

ATTACHMENT V. Notes from Advocacy Organization Breakout Groups

- **Gail Christopher, Joint Center for Political and Economic Studies**

GC: Introduce yourself and tell us why did you pick this session?

LWebb: I get your magazine – *Focus* – you write about issues on which we work

Gishawn Mance : incoming JHU – to gain more information

Wilma: Mentor to Davida Hammond – I’m following her around

Israel: Given the work we’re doing in Detroit – translating research findings into policy – getting into issues of food access and air quality – what you said resonated

Davida: Interested from your intro and working on air pollution policy

Karen Rogers: working at Children’s hospital

Mansoureh: UMA/Lowell – very interested in looking at c-based organizations’ research applied to health policy

Kalahn Taylor Clark: graduating today from Harvard – I wanted to be here to put together educational module to look at public opinion and media

Lester Spence: finishing up postdoc. One grant we recently secured is from CA

Endowment – to design an inclusive approach to disaster response – result of work done with NY Academy. Roz Lasker predicted what would happen in a disaster with respect to marginalized communities. Challenge: You’ve done the study – but if it doesn’t translate into practices in the community - - - we’re trying to connect the dots – we’ve just seen a new health disparity (Katrina) – people of color face a greater risk of harm from disasters – same determinants of that disparity cause health disparities. How build community capacity to address this?

Linda R: We’re cutting the disparities in half – we think we have some strategies that would be helpful to the world. Partnering with the Joint Center.

Q: (Spence) – you gather data. I’ve worked on black empowerment. I’ve talked with Joint Center to get data on black elected officials. Could you talk about some of the data you could provide to researchers?

GC: The political data isn’t under my shop. But we probably have the country’s only database on black elected officials. We do an annual update and annual poll on black voting practices. We were the first to predict the increase in support for Bush in the Black community (and there was tension as to whether we should report on it); now we’re exploring what’s happening and why that occurred. We have a special project in terms of faith-based leadership and the effect of money.

We conduct a national poll every year. The Joint Center is connected to U.S. Census database using the ‘Data Ferret’ system. The former director of minority & diversity data now works with us (Dr. Roderick Harrison). Our central project – “place matters” – we’ve identified the 149 counties where the greatest concentration of people live – social determinants indicators – developing capacity with funding from Ford to issue special reports to individual communities. We’re reporting to counties. We now have 120

indicators; narrowing it down to 60. We want to get data from local health departments and disaggregate it faster than having locals send to state to fed and back to us. We've identified our first 20 counties; asked them to send 4 leaders; determining which disparities we're looking at.

People from traditional PH will assume that increasing vaccinations will improve health; but we need to expand their thinking about disparities to include social determinants. One tool is the "Place Matters" publication and the indicators set we're using.

Each year we'll bring in 40 different teams. Annual publication to track progress, with narrative pieces written by scholars like yours. Some of your research having bearing on social determinants which would be valuable to us.

"Cradle to prison" project – with Dellums.

We're also taking what seemed like a radical approach to infant mortality – "Courage to Love." The underlying theme is the seemingly intractable disparity not just access to medical care or physical environment but the quality of the relationships with the expectant mothers and its effect on fetal development.

The relationality rationale is best described by data on what's the leading cause of death of expectant mothers – it's homicide. This issue of unwrapping the most significant aspect of our humanity in the most significant time (birth) is what our researchers and our team has been bold enough to do. Linda Randolph has put in place a program to mitigate these problems. They provide the "care" and "nurturing" becoming a surrogate for the fractured relationships – and reduce infant mortality by 50%.

Linda: It's a nursing practice model – nurse midwives and pediatric NP's – providing care across the continuum – well woman care before pregnancy; care afterwards. It also includes pediatric care to age 21.

Also one of the methodologies we're using is "Centering Pregnancy" – the group prenatal care model. We group women by their due dates and they come together for prenatal care according to their expected dates of delivery. They bond as a group discussing what's happening to them. The curriculum is their issues at that visit. Also the self-care component of nurse midwifery – they take their own blood pressure and write it into their own chart is empowering. One woman felt she was "managing her health care" because she had access to her chart.

Our Birth Center – the only out-of-hospital birth center within DC – initially 10% of women delivered there – now it's almost 30% - as the women who've delivered there talk about their experience of natural birth and all the supports.

O.B.'s don't deliver babies; midwives don't; "Mothers deliver babies" and the O.B.'s or midwives "catch".

The Center also includes an infant toddler child development center. Moms who deliver there have priority in this center. And we have a Healthy Start program with supportive services.

Christopher: The Joint Center's challenge as a researcher is somehow to get this amazing model in front of decision-makers and policy-makers in a context they can understand, to get this into policy so it's done everywhere.

[She almost lost her second child – was taken to the hospital – overheard doc say that she's Black and I assumed she's on Medicaid.]

The relationality rationale behind our work is gaining momentum. The other critical relationship is the breast-feeding relationship. African American women breast feed less than other groups. We have a researcher on board looking at this, and looking at the various barriers inhibiting African American women from breastfeeding.

Other area: Human genome variation. This idea of race-based medicine and the Human Genome is around the corner. We need to get in front of that. The Joint Center is working with Howard University and others on this. State Legislators need to be informed. "Mastery is a progression from the complex to the simple." The genome discussion is simple – we're basically all the same – but it's not the implications of the pharmaceutical industry. BiDil needs to be used to show how NOT to do this.

There will be individualized health care. Ultimately the differences we have are not race differences but race differences. Will the responses be so costly that we won't be at the table?

The protection of privacy legislation still is stuck in the House.

We must change the face of Congress. Wherever you look – if Congress doesn't change, the philosophical driver for this current administration is one of dismantling the federal government as we know it. There's no more important work for any of you to do today than to work on what happens in this next election. The evisceration of the social policy framework that took decades to build could be gone quickly.

The thrill of being at an institution whose history has been political empowerment; to bring the health agenda to that institution; is a wonderful opportunity.

Partnerships are difficult – but I believe that the combination of what's happened over the past few years; the war in Iraq and what we saw in terms of abandonment of domestic responsibility in Katrina have served to galvanize the progressive community to find out how we can work together.

Mansoureh: Having lived in NC and seeing the voting pattern still causes a shock that people voted for the candidate who supports the injustices because of the religious thing;

the abortion and gay issues. The gay rights issue was timed to put on the ballot along with the national election. They knew what the hot buttons were.

Israel: The weekend before the election, colleagues of mine got phone calls saying vote for Kerry – he supports gay rights. These were targeted in the African American community.

Spence: In the last election the most important thing was voter turn-out. There will be spoiled ballots. If you have people gaming the electoral system – the states where the ballot issues turned up are the ones where there was a close vote. Are there orgs like yours doing study on this issue?

Q. Do policy organizations do anything with the public to disseminate information? For instance the Democrats have to have 90% of the Black vote to win an election?

Christopher: Not enough. Whenever you wear a non-profit bi-partisan research hat there are some constraints on how you can advocate for the public. Yet look at the NAACP and what happened to them? The Advocacy Groups can do much more. We compared the positions of the candidates; we bring together the leaders of associations and groups; but all we can do is educate.

LR: Where's the outrage?

GC: The outrage exists. If you look back to the civil rights movement the black press was a very effective tool for those issues and the Pullman porter issues. That press was different then compared with today. But we started worshiping at different altars as we got more commercialized, coupled with integration dissolving our communities, destruction by gun violence and drugs, you don't have the young people with the time to be leaders. There's been a fractionalization of our community. But it was only a handful of young people behind the civil rights movement, coupled with a charismatic leader.

A: We didn't have the fabric when we were growing up to understand the movement.

- **Phil Tegeler, Poverty and Race Research Action Council**

No notes available

- **Brian Smedley, The Opportunity Agenda**

Smedley wants to use research on communications strategies in his work.

Discussion of ways to link scholars systematically with advocacy organizations. CT track is already connected to community. How do we connect with advocacy groups?

Example: At Michigan, there are instances where you have these kinds of connections.

MD track question from new scholar at UCSF – Brian recommended a group to connect with in that area.

Example: earlier work on relating hospitals to community need would have been useful now when the Closure Commission is taking off in NY.

Shawn: How do we develop a structure where we can have these kinds of discussions?

Smedley: Looking at the groups on the panel – we haven't been engaging with or building bridges with scholars. I may be the only social scientist who was on the panel. Links between residential housing and health – David Williams has done work on this – and if you ask people about causes of disparities, they'd answer that it's behavior. Phil Tegeler and I are working on this issue – the mechanism of housing segregation, housing discrimination, red-lining of mortgages – may help serve as a base for what others do. But you all are producing incredible knowledge about this issue.

Q: Our program has 3 papers. Thinking about publishing. Research is about opinion making – if people feel it's individual behavior, they'll be less likely to support government's doing something about the problem. I have this finding. What do I do with it? Where do I put this? It's political science – can't go into that easily readable policy journal. I want it to have policy weight.

NOTE: As Smedley responded, this kind of work is of immense value to an organization like his. There are groups hungry for this kind of information --groups that would begin to run with this. Smedley doesn't have a good answer but hopes scholars will work with him and his organization. He advised that career considerations have to come first. It's hard to sacrifice that.

BS Question to Jeff Guidry(representing Lovell Jones): What would you do with this kind of paper?

Take JHPPL; Public Health Reports; Journal of Politics; it's not quite political science.

Downing: Psychology might be interested. Applied Social...and Policy (ASAP) – online journal

Guidry: Check what the impact factor for the journal you select is. If you have time, you can get into the advocacy activity.

Q. If you have that kind of paper, do you dumb it down – tailor it – to make it translatable?

Smedley: Those are important questions – no easy answers. I'd like to see more of you write Op-eds – submit pieces to Phil T. for his newsletter – it goes to a network of folks who can use the work. I'd love to have some of you write stuff for our web site

Shawn: How does an organization like yours make it easier for all of us as scholars, structuring new projects, to answer the questions “what are the questions that advocacy organizations want answered?” How can you help us do this?

Smedley: That’s exactly what we hope to do. We want to establish some convenings; interdisciplinary among scholars; to help scholars out with these questions. Often these questions are of critical importance to policies being discussed today. With the CT track you already have some of that. It’s helpful to find out what the advocacy community is asking. How can you – even by yourself – contribute to the public dialogue? That distracts you from your task of getting tenure – but you can become “public intellectuals.” It’s important for scholars to be aware of the operation cycle for major legislation and ask how your scholarship can be made useful in this development.

- **Rea Pañares, Families USA**

Attendants: K Kim, S Kwon, K Hanson, M Spencer, L Randolph

Families USA produces a document of activities in the field for elected officials so that they know what’s going on in the community.

How can we get services that we know are effective with our populations? We need policy makers to help with funding or reimbursement. They should also know that these services could save the managed care companies money. For example, who pays for language access in the healthcare system? Only a few states are reimbursing this service, but we know that it’s a national problem.

Families USA is a voice of the healthcare consumer. We want to inform government how health policies impact the consumer. They build public awareness of the issues of the constituents that Families represents. Folks who are leaders in their communities need to know what the health disparities are in their community. Most people don’t know what health disparities exist. We are trying to build public awareness. We don’t have the resources to break down the research jargon.

Most of the attendants here had never heard of Families USA. And the name sounds “right wing”. Rea explained that originally their name was Families United for Seniors Action (USA). When the focus of the organization changed, they kept USA.

How do you get the word out? Newsletters, listservs

- **Jennifer Ng'andu, National Council of La Raza**

No notes available

- **Mildred Thompson, PolicyLink**

How to get people to talk about broader topics?

Politically limited how far you can push your own agenda, how does all of that work?
How do you frame the discussion so people do not react negatively based on what they think you mean by certain terms?

Health disparity requires a different language. What words, analogies do we use? Is the term functional or does it isolate certain groups. Maybe, we should change the terminology. Stop using the language and talk about what you mean to talk about. Talk about poverty; don't couch it in other words. Disparity term draws a line.

Community plays a critical role in health disparity. How to position conversation where it is not an "us" or "them" debate is crucial. Be clear on the distinction of the words that get you in trouble. Often the terminology drives us away from action.

How to make substantive changes in communities that cross over into other issues?

Race and ethnicity, are overarching issues, that trump all issues, if you don't address these issues than dealing with the other issues don't matter. Economic conditions are as critically important as race. Take a look at specific incidents you are addressing

What are all the factors that contribute to health disparities, access to health care is one piece but not the solution. Advocate for community based care; integrate health so it is not seen as a separate entity.

Mildred: how can PolicyLink be a resource to you?

What questions remain unanswered? How to help with fit or evidence?
Helpful to have more studies on how people live in certain communities have health consequences. How public health departments work with planners before they construct new communities?

Important to know that agencies such as PolicyLink are accessible to us, if we can work on developing multidisciplinary teams.

How do we change curriculum to affect this approach?

You are the new leaders and willing to take risk for research to take broad view. How do you begin to use your voice to change? Everybody must work together. Figure out how to change the conversation, educate people about new information. How to engage them without alienating them? It's all about relationships.

- **Makani Themba-Nixon, The Praxis Project**

Praxis Health Agenda – Praxis works with local groups in responding to local group’s interests.

Initiative What is happening at the county level, re: health care financing, health care access, etc, to develop a model for universal health care program at the community level. (Alameda and Contra Costa counties). Objective: to get a ballot initiative for a community wide vote on a universal health program for those counties.

Initiative Looking at tax structures to finance chronic and primary health care.

Initiative Web-based community report card (Health Care) National Data Set

Q: Does Praxis work to link communities to researchers and other resources related to research?

A: Praxis does attempt to identify researchers and facilitate the linkages (e.g., Miami, Florida)

Q. How do you go about getting out effective communication messages (going beyond publishing in peer review journals?)

A. One strategy is to involve “celebrities” in advocacy efforts – go beyond using celebrities as mere spokespersons. Communicate and inform prominent spokespersons (musicians, entertainers) of research in an effort to have them become advocates. It has worked effectively.

Q. Is there any value/what is the value of publishing in peer reviewed journals.

A. Yes, we need to communicate at all levels. Journals are a necessary fact because they are codified by academicians.

Q. Value of ethnic studies departments, etc.

A. Provides “institutional infrastructure” for the involved population to promote scholarship re: race and related issues. Provides an “institutional” home for scholars of color, etc. Without such “institutional homes” for this scholarship it allows others to develop and interpret the research:

Comment: Failure of public health research is that it does not always reach across other non-health disciplines. Researchers/scholars of color often have “social networks” among which they can forge professional academic relationships. Must begin to see the power in drawing upon their social networks and how those relationships can be used to advance advocacy.

Q. How to write an effective grant that goes beyond/outside traditional research paradigm and still gets funded.

- A. Think about applying to more “flexible” sources of funding.
- B. Don’t only apply to RFAs.
- C. Most appropriate ways to do this is getting invited to the table where the ideas behind the RFA/RFPs are being developed. Get invited to the decision making table.
- D. Important for people of color, women, etc. are a part of the initial planning.

Q: How do you guard against the popular media “reducing” your research to a sound byte?

Considerations:

- ❑ Being savvy in interactions with journalists. Think about what you are going to say before you get to the mike.
- ❑ Think about the dissemination of your research (the “picture”) before hand.
- ❑ Need to work with journalists so that they understand the story.
- ❑ Possibly should add media training to CHSP training. E.g. Peggy Toy at UCLA teaches the DATA Program. peggytoy@ucla.edu
- ❑ Media justice movement asks:
 - How the questions are framed
 - Who is asking the questions?
 - Who if interviewed, who is asked the questions?
- ❑ Training with academics: Challenge for social justice, health justice researchers is to change the current discourse. Any media training must include strategies for reframing the discourse (e.g., From health care as a commodity to Health Care as a basic right.)
- ❑ STORIES TO TELL
 - Important to remind people of where we are making a difference
 - Of where there is cooperation and collaboration among races.
 - Of where there is hope.