

Communities of Color & Genetics Policy Project

SUMMARY OF POLICY RECOMMENDATIONS

Access to Genetic Testing and Services

Issue: Who should have access to services resulting from genetic research?

Recommendations:

1. Access to cost effective genetic testing of proven benefit should be made available to all who would potentially benefit as part of basic health care. The federal government has the obligation to ensure these services are granted to the public equitably.
2. An ethnically and racially diverse commission should be formed to prioritize basic health services to be federally funded which would include some genetic tests that have great potential to benefit much of the population, especially those which have the potential of reducing health disparities.
3. Religious beliefs should not be the basis for legislation dealing with genetic testing which limits the choice of the individual to undergo testing. Legislation regarding testing should be made based on the need for safety and a risk/benefit assessment of the test and the usefulness of the results.

Education

Issue: Who should be responsible for the education of the community about genetics and the emerging technologies?

Recommendations:

1. The federal government should take the lead in funding broad public educational efforts regarding emerging genetic technologies, current genetic research and current policy issues.
2. A diverse group of educators, parents, community leaders, and citizens should jointly decide the precise form of genetics education in the school system. This education should include both science issues and the ethical, legal and social implications of genetics research and technology.
3. The health care industry should take measures to include people of color when engaging in genetic education programs.

Playing God – Perfect Children

Issue: Should human cloning and genetic engineering be regulated or prohibited?

Recommendations:

1. Human cloning should be prohibited by federal law, with substantial penalties to assure compliance with the prohibition.
2. Cloning of human cells for the purposes of developing treatment for disease, and not for the purpose of replicating humans, should be permitted.
3. To the extent that cloning research is permitted, it should be restricted to publicly funded research, with controls to assure that it does not lead to cloning of human beings.
4. The use of other reproductive genetic technologies should be regulated by a commission, broadly representative of the diversity of the U.S. population. The commission should assure that these technologies are used only for the universal and equitable prevention of disease and not to affect traits or characteristics not constituting diseases.

The Right To Genetic Privacy

Issue: What level of privacy should individuals have for their genetic information?

Recommendations:

1. Privacy of genetic information within the doctor-patient relationship must be very strongly protected. There should be legal penalties for any physicians who disclose confidential medical information to an employer, insurer or anyone without the explicit consent of the individual who is the subject of the medical information.
2. If physicians are to communicate genetic test results to other members of the family, then they must have the explicit permission of the patient to do so.
3. It should be illegal for anyone to access medical information about an individual without the written consent of the individual.
4. There should be a law that would forbid insurance companies and employers from requiring any DNA tests or using the results of such tests against individuals. Specifically there should be explicit laws that would prevent insurance companies from discrimination against individuals on the basis of possible genetic illness on the grounds of pre-existing conditions.
5. There should be a law that would prevent employers from accessing genetic information about their employees or using such information to discriminate against them.

Genetic Research

Issue: How do we continue to embrace the promise of genetic research and ensure that the proper safeguards are in place?

Recommendations:

1. In order to ensure equity and equality in research, steps must be taken to ensure that people of color are adequately represented among researchers and research participants.
2. There should be careful assessment of the risks associated with all human research, and this information needs to be widely publicized. There also needs to be ample opportunity for debate and community input on these issues via community forums.
3. There must be a strong commitment to the principles and practices of voluntary informed consent for all research involving human subjects.
4. Human embryonic stem cell research should be approached cautiously. If public funds were to support such research, then human embryos that are left over from in vitro fertilization efforts should be used only if the couples gave their explicit consent for the specific use of their embryos. However, public funding should not go to the creation of human embryos for the purpose of stem cell research. There must be policies in place that would prevent human embryonic stem cells from becoming a market commodity. Therefore, payment for sperm and egg donors in connection with human embryonic stem cell research should not be allowed.
5. There should be policies encouraging private companies doing genetic research to hold community forums during which they would inform the public about the type of research that they are engaged in.

Genetic Testing

Issues: What principles and policies should apply to genetic testing?

Recommendations:

1. Clinical genetic testing should occur within the confidential doctor-patient relationship. There should be legal penalties for any physicians who disclose confidential medical information to an employer, insurer or anyone without the explicit consent of the individual who is the subject of the medical information.
2. If physicians or other health care professionals are to communicate genetic test results to other members of the family, then they must have the explicit permission of the patient.
3. Choice must be preserved with respect to genetic testing. We should have no mandatory genetic testing, no matter how apparently worthy the social goal.
4. Fair balanced education regarding genetic testing should be enhanced through various forms of public education and counseling.
5. Everyone should have access to genetic tests when those tests show considerable likelihood of benefit for individuals, regardless of the ability to pay.
6. All entities doing DNA testing should be regulated through licensure and accreditation. There should be no mandatory pre-marital genetic testing.
7. There should be no policies that mandate testing including racial or ethnic group testing.
8. Personally identifiable genetic test results and samples should not be retained without the approval of the individual being tested or parent or guardian for a minor individual being tested.

Trust And Distrust

Issue: Issues of trust and distrust run through each of the other six position papers. All dialogue groups voiced distrust of the ability of government, research institutions and private sector organizations to conduct research and apply genetics technology to benefit communities of color and to avoid discrimination against and exploitation of these communities.

Recommendations -- In view of the distrust expressed toward government, the academic community and the private sector, these recommendations are directed to each of these sectors:

1. Advisory committees to the principal governmental agencies carrying out genetic research and regulating such research must be diverse in their membership, both as to diversity of citizen or lay members and diversity of expert members.
2. Private industry, including research organizations and health services providers should be urged to create advisory bodies reviewing their genetics research and the provision of genetic services, to assure the protection of research subjects and service recipients. These groups should be diverse as to their lay and expert membership.
3. Advocacy organizations should network with the advisory groups referred to in recommendations 1 and 2, to share their findings and recommendations, to strengthen the impact of their work, and where appropriate, to recommend and advocate for government policies furthering their goals.
4. Federal funding for genetics research must be maintained at a high enough level related to private funding of research, to maintain open-ness of the research and to minimize the impact of profit motivation.
5. Institutional Review Board procedures should be amended to address the protection of groups as well as individuals, with particular emphasis on minorities.
6. More people of color should assume ownership and executive positions in private industry. Increasing the number of people of color who receive genetics education is one strategy to promote such involvement.