Final Report on the Presidential Fellows Award 2008-2009

Genetics and Social Justice: A Study of Race, Medicine and Health Disparities

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This report summarizes work completed during my Presidential Fellows Award for the period from May 2008 to July 2009. The project has progressed very well. I organized or presented several talks related to this area of scholarship that were of great interest to the BSC community, the public and K-12 educators. I led the effort to bring in Dr. Alan Goodman, an expert on race from the perspective of biological anthropology, as the keynote speaker for the annual Center for the Advancement of Science Exploration (CASE) conference. Two additional presentations were held during the Center for the Advancement of Research and Teaching (CART) May celebration. I participated as a panelist in a discussion led by members of the Diversity Inclusion Research Institute (DIRI) and presented an additional lecture on genes and ancestry. During the fellowship, I also developed curriculum resources based on this scholarship and organized a workshop for teachers at which I presented some of these resources and the scientific background and social issues related to this rapidly advancing scientific field. This report provides further details of these and other accomplishments for the year along with future plans for continuation of this scholarship and engagement of the BSC and broader communities.

PROJECT DESCRIPTION

Currently race and ethnicity information is collected and utilized in healthcare and medical research along with other categorizations, such as age, sex, education and income. In this project, I have been studying the widely held, but controversial belief that 'race' can act as proxy for a genetically defined population. In medicine this view has led to race-based diagnosis and treatment differences as well as race-based pharmaceuticals, one recently approved through the Food and Drug Administration. Racial genetic difference has also been used to explain health disparities. Health disparities, as defined by the National Institutes' of Health, are: "the differences in the incidence, prevalence and mortality…that exist among specific population groups."

I believe that equating 'race' with genetic difference in this context is incorrect and leads to negative social consequences. Promoting genetic explanations for health disparities ignores important social determinants of health, such as unequal distribution of resources and discrimination. This in turn may lead to failure to address these inequalities. The four approaches that I undertook to engage in this area of scholarship were: 1) to attend conferences and to work directly with experts in science, the social sciences and medical ethics; 2) to build and read extensively from a resource library (books, journal articles, multimedia); 3) to engage members of the BSC and broader communities in new learning opportunities; and, 4) to develop and disseminate curriculum for use in the high school and college classroom as well as new courses for BSC undergraduate and graduate students.

WORK COMPLETED

The BSC Presidential Fellowship has enabled me to develop resources and collaborations supporting an interdisciplinary approach to the study of human genetic difference, race and human health. The collaborative connections that I have established with colleagues in the sciences, humanities, social sciences, social work and biomedical ethics has been through my active participation this year as member of the BSC Diversity Inclusion Research Institute, attendance at conferences and seminars and participation in two Boston area groups focusing on issues of human genetics and race. The knowledge

resources that I have read or viewed include an extensive library of journal articles, reference books, news media, multimedia, and web resources, including both blogs and web conferences.

Experts have commented on the rapid pace at which technologies are being developed and new discoveries are being made in the field of human genetic variation as it relates to ancestry, 'race' and medicine. Therefore, the resources that I have studied for this project include both the articles in the news media that convey basic knowledge and exciting advances in genetics related to health and ancestry to the general public, as well as the technical research papers in this field. I have explored the differences between human population groups at the genetic level, conducted my own computer analysis on raw data of human DNA sequences and I have researched and co-authored a peer-reviewed article. Using this information, I have also developed teaching and research materials related to human genetic variation and have piloted some of these materials at a workshop for area high school teachers. These activities are presented in more detail below.

Attend Conferences and Work with Experts in Science, Social Science and Medical Ethics

Prior to the beginning of the fellowship, several opportunities for learning about and establishing important interdisciplinary connections were begun. The first of these was attending a two-day conference on the topic of Race sponsored by MIT's Center for the Study of Diversity in Science, Technology and Medicine. During the fellowship, with grateful support from the presidential fellowship budget, I was able to attend four additional major conferences. The presentations that I attended at these conferences were from experts in the fields of medicine, anthropology, genetics, sociology, law, public health, ethics, communications, as well as from editors of prominent journals in science and medicine. I have continued to read scholarly works from many of the individuals that presented at these conferences to further develop my expertise in these fields.

A second opportunity involved my invitation to attend the monthly discussions on race organized by Dr. Evelynn Hammonds, currently Dean of Harvard College. This interdisciplinary group includes prominent researchers from the sciences, social sciences and humanities focused on matters of race and gender, drawn from the larger New England area. I attended two of the group's meetings in April and May of 2008. Although the group did not meet this year, I am scheduled to attend the monthly meetings when this group reconvenes in September 2009. Through this group, I have made connections to experts in history, anthropology, Women's Studies and African American studies. I will utilize this network of experts to help me develop new ideas for experiential learning projects that I will initiate with my seminar students when I return to the classroom.

The third and most active interdisciplinary connection during my fellowship period has been through membership in the Genetic Screening Study Group. Based in the Greater Boston area, this group hosted a 2005 conference on race that I attended. Leading the group is Jon Beckwith, my former postdoctoral advisor, and a geneticist who is also world-renowned as an expert in examining and taking action on important social issues related to science. Other group members include scientists, physicians in training and Lisa Geller, a lawyer and bioethicist. I have met twice a month with this group to discuss current issues in human genetics, genetic testing, race and ancestry and numerous other topics. I have been involved in an ongoing project that is examining issues related to direct-to-consumer genetic tests, with goal to bring this issue to better attention of Massachusetts State legislators. Recently, I have initiated a project in collaboration with the Genetic Screening Study Group and the group organized by Evelynn Hammonds. The project will involve building community and educational connections to the upcoming Boston Museum of Science exhibit "Race-Are We so Different?". I will discuss this under the section below entitled, "Future Work".

Working with Jon Beckwith, I co-authored an article titled, *'Race', IQ and Genes* for the Encyclopedia of Life Sciences, listed as "the premier online reference in the life sciences". The original edition of the article was written prior to many of the significant developments that resulted from the sequencing of the human genome and the discussions and ongoing debate related to the relevance of race in medicine. The new literature needed for the article related specifically to race and human ancestry. I used this writing opportunity to gain considerable expertise in this area and this effort led to the development of a substantial bibliography and publication of this peer-reviewed article.

Build Resource Library

The reading and research that I have done has been extensive within my field of genetics and also within areas of scholarship that were less familiar to me, including the social sciences, humanities and medical fields related to race, ancestry and health disparities. Throughout this project, I have built an extensive library of journal articles, books and DVDs. I have organized these resources using the Endnote bibliographic system. In addition, I have collected and critically analyzed reports from science sections of major news publishers as well as less formal science blog websites. To develop knowledge of the field of consumer genetics related to health and ancestry, I have read scholarly articles, studied the websites of several consumer genetics companies and attended the first ever Consumer Genetics Conference, held in June of 2009. I have collected data on human genetic variation from public bioinformatics databases and utilized these to research human genetic variation using computer tools. The library of resources that I have organized will be an valuable asset for continuing research in this area, as well as serving as a reference library for students whom I will engage in future research projects related to this scholarship.

Engage Members of BSC and Broader Community in this Scholarship

As a member of the Project Compass Community of Practice during 2007-2008, I established connections to many BSC faculty and administrators involved in campus climate and diversity initiatives. I have maintained these on-campus connections during my fellowship year by attending the two initial Project Compass meetings, the Project Compass faculty reception and two faculty professional development workshops. I participated in book discussions sponsored by CART and the Office of Institutional Diversity, campus brownbag discussions on multicultural issues and attended additional seminars both on and off the campus.

As a way of connecting initiatives that would develop from my fellowship work to the many other initiatives on campus, I applied for and was accepted as a board member on the Diversity Inclusion Research Institute (DIRI). I have participated in the early organization of this institute, board meetings, discussions and an all-day retreat that helped guide the further development of the institute and its role in the BSC community. I developed a panel presentation with other DIRI members, given as a plenary during the CART celebration in May 2009.

To engage the campus community further, I arranged for a renowned expert, Dr. Alan Goodman, to share the important message from social scientists that 'race' is socially constructed. I worked together with CASE, the Office of Institutional Diversity, the Center for Multicultural Affairs, Project Compass and individual faculty members on campus to promote this lecture within the campus community, the community of K-12 educators affiliated with CASE and other interested members of the public. Held at this year's CASE conference, over one hundred people attended this lecture. As a way of exploring this scholarship further, I presented two additional workshops. The first of these, on the topic of race and biology, was held for eleven high school biology teachers. The second was a talk on genetics and ancestry that I presented during the CART celebration in May 2009.

Develop Curriculum and New Courses

The scholarship that I have developed during this presidential fellowship will be used as basis for a new course for BSC undergraduates and a new course for students in the graduate degree program, Master of Arts in Teaching. During my sabbatical in Spring 2010, I will continue to work on course development. The undergraduate course, a second year seminar on race and biology, will provide experiential learning experiences within the community focused on important social issues related to race and medicine. The course for graduate students will be based on in-depth exploration of the methods for analyzing human genetic variation, important social issues related to race and biology and will also study the way in which this information is utilized in healthcare and medical research.

FUTURE WORK

Additional work on curriculum development for high school classrooms and inquiry based student laboratories will be a collaborative project within CASE. Some of the curriculum that I developed during the presidential fellowship has already been presented to teachers at a workshop this past spring. A new curriculum project that I plan to develop will be based on a published multidisciplinary perspective on the scientific use of racial categories (Lee et al., 2008).

Areas of the scholarship that I worked on this year will provide many new topics for my undergraduate and graduate courses as well as new projects for my biology undergraduate research students. The expertise that I gained and the connections that I have made during the fellowship will allow me to supervise students whose projects integrate the science with the important social issues related to the study of human genetics, ancestry and medicine.

I will continue to engage the college community in the areas that I have studied during my fellowship through the Diversity Inclusion Research Institute, the Office of Institutional Diversity and other campus organizations. Through collaboration with Andrea Garr-Barnes, Center for Multicultural Affairs, we are planning one or more film showings and discussions of important issues related to 'race' and biology. Based on our discussions, the PBS series, *Race-The Power of an Illusion*, has been selected for the first film showing.

Finally, as a result of the many important connections that I have made and the reading and scholarship that I have accomplished, I expect to be actively involved in an exciting new project. This opportunity is associated with the upcoming exhibit "Race-Are We so Different?" which will arrive at Boston's Museum of Science in January of 2011. I have contacted the members of the American Anthropological Association affiliated with this project and will be contacting the representatives from the museum in the next few weeks. With the support of my colleagues from the Genetic Screening Study Group and the group organized by Evelynn Hammonds, as well as colleagues at BSC, I will utilize this opportunity to further disseminate what I have learned during my Fellowship. Specifically, I am actively pursuing becoming a member of the organizing committees related to this exhibit and in building community and educational connections to the exhibit. As this project unfolds, I will be bringing new opportunities to explore this area of scholarship to the BSC community and also to the broader educational and public communities served by our college.