Communities of Color & Genetics Policy Project

PROJECT SUMMARY

The Communities of Color & Genetics Policy Project [the "Renewal Project"] is conducted by a consortium of three universities: University of Michigan, Michigan State University, and Tuskegee University. It is a renewal of an earlier project which held a series of public dialogues to develop policy recommendations to guide the use of genome technology related to reproductive decision-making and to test the effectiveness of the dialogue process to engage the public in the shaping of policy recommendations which involve value-laden issues. The Renewal Project is developing a process for engaging communities of color of diverse socio-economic levels in similar dialogues relating to genome research and its resulting technology, and from these dialogues will develop recommendations for laws, professional standards and institutional policies regarding the use and application of genome research and technology.

The initial project, entitled Genome Technology and Reproduction: Values and Public Policy, lasted three years and involved participants from seven Michigan communities. The initial project sought to identify values, attitudes, and beliefs that citizens, patients, and practitioners hold toward genetic technology. Based upon these insights and perspectives gained through focus groups, extensive community dialogues, and a policy conference, the initial project developed recommendations and approaches for public policy and reproductive options. These recommendations were then disseminated through publications and a national conference held in Washington DC in May, 1998.

In the initial project, community participants represented some of the racial/ethnic diversity in Michigan, but the absolute numbers of these groups in communities were small, and the distinctiveness of their voices was often lost in the overall conversation. It is for this reason that this Renewal Project concentrates on communities of color. The Renewal Project is similar to the initial project but incorporates important changes to successfully engage people of color. Most importantly, 15 African American and Latino community-based organizations (CBOs) in Michigan and Alabama play a key role in the renewal project, and a Community Advisory Board with representation from the participating CBOs provided input to all project phases.

Focus Group Phase

Focus groups were held with constituents of the CBOs. The focus group participants were African Americans and Latinos broadly representative in age and socio-economic status. The purpose of the focus groups was to develop a “menu” of issues of concern relating to the development and application of genetics knowledge and technology. The Community Advisory Board reviewed all educational materials used at the start of the focus groups and those used in dialogue sessions.

Community Dialogue Phase

During this phase, 15 dialogue groups of 15-20 participants each met over a period of months for five times. CBOs recruited participants and hosted the dialogue sessions, and the Community Advisory Board assisted in the selection of dialogue facilitators. The objectives of this phase were to: 1) open up community discussion about those issues identified in the focus groups; and 2) allow community members to transform their moral and
ethical concerns into a consensus on general values and desirable policies pertaining to the issues discussed. Participants were educated about the genetic concepts and participated in dialogue about the topics chosen from a menu developed by the focus group participants.

Policy Phase

Once all community-based dialogues were completed, the project team, with the assistance of the Community Advisory Board, developed position papers on the issues identified to be of most concern among the 15 dialogue groups. In the fall of 2001, one-day policy conferences were held in Michigan. Participants included representatives, members of the project team, members of the Community Advisory Board and policy makers. The objective of these conferences was to consider strategies that would lead to the adoption of the recommendations.

Dissemination Phase

Outcomes of the Renewal Project including final policy recommendations and the evaluation report are being publicly disseminated through the peer-reviewed literature as well as presented at a series of conferences on public policy, genetics, and medical ethics for the benefit of policymakers, health care providers and organizations, and consumers.

Advisory Sources

The Community Advisory Board advised the Renewal Project regarding all project phases. A National Advisory Board of experts in genetics and people of color, law, medicine, and policy met annually to provide broad oversight of the project, to evaluate its overall progress, and to ensure incorporation of the latest developments in the field. Members were available for telephone and e-mail consultation during the entire period of the project.

Funding

The National Institutes of Health, National Human Genome Research Institute, Ethical, Legal and Social Implications Branch has granted $1,175,000 to conduct this three year project.

For further information, please visit our website (www.sph.umich.edu/genpolicy) or contact:

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