ariel: A little of both. Actually, the majority of the council are survivors. It's self-selecting. There is one lady who is not a survivor, so that's just a testament to someone who is really activated. It's just a mechanism to support women and hopefully gather and share tools. I'm not the expert, but let's gather together and work together to educate our communities, our neighbors, our friends.... Not just about us, but the services that are out there because women don't know about them.

Amber: At what age are you supposed to receive your first mammogram?

Ariel: It's 40. There has been a controversy because there has been conflicting guidelines that have been put forth. We advocate for screening to begin at age 40 unless you have family history, which would suggest to get your baseline mammogram earlier. Let's say a first degree relative – a mother – had breast cancer at 40, then her daughter should get her mammogram at 30. We definitely advocate for 40 because we know the population we work with have more aggressive breast cancer earlier in life, and pushing it up to 50, that doesn't jive with our message and what we know. So, it's tough. And different organizations follow different guidelines.

Sarah: Was there a moment or experience you had that made you want to go into health equity?

Ariel: It was probably a little that my father is a physician, so I grew up helping him in the office, but I never was like, "Oh, I want to be a doctor when I grow up!" I think just getting older, that exposure of working to support people access healthcare and have a positive experience while doing so probably seeped into my unconscious mind. I asked myself, "*What can I do where I can help people and be of service?*" and here I am, doing work that is life affirming.

Amber: Did you have any significant mentors?

Ariel: In undergrad, not really... Of course, I had great professors who I sought encouragement and guidance from. It wasn't until I began my professional career that I truly understood the value of great mentors. I can say I have several people who I consider mentors, unofficially and officially who are in public health, the nonprofit sector, and philanthropy. They've encouraged me to take on leadership roles. I would definitely encourage young professionals, especially women, to secure a trusted mentor. It's good to get honest feedback in a safe space, I think that's extremely important.

Amber: What would you say best prepared you to take on the health policy and advocacy role?

Ariel: Honestly, I would back my navigation experience. I believe it's really important to have first-hand experience working with folks day-after-day. Listening to their struggles and frustrations to really understand the intrapersonal and community level barriers, not high level all the time. I would say that the first-hand perspective really helped me to solidify and clarify for me why policy is so important, because that's the foundation for systems.

Amber: Right? How would you advocate for a policy if you aren't speaking to women and really trying to understand their day-to-days struggles with breast cancer.

Sarah: With your different roles here, has there been one particular lesson learned that sticks out to you?

Ariel: One lesson I've learned is to not take things too personally. I learned from originally learning from working as a navigator, to expect to encounter different personalities and frustrations. There are issues in the systems – we're talking about policy – and working within the system to get something that they need and sometimes encouraging people to consider something that is beneficial to them.

Also, I am always checking in with colleagues from different communities to make sure that we have the correct message and that we are understanding what is going on and what's happening on the ground. We can have our perspective as the Taskforce but we need to make sure we are doing our part and ensure we are expanding and learning from all sides. For example, undocumented ladies are something

that I am learning more and more about because primarily, we talk about the Black and White disparity. There are gaps in terms of stabilized data in Latinas. So that's something that I am learning. There is always room for improvement. Are we hitting all the bases in terms of need?

Amber: What are the biggest barriers to improving breast cancer awareness in Chicago?

Ariel: I would say access of quality of care and funding. We know the city has released a lot of funds for screening, but helping ladies getting access is the issue. It's leveling the playing field for women who don't necessarily believe the risk applies to them, or believe mammograms will help. There is a lot of information out there. We love our community partners and we want to make sure women have access to the highest quality of care. We've seen barriers in terms of implementation of legislation that has been passed that will expand the quality of care. For example, women of color – especially younger African American women – have dense breasts and mammography is not sensitive enough to actually distinguish cancer from normal tissue in dense breasts. There is proposed legislation that calls for women to be informed that they have dense breast tissue – this information can be used to empower women. Knowledge is power.

Sarah: So talking about the future of health equity in Chicago, are you optimistic or pessimistic about the future?

Ariel: I'm definitely, optimistic. We have so many organizations like the Taskforce working in tandem to mitigate this issue. We're not the only folks doing navigation and really hitting the streets and talking to women. There are so many folks doing outreach. I am optimistic we will continue to reduce the disparity. The African American community and the mistrust, all of that is generations of adaptive behavior due to circumstance and experience. So, that's something that will be an on-going struggle, but I'm optimistic that the more we get out there and have folks feel activated enough to speak about their experiences and talk about family history, for example, the more progress we as public health professionals can make in partnership with communities.

Amber: Do you have any advice for those newly graduated who are just starting who are just starting their careers?

Ariel: Unless they know exactly what they want to do, I would say collect a broad range of experiences. Those broad range of experiences in life and public health will serve you well in whatever position you are in. Whether it be internships or volunteering. Having a broad understanding of community is extremely important in becoming a well-rounded professional. And going back to mentorships, is really important to have a mentor. It may be little nerve-wracking to reach out to someone you may not know, but you may be pleasantly surprised by how friendly people are – so just reach out and introduce yourself as someone interested in learning more about their given field. Set up informational interviews, most people love to talk about their work. Attend events, attend talks on subjects aligned with your given field.