neticists. Accolades to the contributors and editors of this outstanding work!

Cynthia Curry

Division of Genetic Medicine
Valley Children's Hospital/UCSF
Fresno

© 1997 by The American Society of Human Genetics. All rights reserved.
0002-9297/97/6103-0041$2.00

Am. J. Hum. Genet. 61:781, 1997

Optimizing Genetics Services in a Social, Ethical, and Policy Context: Suggestions from Consumers and Providers in the New England Regional Genetics Group (NERGG). By Dorothy C. Wertz and Robin Gregg. *The Genetic Resource,* Special Issue, Volume 10, Number 2, 1996. $10.00.

The active New England Regional Genetics Group has produced a detailed document describing ideal interactions between consumers and providers in the provision of genetic services. The project included contributions from five focus groups: three groups of consumers (from three different states), one of M.D./Ph.D. geneticists, and one of M.S. genetic counselors. The project team does not intend for this to be a "standard-of-care" document. The goal is that this document "could serve as a resource and reference for persons wishing to improve various components of genetic services" (p. 2).

The document is divided into three parts. Part A, "Approaches to Consumer-Provider Interactions," emphasizes the information obtained from the consumer groups and the consumer members of the project team. This section first discusses general considerations for these relationships, such as respect for persons, preserving family integrity, and the responsibilities of both the professional and the consumer. The needs and experiences of consumers are then listed as a message to providers. Part A concludes with an acknowledgment of the need for the general public to have some basic genetics education and with information that a consumer should know about a genetics referral.

Part B, "Social, Ethical, and Policy Contexts of Genetic Services," is the largest of the three parts, with 16 sections containing detailed information about a variety of issues. A team approach was an important consideration for consumers and is described first. Screening versus testing (including testing children), informed consent, and confidentiality are entries one would expect. There are also entries on parenthood for persons with disabilities, what consumers need to know when participating in research projects, and the danger of stigmatization involved with behavioral genetics. The uses and ethical limitations of cost-benefit analysis come next, followed by a discussion of the roles of the genetics center and the public health department.

Part C, "Specific Points for Direct Interactions," again uses the contributions of the focus groups for a more clinical approach to the preceding information. This part addresses optimal genetic counseling, the need to recontact patients, presymptomatic and susceptibility testing, various settings such as family planning clinics or pediatric clinics where genetic issues arise, adoption, prenatal diagnosis, and abortion.

This work represents thoughtful, detailed information that can be of use in a variety of ways. Examples of focused applications would be use of the section on duty to recontact as the basis of a review of policy in one's own genetics group or the use of the information contained in some of the many tables to make slides for a presentation enhancing genetics knowledge. Broader applications will include the use of the information included for education and policy decisions that will enhance health care in general and genetics health care in particular.

Copies of this document may be obtained from Joseph Robinson, MPH, Coordinator, New England Regional Genetics Group, P.O. Box 670, Mt. Desert, ME 04660 (telephone: [207] 288-2704; fax: [207] 288-2705; e-mail: 76363.3114@compuserv.com) at a cost of $10.

Pat Schnatterly

Division of Medical Genetics
Department of Pediatrics
University of Virginia Health Sciences Center
Charlottesville

© 1997 by The American Society of Human Genetics. All rights reserved.
0002-9297/97/6103-0042$2.00