

ATTACHMENT IV. Notes from Advocacy Organization Panel

Gail Christopher- Joint Center

Joint Center is 30 years old. It is the only advocacy group looking at African Americans and policy. Historically, the Joint Center worked on economic issues but in last 10 years, with funding from WKCF, it developed a health policy initiative and established the Joint Center Health Policy Institute. Our focus is on how social determinants affect health disparities. The mission statement of the Institute is to ignite a Fair Health Movement, building on Movement, look at our 7 areas of focus.

I have two illustrations that show the intersection of policy research and practice:

Manufacturers are required to list the % of trans fats, which are associated with infant mortality, cancer, heart disease. It took 20 years to get manufacturers to let you know how many trans fats are in the foods you eat. Now, just drive down an urban neighborhood and look at the trans fat sources of food. Now what research do we need to look at in health disparities.

Cradle to prison pipeline and disproportionate impact on young men and increasingly young women of color. We are doing research to show the effect of the policies that have been put in place to warehouse our young men of color. A report being released today showing the failed system of prisons and the need to break the cycle of cradle to grave.

We have a sense of hope, there is a movement that embraces social determinants and is working to bring health equity and social justice.

Phil Tegler – PRRAC

We are a small non-profit civil rights research organization founded in 1989 by several organizations including NAACP, (etc.). Our purpose is to connect social science research in policy and bring a race perspective to the field of poverty law and bring a racial justice analysis.

To better connect research and advocacy really means understanding the mechanisms of structural racism and developing a better understanding for example of how health disparities affect the educational achievement gap.

Researchers need to plan their research with advocacy in mind. PRRAC has a small program to fund social scientists that do this. This helps to answer the questions that lawyers need. This program helps researcher learn to translate research into policy.

Health disparities, housing, education policy is what they are working on and is funded by WKCF. One of the main focuses right now to add value to health disparities discussion is the role of place in health employment, victimization, criminal justice housing outcomes. Poor segregated neighborhoods are one of the main mechanisms we have developed to perpetuate health disparities and are the direct result of government

policy and some of it was intentional. The research of David Williams informs this work and so is the work of Dolores Acevedo Garcia. We're interested in sponsoring this kind of work. At lunch, I'd like to do some brainstorming to connect the health disparities work to institutionalized racism work. I'd also like to bring the housing mobility work into the health disparities discussion. For example, children who are impacted by their housing, we'd like to explore helping families move, voluntarily to a better environment.

We have a bimonthly newsletter, which in addition to our small grants, is a great way to interact with our organization: poverty & race, if you would like to get your work out to a broader audience, particularly to the advocacy community, I'd encourage you to submit your ideas for publication to us.

Brian Smedley – Opportunity Agenda

Through this program, you are exposed to a wealth of ideas and people. Assembled in front of you are people who have been working for many years on health and social justice as well as translating research into policy. So the question is how do we help you and how can you help us to engage and broaden the social justice movement. This is an exciting time for health disparities research despite the political climate. Science on this is developing rapidly, the state of this literature has developed so that social science is way ahead of the politics

Media coverage is improving even if it is problematic. It focuses on the individual while we know that we can contradict this reduction perspective on individual behavior. It is also presented without context, for example, that African Americans have a more aggressive breast cancer. Out of context, people might assume genetics and biological race. For example, targeting drugs such as Nicromed at African American patients. It's a huge responsibility to counter this misinformation and educate the public.

The Opportunity Agenda, - From my IOM work, I realized that reports are not enough. You need to consider the ways that policy moves because ideology trumps science in many ways. So I determined to hook up with other folks who are trying to identify policy levels and create policy change -- links civil rights, human rights, public health, social science.

Working at local and national level:

For example, in NYC they are working on a local pressing issue, there is a state level commission to "right size" the hospitals. But in central Brooklyn, this is not the case. We believe health care should be "Rights" sized to meet the needs of communities. This commission will be coming out with recommendations December 1. Linking research, communications, and advocacy in this situation to show that "place" is important and show that this health care system is already inequitably located in this community. They are mapping the distribution of primary care and helping advocates frame messages. We will help identify legal and policy levers that advocates might use.

I hope that all of you in your work will engage with us actively. I know that you have challenges and have to publish in peer reviewed journals, but to really make an impact you need to get your research out in other circles.

Rea Pañares – Families USA

The vision for achieving our mission is to strengthen public programs, such as Medicaid. Minority health initiative, through our policy/think tank activities: policy briefs, also more grassroots work, through funding with WKKF. We also engage policy makers, leaders in communities, in discussions about health disparities.

We want to be thoughtful about our niche in health disparities work. First, we continue to work on the programs we are already engaged in to see how health disparities might be involved in them. Also, we are looking at other policies that impact communities.

We use research in its simplest form, we use it to tell the story. We build public understanding of the issues and engage policy makers. We also serve as a watch dog of research. For example, the media picked up a NEJM study which looked at quality by race and found that the quality of health care was mediocre for all. They looked at the actual study and found several problems in the methods. They created talking points for advocates, and actually the author agreed but the media wrote about different points. The researcher actually engaged in the discussions. As these messages come out that question the body of work about health disparities, we need to be prepared to counter incorrect messages in the media and such.

One issue we are working on is Medicare, Part D. We are having trouble finding data on who is enrolled. We have found data about who has drug coverage, before and after. The numbers are distorted and we can't confirm what the impact is.

Another area is identifying at the community level on what programs don't work and why and help in translating this for policy makers. Having expertise at the local level is integral to being able to have impact on health disparities policy.

Jennifer Ng'andu – National Council La Raza

NCLA is a civil rights and advocacy organization. We do some research but work on equity. We have programs to build the capacity of Latino advocates to carry out their missions. We do policy work at national level. Our health policy work has been around for about 10 years with the passage of welfare reform which disproportionately impacted immigrants.

The disparities for immigrant in access to health care still remain. We do research to determine major impacts – access to health care, cultural/language barriers, social determinants to health. We inform our work with primary research. For instance Glen Flores, studied use of CHOW to enroll people to decrease access to health care.

What we need is a comprehensive picture of the Latino community.

As a side bar, I want to talk about immigration reform. It will impact the health status of the Latino community.

Mildred Thompson - PolicyLink

We believe that all of the wisdom to do this work exists at the local level and we only have to help people get it into policy.

Our primary framework for looking at health disparities. See handout. Community factors of health. Only 10% of actual health is influenced by access to health care. Our research is focused on how can we use research and data to explain what is happening in communities with regards to health disparities

At a recent conference, one funder said that they were not going to fund programs for individual change until the conditions of the community change.

They also have a project funded by Kellogg, how did Community Voices make changes at Morehouse University.

Also funded by California Endowment to train grantees to advocate for change. Similar effort to reduce obesity. How can you make changes in access to food in communities? How to make this real in peoples everyday lives? People are learning to speak the language and feel some power and momentum to make changes in policy affecting communities.

We publish reports for example what leaders in communities think can be done to reduce health disparities. All of these reports are available on their websites.

We were very involved in the publication of the Covenant with Black America, which is very down to earth.

Makani Themba-Nixon – Praxis Project

The best policy starts where people's vision is, not solving problems. Getting ideas on the public agenda requires communicating on three levels: setting the fire, building legitimacy and vetting the details. Issues are layered, for example health disparities. Color blind is okay if people are not privilege blind. That is the current context of this debate, there is an historical context such as race of a biological construct and the invisible history of privilege and oppression.

Strategic “Bop gun” communications hitting it from all sides. The right is telling stories about what they have discovered. They are framing this story in the current context.

If you don't remember anything else I say, ASK QUESTIONS THAT LEAD YOU TO THE STORY.

Toby Citrin – This panel gives us some direction about how our joint program can proceed to implement this new joint program to translate research to policy.