

**National Workshop on
Achieving Equity in Genetics Policy
through Diversity in Decision Making**

Co-Sponsored By:

Life Sciences & Society Program and the Center for Public Health and Community Genomics
at the University of Michigan

In Collaboration With

The National Human Genome Center, Howard University
The Joint Center for Political and Economic Studies, Health Policy Institute

FINAL REPORT

Purpose

On October 5th 2006 the **Genetics Equity Network** was launched at the **National Workshop on Achieving Equity in Genetics Policy through Diversity in Decision Making**, an event funded by the University of Michigan's National Center for Institutional Diversity. This event focused on strategies for turning genetics-related issue areas into action plans. Primary discussion areas included how genetics, racial/ethnic health disparities, and policy are inter-related, and how best to work in the policy arena to move toward the elimination of health disparities and the improvement of health for all. The workshop was attended by forty-two individuals representing a diverse set of 32 organizations which work on health disparities issues in communities, policy, and research. 35 additional organizations, whose representatives were unable to attend, have also indicated their desire to participate in the Network.

The purpose of launching the **Genetics Equity Network** at the Workshop was to assure that the ideas shared at the event would be turned into action. Such an alliance of diverse groups is essential amid the explosion of genetic knowledge and technology that influences research and health care. How this information is managed, who decides what and how to study genetics, and which technologies to develop for whom, are all key questions as their answers have powerful and meaningful implications.

Over the last decade, the Human Genome Project has stimulated an avalanche of genetics research that is consuming approximately 20% of NIH's annual budget. Francis Collins and the National Human Genome Research Institute are currently lobbying congress to raise 3 to 4 billion dollars to conduct a one million person cohort study on the genetic factors and gene-environment interactions that underlie common chronic diseases in the United States. Newborn genetic screening policies and adult genetic screening policies are expanding in scope yearly.

Not only are genetic screening policies expanding, but a variety of genetic policies are evolving and expanding rapidly, developed by federal and state government agencies, legislatures and Congress, private and public sources of funding for healthcare, and by corporations in developing and marketing genetics technologies. The leaders of these organizations are overwhelmingly homogeneous and reflect the relatively advantaged in society. Influencing this policy process are special interest groups and industry representatives that speak for those with rare genetic disorders or those in biotechnology who have a stake in the business of genetic advances and technology. Like the policymakers themselves, the leadership in these interest groups is likewise overwhelmingly homogenous and the relatively advantaged in society.

Advances in genomic research and technologies carry hope for the dramatic reduction of disease, especially chronic diseases and others traditionally detected through Newborn Screening Programs. There is little doubt that many of these hopes will become reality. What is not so clear, however, is whether these advances will be applied equally across society and the extent to which the new information derived from genetic advances will be used to reduce rather than increase disparities.

Diversity in the decision making processes of the institutions that define genetic policies is paramount to assuring fair application of advances, and is a necessary precondition to the application of genetics toward the reduction, and eventual elimination, of health disparities. Because the proliferation of genetic advances and policies is imminent, sustainable

engagement of institutional leaders, especially community leaders who have been left out of decision making processes to date, is essential. Unless we achieve a more diverse representation of society to participate in genetic policy making we are likely to repeat the troubled history of public health genetics –e.g. the sickle cell screening of the 1970's that increased genetic discrimination and stimulated the creation of marriage laws in two-thirds of the United States, or a repeat of the history of eugenics that applied distorted views of inherited traits to the development of policies harmful to non-whites and other minorities.

Event Goals

Goal 1: *Stimulate interactions among leadership of key organizations committed to reducing health disparities*

The Steering Committee was comprised of the directors of the four sponsoring agencies as well as their staff. The Committee met 1 -2 times per month from May 2006 until the date of the workshop, October 5th to plan the agenda, identify speakers, and an invitation list. One of the first decisions was that we would invite community-based, policy, and research organizations with a primary interest in health disparities, and invite them to consider the role of genetics in their shared mission of reducing health disparities.

Invitations to the workshop were extended to organizations previously identified by the Poverty and Race Research Action Council (PRRAC) as working in the area of health disparities. Also approached were representatives in the Congressional Black Caucus and Hispanic Caucus, and the leadership of the National Community Committee (NCC), which represents the community-based organizations that work on issues of health disparities and are affiliated with CDC-funded Prevention Research Centers. While a majority of invitations were extended to organizations in the Washington D.C. area, we were able to provide travel scholarships to NCC leaders and the West Harlem Environmental Action Council (WE ACT). Organizations represented at the workshop included the Association of State and Territorial Health Officers, NIH's National Human Genome Research Institute, National Health Law Program, and Families USA. Staff members from the Offices of Senator Kennedy and Representative Edolphus Towns attended, as did the past and current presidents and president-elect of the NCC.

Potential participants received two mailings, and a phone call. In the initial packet of material, invitees received a survey to indicate their main areas of interest, as well as information from the popular media or developed in-house that explained the potential impact on health disparities of race-based medicine, genetic discrimination in the workplace, the impact of genetic testing on health insurance policy, and the current research plans for a ~\$3 billion study of gene-environment interactions that would involve as many as 500,000 individuals. We also developed a brochure that was mailed out during the Summer 2006. Because genetics was a new area for many of these organizations, subsequent phone contact helped in recruitment and in identifying areas of interest so the workshop could be tailored to the audience.

The list of Steering Committee members, brochure, and a full participant list are attached (Attachments 1, 2, and 3). Attachment 4 contains a list of all organizations who have indicated their desire to participate in the Network, whether or not they participated in the workshop.

Goal 2: *Share knowledge of how decisions are currently made by institutions shaping genetics policies*

The day-long workshop, facilitated by Dr. David Campt, was designed to provide general information and pique interest in genetics, health disparities, and policy, during the morning session. The final agenda is available as Attachment 5. Sharon Kardia, PhD, of the University of Michigan presented on the link between genetics, environment, and health disparities. Marcel Welty, National Council of Churches, Vence Bonham, National Human Genome Research Institute, and Gail Christopher, Health Policy Institute, co-presented on policy issues at the intersection of genetics and health disparities. Aranthan Jones, Chief of Staff for Congressman William Jefferson of the 2nd-District of Louisiana, had been scheduled to speak on this topic, however he was unable to appear due to a last minute conflict. Makani Themba-Nixon, Executive Director of the Praxis Project spoke about how communities can become involved in the policy process and in actively changing current policies. Biographies provided to workshop attendees are provided as Attachment 6.

This unique combination of research, community advocacy, and policy expertise stimulated ideas and conversation. As the evaluation report (Attachment 7) suggests, these presentations carried the dialogue throughout the day, especially Dr. Kardia's.

Goal 3: *Consider strategies that will enable a more diverse group of stakeholders to develop meaningful roles in shaping these policies*

In the first of two afternoon sessions, we drew from the diverse experience in the room and discussed what the lessons have been in forming other networks (i.e., what works, what doesn't work). Two main themes came out of this session: First, practically speaking, a network needs some structure and resources. For example, funding and staff time, training, and a listserv. On the other hand, over-reliance on technology for communication and time limitations are classic pitfalls. Second, according to the group, network needs an environment conducive to growth and development: Good communication, evaluation, inclusivity. Exclusion, and "worthy but unrealistic goals" are detrimental.

Also during this part of the event, participants were polled on their primary areas of interest for the Network. These were:

- Current genetic anti-discriminatory legislation
- Racial categories in genetics research
- Participation in genetics research
- Informed consent issues
- Access to genetics health care
- The biotech industry and patenting
- Health information technology
- Community genetics education
- Participation in genetic research; identifiability in large databases
- Environmental justice
- Message framing

Receiving the most votes were education, and genetic anti-discrimination legislation. Also high on the agenda for the group, were participation in genetics research, and message framing. Participants were asked to select a topic of interest to discuss one of these four issues, or the question of sustainability in small group discussion.

Interestingly, most people were drawn to internally, rather than externally, focused questions. Despite being high on the interest poll, Genetic Discrimination Legislation had no group

members, while the largest groups discussed education, participation in genetics research, and message framing. While there was no small group discussion of sustainability, this was addressed as a larger group.

The group discussions provided valuable feedback on how we conceive of this network; for example, we were encouraged to facilitate networking by sharing information about the member organizations, communicate via both electronic methods and “regular old mail.” Other suggestions included articulating a set of values that we share that would guide the development of the field of genetics, education, and maintaining a sense that the Network is essentially a “fuzzy institution” wherein the overall mission would reflect broad values that many organizations can agree upon, but allows for activity among sub-groups interested in common topics to come together on policy issues as they arise.

The notes from the afternoon discussions have been typed up, and are provided as Attachment 8.

Goal 4: *Develop an action plan to implement these strategies*

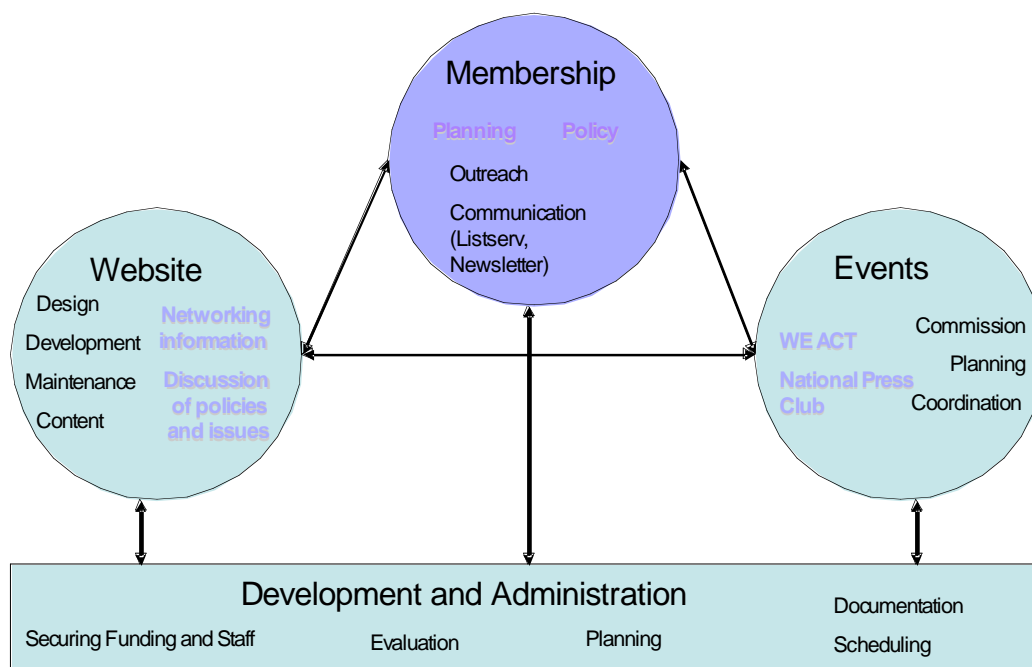
At the end of the day, we launched the website that will support the activities of the Network: <http://www.geneticsequitynetwork.org> (See Attachment 9). The website provides education resources and information about the Network. It will also host recordings of the recorded morning speakers. We are currently developing a plan for further development of the website to include interactive elements that will assist in collaboration, networking, and the development, comment, and advocacy of policies.

We have also further refined a listserv that is active in commenting on a variety of policies. The Network provided feedback on a bill that is yet to be introduced by Senator Kennedy that would regulate genetic tests to assure clinical and analytical validity. The Network is currently working on creating a statement on the recently introduced Genetic Information Non-Discrimination Act. Considering the desire for multiple channels of communication, we have held conference calls to stimulate discussion and use the telephone to keep in touch with members in addition to the communication via email.

Beginning in February 2007, we will be holding a regular meeting among members of the Network to identify issue areas, activities, and priorities for the year. The Steering Committee continues to meet to strategize for the continued success of the Network. The Genetics Equity Network will be a resource for the Midwest Community Genetics Forums that will be held this year through a grant awarded by NIH’s National Human Genome Research Institute by serving as forum for discussion of the policy implications of genetic research agendas. Figure 1 (below) depicts the relationship between the activities of the Network and demonstrates the partnership between members and the Steering Committee, which originally conceived of this project. The Life Sciences & Society Program and Center for Public Health and Community Genomics at the University of Michigan, the Joint Center for Political and Economic Studies Health Policy Institute, and our partners at Howard University are also committed to furthering the success of the Network through the provision of funds and staff time.

Figure 1.

The Genetics Equity Network



KEY
Members
Steering
Committee