

## ATTACHMENT II. Notes from Presentations "Using Research in Policymaking"

### **HON. DONNA CHRISTENSEN**

Welcome the KHS's – opportunity to make a difference through your research.

Congratulate CFAH and Krimgold and Co-Director Toby for putting on this program – continuing to give us the kind of expertise that helps guide our policy.

Taking research to policy is a major challenge especially on Capitol Hill. The work of the Congressional Black Caucus and the Tri-Caucus – this is where our work comes together – on the elimination of health disparities depend upon scholars for the research as we use push our initiatives.

I've had Dr. Natasha Williams, a Geiger Fellow, in our office this past year – and recognize Dr. Jack Geiger and the Geiger Fellows Program. She's helped us to develop our legislative initiatives – like the Health Care Equality legislation – responding to the inequalities report, legislation to address those without English language skills, and offices within HHS, like OMH, Office of Civil rights, etc. We have also developed the KARE act – responding to Katrina.

I've been fortunate to have excellent staff – e.g., A.J. and Brett Weinstock, who's with us now and was formerly with Families U.S.A. These staff members are the ones who translate research into policy, work with our research arm and are in touch with our communities. They also take the heat for policies we work on (e.g., A.J. took the heat on the Medicaid Commission bill). When we tried to do the Medicaid Commission to delay the cuts in Medicaid it created many problems in the Energy & Commerce Committee and A.J. was the scapegoat for that.

Led by Mike Honda when we launched the Health Care Equality Act – we hoped the Senate would take action to address disparities. We're at a starting point on this now. If we get any bill addressing health disparities it will be meaningful.

Our Lou Stokes Fellow has also been intimately involved in reauthorization of Ryan White Care Act.

It's been said that legislative bodies are the greatest threat to health. It isn't always that research determines what policy is. We see research from CDC on the effectiveness of comprehensive health messages on AIDS prevention, yet we have legislation promoting abstinence. We know that needle exchange programs are effective in preventing the spread of HIV/AIDS and do not promote drug abuse, yet we can't get the ban lifted on needle exchange. And there is an aversion on the Hill to dealing with minority health issues – it often brings the accusation of "playing the race card." When we were considering the bill to establish the NCMHD, the bill was removed from the floor for a while because it used the word "minority."

We have a barrier to developing the political will to deal with these issues. In addition to the research showing what the disparities are and the impact of those disparities, we need research on how to overcome the aversion to dealing with these kinds of issues – and how to overcome the aversion to dealing with “minority health.” We need research on what Members respond to.

Some of the research that we’ve been asking our partners to do is on the economics of health care – how to make the economic case for addressing health disparities. What will get our Members and our leadership to respond?

We’re pleased to have the opportunity to have a new cadre of fellows to provide the important research that justifies, informs and guides our policy.

## **HON. MIKE HONDA**

### **INTRO:**

Chair: Asian Pacific-American caucus; coordinating with allies in CBC.

His passion for civil rights. Personal story – as a child in CA he was interned with his family in the U.S. internment camps for Japanese Americans. He has channeled that into a passion for civil rights, racial justice. He leads the CIPAK group [sp.] and an Advisory Committee member of the Geiger Fellows.

### **HONDA:**

Dr. Emily Ihara – a Geiger fellow – is on my staff. When she was checking out offices where she’d land, I found out what her background was. Being Asian was a big factor. I wanted to have her on my staff. Her area of study is critical for our office. Working with Dr. Christensen, the Brain Trust, it was important that she was with us.

Disparities are about lack of understanding even within the communities. The kinds of programs you’re involved in, linking research and policy to its practice and applications, is critical. As an elementary school teacher, I understood the link between our school nurse and the attendance of our students, who were mostly from immigrant families. We needed to understand who our communities are and how to serve them in a dignified way.

Listening to Dr. Christensen – those of you who are working on disparities – the linkage between research and policy is critical. We all come to this point with the collection of all our experiences. When we look backwards and forward, we still find spots that are “black spots” because our experiences don’t give us lenses to fill those gaps. Groups like yours help us overcome these gaps and become more adept in addressing disparities in health.

Women say to us men – when you do research don't do it just on men and extrapolate on us – do research on women also. We look at our communities both physically and in the way they're structured. We can start to see where the disparities are.

The Tri-Caucus (CBC; CSC; CAPAC) and the other caucuses (e.g., Native American) can leverage to get the attention of leadership and the public. We number over 70 Members in the TriCaucus.

Some people won't be convinced even when you give them the information. We put a bill together dealing with those who don't speak English and were harmed by Katrina – but some still don't get the importance of communication in the delivery of health services. Perhaps, they should be subjected to health care in a language they don't understand. In Alameda County there was a Hmong man who was supposed to have his leg removed – the doctor asked if this was the proper leg – the patient didn't understand – and the wrong leg was removed.

One of the things I've learned is the impact of Hepatitis-B to our communities. I took part in health fairs and went to the screening. The fear was greater in not knowing that drove me to be tested – so I could make decisions on maintenance, immunization, etc. Luck had it that the test was negative and I'm now going through the immunization process.

When we talk about diversity and apply that in the field, it's critical that we teach each other. "Each one reach one; each one teaches one".

Thanks to the Foundation, scholars, mentors, for doing what you're doing. I'm not an expert, but we do have staff to translate research into policy.

Dr. Ihara will be teaching – and now has had experience in a policy office. She knows what the gaps are – can teach students to be more effective h-care workers and teachers.

## QUESTION AND ANSWER

Q: (Pokras): In our immigration workshop yesterday, we discussed what your views are about this obsession about English as a National Language – do you see that going anywhere?

Donna C: To me it's one of those political issues that have very little meaning for translation into policy. They were careful not to make it an "official" language but to call it a "national" language – but legislation like that can be a first step toward doing something further. It's a part of the way the whole immigration debate is going. One bill we worked on was the one that requires passports and birth certificates applying to Medicaid – another way to come sideways at an immigration issue. We're seeing lots of legislation like that. Today the Tri-Caucus staff will be meeting to develop strategies to push H.R. 5023 – to try to rescind that provision.

Honda: The issue in itself, for me, this movement of English-only is stupid. Some of us members of the community are responsible for stuff, too. Hayakawa was the one who started the English-only movement. He's a semanticist. He was a scholar in that area, but NOT a scholar in politics or history in this country. He probably has a different vision of this country. It's all play for me. To me, English IS the official language of this country – language of commerce; of instruction; but NOT to the exclusion of other languages. People come here from other countries and speak English. When we go to other countries we need interpreters. The idea of having more than one language should be something inherently American and global. People pride themselves that this is the only way to be American. This is plain racism. We have to embrace all the other languages to be global partners, competitors, to be marketable, and not to be ashamed of our language.

Christensen: It is difficult to deal with any legislation with the word “minority” – this is all part of this same atmosphere that makes our job harder and the need for our researchers more important.

Q: What do you expect the next version of the H-Care Quality and Accountability Act to be? What do you expect from the Senate?

Christensen: There was a large disparity between their bill and ours earlier. We've singled out a few main things that need to be in the Senate bill to get our support:

- Health workforce
- Language
- Health empowerment zones
- Urban Indian Health Program

We'll work to improve our version. The bill comes out of all the meetings we have about partners, the work of fellows, and community organizations that meet with us. The revisions made in the second introduction came out of these discussions. We invite you to take a look at H.R. 3561 and make your recommendations. And we invite your advocacy to get the bill passed and as much as possible of our provisions to get into the Senate act.

Honda: Being a staffer can drive the policymaking in this country – to the extent that we have good staff that are scholarly and help us shape policies it helps our offices. It's important to have people like you on staff – that's what drives us toward providing the kind of health we want to see. Our job is the art of compromise. How much can you compromise in the area of health? If health care were like math, we'd be precise. But it isn't. But if we did math like we do policy, we'd never be on the moon.

## **CAROLYN CLANCY**

My main message: Data do make a difference in policy making

1. Disparities research and policy making.

NOTE: Christensen's point that research alone isn't enough.

AHRQ puts out two reports a year – Quality and Disparities

We believe an important contributor to the Unequal Treatment report was an article in NEJM – having actors portraying patients and making videos. Because it was an experiment it was carefully controlled. Actors used exactly the same language. The doctors were significantly less likely to recommend evidence-based treatment for older African American women.

People know about disparities in health, but the fig leaf people cling to is that once people get through the door people are treated equally. That study and another in the V.A. system challenged that belief. And anyone studying Katrina learned that we have a lot of work to do.

We're going to have to redefine the term "minority". In CA, minorities are the majority. In D.C., it will be true in 2010. Yet for a lot of Members these demographic changes aren't happening.

The mission of the Agency is to improve quality, safety, efficiency and effectiveness of health care for all Americans. We felt it was important to link the quality and disparities reports together, even though the requests for these reports came from different portions of Congress.

Why is it important to link? Every study of quality of care finds there's a big gap between best possible care and the care that we all receive – a gap that's larger for racial/ethnic minorities. If we link the two reports, this belief will be challenged.

Distribution of the uninsured is also relevant.

8% increase in health expenditures occurred while quality improved 2.8%.

In areas where there's lots of public reporting, there are bigger improvements. We saw 10% improvement in these hospitals.

We've started to see some narrowing in disparities. For the first time, we've got reports that track every year. For Latinos the news is not good. Gaps in disparities in care and access are widening. Biggest disparities: Approx. 4x likely to be diagnosed with AIDS; 2X times to report lack of needed care.

It is clear that you're on a great track to help policy maker's deal with these things.

There IS value in measuring performance and stratifying by race and ethnicity. For HEDIS measures, researchers found that 7 of 9 measures improved substantially over the

past 2 years. Why is your merger important? The two measures where there isn't improvement is control of diabetes and lead – that's all about building better bridges between the providers and the communities they serve.

We have leaders in health care with whom you can work with who weren't aware of the pervasive problem. They're concerned that more people will complain about it.

Consider how we might work more collaboratively with NCMHD – connecting your programs with our agendas.

Targeting people on the ground in New Orleans has been challenging and energizing – they say don't reinstate the earlier organization of health care.

### **JUDY MILLER JONES**

INTRO: She's trained each generation of scholars into bringing new staffers on the hill a deeper understanding of issues:

JUDY MILLER JONES: In a nutshell – our program is the National Health Policy Forum. Our principal support is from Kellogg. We also receive funding from other foundations. Our goal is to help agencies to come together with House & Senate, both parties, to come learn together about health care issues. Because there's so much turnover in the Congress and the agencies, we do lots of briefings on health care policy (e.g., meaning of “cultural competence”; basics of the federal health programs). A major problem today is overload of information and inability to sort it out; also bitter partisanship so Members don't talk across the aisle – and only staffers do so and even that is difficult.

We're going to compete for your minds and bodies. We have the ability to bring people into the policy environment. Most of you are on academic tracks – want to prove yourselves – but for those who'd like to take a couple of years out to work with staffs on committees and in agencies – we'd love to talk to you about the possibility of working for us or with other policy organizations we relate to. You have lots of options. You should be very clear about the kinds of things you want to do in your trajectories. If writing if what you want to do, negotiation, advocacy, etc., or to understand difference between advocacy and analysis, I'd love to talk to you.

### **JOY JOHNSON WILSON**

I'm not a researcher but I talk to a lot of staff. I've figured out that the biggest challenge is to move from your silo of database and research and turn it into a form into something that is useful for the policy makers. Much of what I do is to take large research reports and turn them into 1 or 2 pagers useful to legislatures.

I encourage all of you to take a leave of absence as a state legislator to find out how this all works. For example, compliance, how do we get people to do what we know works? We need research on this. What are the barriers to patient compliance, what does research show? Let's take script limits, for any given client; you can only have so many prescriptions in a month or a period of time. Finding evidence on this is hard. Are script limits bad for everybody? Unless someone can point them to some information that disputes what they are being told, they say, fine.

Most health policy is done as part of budgeting. What can we afford, what won't be really bad? This is not what researchers want to hear. Often policy makers need answers to simple questions such as tuna – who should or should not eat tuna. And once we know, how do we get these out to the tuna eaters of America. And what is the tuna word? This is a policy issue and right now, there is a bill that says we should not put anything on the can. Would a sign in the grocery store work? What would it say? Who would read it? We don't know any of this right now and it affects pregnant women.

We have some evidence about whether certain drugs have an effect based on race, age, etc. Many people think this does not make a difference, but what does the research show. Between sessions, there are study sessions on issues and I invite you to volunteer for this commission.

We have many issues like this. What motivates people and how do you make it happen? How do you increase compliance for prenatal appointment? One doctor started a cell phone goodie bag program which increased appointment compliance in a Medicaid HMO contract.

There's that database stuff, and it's very useful, but you need to translate this into budget implications and translate these results into something useful for policy makers. Because that's where it all happens, how do you get your information outside of the hallowed walls where it can be useful to policymakers?

## **LYNN ETHEREGE**

Health Affairs – on rapid learning (on web first ) that will deal with problems of current evidence-based, and present dramatic opportunities for a whole new research agendas looking at large electronic data sets that will allow us to learn real time about the collective experience from real people.

The problems of evidence base are getting so large, that we are seeing it in the popular media such as Vioxx, asthma medication that may be the cause of 4000 of the 5000 deaths, ace inhibitors may be leading to many birth defects. We should have been able to nail these much earlier.

It has been found that several seminal articles that are highly cited, 30% are wrong.

So what will be done about the problems with evidence base? Whole new data bases are being created, for example in NJ establishing a database for 100,000 children. Kaiser Permanente is looking at a database with 2 million. So we will be able to look at genetics and such. Linking patient experience to problems in health will be powerful.

Predictive modeling, for instance in diabetes, computer modeling, is going to be a useful tool in looking at evidence based.

A key concept is the inference gap – the difference between the randomized clinical trial and the real world experience of patients. These trials leave out women, minorities, seniors, etc. This is a problem for the practicing physician and the patient. We are finding a wider gap because of the aging population using these drugs and there are little clinical guidelines.

We also have a large problem in heterogeneity of results. Even within the average results, we find wide variations and so it will be very important in the future to see which populations these drugs do work with.

We also have a credibility problem based on who is funding these clinical trials with the majority being funded by drug companies. The average typical research result is being reported as wrong.

Solutions: we're at the leading edge of this. KP is building a national research database with 8 million entries and new software system. This should be a great help to reducing the time to get results because it won't take years to build a good data set. Hopefully we are moving into a world where good data is readily available.

The VA will be another good source of data. The VA is talking with Microsoft about new technology.

Another major type of development is the National Cancer? Who has 10 million members and NIH sees this as the way of the future to have these large datasets and rapid turnaround on evidence.

In my paper, I outlined 7 policy issues that need to be dealt with. Why are health care costs increasing, what are comparative benefits and risks of prescription drugs? What is the evidence based for procedures, what explains variations in health care spending and use? How do environmental factors affect disease patterns? Minorities and special needs, what does this mean for patients like me?

The biggest problem is Medicaid. There is some work to be done to get a big breakthrough to get the database we need here. We also need clinical trials funded by NIH and required by the FDA to be put on line so that we have an accumulating database nationally. We need to be able to capture those research results accessible to all researchers. This will make the research available to researchers a hundred fold.

So I am envious of those embarking on a research agenda at this point in time. We also need to get the funding in place, I forgot to mention that, but we're working on that.