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## National Institutes of Health Workshop Statement. Reproductive Genetic Testing: Impact on Women

Karen H. Rothenberg

University of Maryland School of Law, krothenberg@law.umaryland.edu

Elizabeth Thomson

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## NATIONAL INSTITUTES OF HEALTH WORKSHOP STATEMENT Reproductive Genetic Testing: Impact on Women

Reproductive genetic testing, counseling, and other genetic services can be valuable components in the reproductive health care of women and their families; they can also have negative effects on individuals, on families, and on communities. These services have the potential to increase knowledge about possible pregnancy outcomes that may occur if a woman decides to reproduce; provide reassurance during pregnancy; enhance the developing relationship between the woman, her expected child, and others; allow a woman an opportunity to choose whether to continue a pregnancy in which the expected child has a birth defect or a genetic disorder; and, if continuing, both facilitate prenatal or early infant therapy for the expected child, when possible, and prepare the family for bearing and rearing a child with a disability. Conversely, these services have the potential to increase anxiety; place excessive responsibility, blame, and guilt on a woman for her pregnancy outcome; interfere with mother-infant bonding; and disrupt relationships between a woman, family members, and her community.

The challenge is to provide each woman with an opportunity to have access to desired genetic services, in a way that will improve her control over the circumstances of her reproductive life, her pregnancies, childbearing, and parenting, within a framework that is sensitive to her needs and values and that minimizes the potential for coercion. The value that women and their families place on these services depends heavily on a mixture of psychological and ethno-cultural influences, religious and moral values, and legal and economic constraints that are unique to each woman. In addition, it may be influenced by a woman's perceptions about and past experience with people with disabilities. As a consequence, women in different circumstances may weigh the merits of reproductive genetic services quite differently.

These complex individual differences among women

challenge efforts to evaluate the safety and efficacy of reproductive genetic services. To reflect the function of genetic services in reproductive health care, evaluation criteria must be client centered. That is, beyond assessment of the biological safety and technical reliability of reproductive genetic services, there should be assessment to determine whether they fulfill the roles that their clients define for them. Women may be interested in knowing to what extent reproductive genetic services can reassure, facilitate planning, and improve informed decision making, as well as how they can limit potentially offsetting costs such as the risk for coercion, increased anxiety, and compromise of their own values. Further, it may be important to determine to what extent reproductive genetic services can be modulated to respect the needs and interests of individual women and their families. Research designed to evaluate reproductive genetic services in these terms is urgently needed.

This understanding of reproductive genetic services has several important implications that should be considered in the development of a future research agenda in this area.

1. *Reproductive genetic services should not be used to pursue "eugenic" goals but should be aimed at increasing individuals' control over their own reproductive lives. Therefore, new strategies need to be developed to evaluate the success of such services.* Reproductive genetic services must ultimately serve personal—not public—interests, in improving the overall reproductive lives of women. Whatever societal gains might be realized through the eugenic use of reproductive genetic services should be heavily outweighed by the personal needs of women and their families. The ideals of self-determination in family matters and respect for individual differences, ideals that lie behind the client-centered view of reproductive genetic services, are jeopardized whenever the primary goal of these services becomes the prevention of the birth of individuals with a disorder or a disability.

Such a goal has the potential to constrain the choices available to women and to further stigmatize those individuals affected by a particular disorder or disability. To the extent that voluntary reproductive genetic services are evaluated even indirectly in eugenic terms, societal pressures have the potential to threaten the important interests and desires of individual women and their families.

2. *Reproductive genetic services should be meticulously voluntary.* Since the primary goal of reproductive genetic services should be to enhance personal reproductive decisions, such testing should not be swept in with other "routine" or "universal" reproductive interventions, unless informed consent or refusal can be assured. Assisting women to give a fully informed consent or refusal to genetics education, testing, and counseling services is at the heart of these services. Whether reproductive genetic services are provided by genetics professionals or other health-care professionals, it is vital that these services be provided in a nonjudgmental and noncoercive manner and that the testing be carried out only after adequate education about their benefits and risks, including those beyond biology. The success of reproductive genetic services depends on their ability to effectively empower people to make knowledgeable and informed decisions. As a result, methods to evaluate the success or failure of these services should be devised with this goal in mind.

3. *Reproductive genetic services should be value sensitive.* Providers of reproductive genetic services should be particularly sensitive to individual differences and similarities—including ethno-cultural differences and similarities and various constellations of beliefs, value commitments, and relationships—and should adapt their services accordingly. In particular, providers of reproductive genetic services need to be aware of their own value system, which has developed within the context and culture of the biomedical sciences, and to be aware of the language, undertones, assumptions, and values hidden within their own professions. Training of professionals who will provide these services should include special emphasis on influences of psychological, sociodemographic, religious and moral values, and ethno-cultural diversity in women's needs and interests regarding reproductive genetic testing services. The true impact that the providers' gender, race, ethnicity, class, and educational discipline have on how services are provided must be evaluated.

4. *Standards of care for reproductive genetic services should emphasize genetic information, education, and counseling rather than testing procedures alone.* To the extent that reproductive genetic services are designed to facilitate personal reproductive planning, providers of reproductive genetic testing and counseling should tailor their services to meet the needs and interests of individual women from the beginning. Extreme efforts should be made to assure that the content of information shared regarding the disorders for which testing is carried out is comprehensive, accurate, and provided in an unbiased manner, so that a true picture of what life with such a disability may be like is presented.

Evaluation measures to determine when women know enough to have these interests met could serve to establish professional standards of care that do not drive providers to encourage testing when it is not desired. Conversely, sometimes providers do not offer reproductive genetic testing unless a woman knows enough to ask for these services. Further evaluation must be done to determine the balance which must be reached in educating women so that they have enough information about these services but do not feel pressure to utilize them when they are not desired.

5. *Social, legal, and economic constraints on reproductive genetic services should be removed.* Government and institutional policies have continued to influence legal and fiscal rules that limit the reproductive genetic testing choices that women have available to them. Research is needed to clarify such constraints and how they affect the choices and availability of services. Research is also needed to develop and test alternative models for delivery that would improve access and reduce barriers to reproductive genetic services for those women who desire them.

6. *Increasing attention focused on the development and utilization of reproductive genetic testing services may further stigmatize individuals affected by a particular disorder or disability.* The values that some place on health and disabilities, what people may be told about disabilities, and even the use of certain language to describe the benefits of reproductive genetic testing have the potential to devalue the worth that individuals with disabilities have in society. Both increased sensitivity to these issues and improved communication between the biomedical and the disability communities are urgently needed in order for the true impact of these developing technologies to become known. Individuals with disabilities, who have a vari-

ety of information, experiences, and views to share, must be involved in the development and implementation of further research to be carried out in this area.

In summary, there are a number of ways that reproductive genetic services may continue to be, in many cases, less than ideal. This system of care will fail not only if providers are not informed about and sensitive to the importance of individual differences among women, but also if women themselves do not understand the complexity of making decisions about whether to utilize these services within the context of their own needs. The future of reproductive genetic testing within the context of reproductive health care of women and their families depends on research activities that are aimed at a better understanding of how best to address these challenges.

*Note added in proof.*—This statement and the entire proceedings of this workshop will be published in the December 1992 issue of *Fetal Diagnosis and Therapy*.

## Appendix

### Workshop Participants

Members of the Workshop were as follows: co-chairs—Elizabeth Thomson, R.N., M.S., University of Iowa, and Karen Rothenberg, J.D., M.P.A., University of Maryland School of Law; Panel members—Ruth Schwartz Cowan, Ph.D., State University of New York at Stony Brook; John Meany, Ph.D., Council of Regional Networks for Genetic Services; Jessica Davis, M.D., Cornell University; Ellen Wright Clayton, M.D., J.D., Vanderbilt University; Barbara Katz Rothman, Ph.D., The City University of New York; Deborah Kaplan, J.D., World Institute on Disability; Mark Evans, M.D., Wayne State University School of

Medicine; Dorothy Wertz, Ph.D., Shriver Center for Mental Retardation; Rayna Rapp, Ph.D., New School of Social Research; Nancy Press, Ph.D., University of California, Los Angeles; Mary Ann Coffman, M.S., Oklahoma State Department of Health; Laurie Nsiah-Jefferson, M.P.H., New Jersey Department of Health; Ruth Faden, Ph.D., Johns Hopkins University; Patricia King, J.D., Georgetown University Law Center; Alta Charo, J.D., University of Wisconsin; Adrienne Asch, A.C.S.W., C.S.W.; Rita Beck Black, D.S.W., Columbia University; Sandra Tunis, Ph.D., University of California, San Francisco; Abby Lippman, Ph.D., McGill University; Bartha Knoppers, Ph.D., University of Montreal; Victor Pencbaszadeh, M.D., Beth Israel Medical Center; Suzanne Braga, M.D., Medizinische Universitäts-Kinderklinik; Neil A. Holtzman, M.D., The Johns Hopkins Medical Institutions; Ann C. M. Smith, M.A.; Elena Gates, M.D., University of California, San Francisco; and Frederic Frigoletto, M.D., Harvard Medical School.

Workshop moderators were as follows: Jane Fullerton, M.P.A., Institute of Medicine, National Academy of Sciences; Robyn Nishimi, Ph.D., Office of Technology Assessment; Nancy Wexler, Ph.D., Columbia University and Hereditary Disease Foundation; John Fletcher, Ph.D., University of Virginia; Anita Allen, J.D., Ph.D., Georgetown University Law Center; Robin J. R. Blatt, M.P.H., R.N., Massachusetts Department of Public Health; Maurice J. Mahoney, M.D., Yale University School of Medicine; and Elsa Gomez, Ph.D., Pan American World Health Organization.

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