

Genetic Services Policy Project Fact Sheet

The Genetic Services Policy Project (GSPP) aims to describe the current model of genetic services delivery, collect information from key stakeholders, and use stakeholder perspectives to translate genetics research into practice that will lead to more effective genetic service delivery models. GSPP is a collaborative effort involving:

- The Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau;
- The Washington State Department of Health, Genetic Services Section; and
- The University of Washington, School of Public Health and Community Medicine, Department of Health Services, Resource Center for Health Policy.

Two closely related projects comprise GSPP:

Delivering Genetic Services

The overall purpose of this project is to assess the model through which genetic services are delivered, to explore alternative models of service delivery, and to identify changes in public policies that would promote appropriate and cost effective access to a broad range of genetic services to all who might benefit from them. Assessments include evaluating the economic, legal, cultural, and policy aspects of the existing system and alternatives. Specific genetic service markets such as screening and testing, and markets for complementary services such as genetic counseling and education, are examined. Project analyses also consider the organization and financing mechanisms of the health services system within which genetic services are delivered.

The three specific goals for the Delivering Genetic Services project are to:

- Characterize and evaluate the current model for genetic services delivery, focusing on the economic, legal, cultural, and policy aspects;
- Characterize and evaluate potential alternative models for delivery of genetic services; and
- Identify and assess options for public policies that promote cost effective, accessible, and equitable delivery of genetic services.

Our approach to achieving these goals is multidimensional and includes an exhaustive review of what is already known about current service delivery models from the scientific, economic, legal, policy, and health services literature, combined with structured interviews with a variety of key informants, as well as formal legal, cost-effectiveness, and policy analyses and case studies of a number of specific genetic services. Our work is guided by the involvement of our HRSA partners and informed by an advisory committee representing key stakeholder groups from the public and private sector.

Translational Genetics Public Policy

The overall purpose of this project is to translate research relevant to genetic services into practice for those audiences and stakeholders who can benefit most from a focused and objective communications program. Such a program will promote appropriate and cost effective access to a broad range of genetic services for patients, families and consumers who will benefit from them.

In order to promote effective translation of the information derived from the project we directly engage the stakeholders who will be the beneficiaries of the work in a process of information exchange that allows them to improve the model through which genetic services are delivered (the

overall approach). Hence, throughout the project, we seek input from stakeholders about what information is most relevant to them and how it should be delivered to make it most accessible.

Our three specific goals for the Translational Genetics Public Policy project are to:

- Develop an agenda to translate genetic research and information into practice;
- Discuss and develop consensus about the most effective methods to translate genetic services information and research; and
- Disseminate genetic services information and research to a wide range of decision makers involved in the financing, delivery, and consumption of genetic services.

GSPP Advisory Committee

GSPP has convened a diverse advisory committee to inform and guide the project. The Advisory Committee members represent key stakeholders such as payers, providers, consumers, researchers/academic institutions, and developers of genetic and information technologies and services. In-person advisory committee meetings are held annually; in between meetings the advisors and project personnel communicate regularly. The advisors share their perspectives on related issues and assist with developing informational materials.

Notable Publications and Presentations

▪ **Stakeholders' Perspectives on the Delivery of Genetic Services**

Panelists: Rick Carlson, JD, Clinical Professor, University of Washington; Debra Lochner Doyle, MS, CGC, State Genetics Coordinator, WA Department of Health; Sharon Terry, MA, President, Genetic Alliance; Alissa Johnson, MA, Senior Policy Specialist, National Conf of State Legislatures; Eric Book, MD, Senior Vice President and CMO, Blue Shield of California; Frank Papatheofonis, MD, MPH, PhD, President and CEO, Aequitas

Presented at: Annual Meeting of the American College of Medical Genetics
San Diego, CA March 2006

▪ **Expert Panel on Reimbursement**

Panelists: Rick Carlson, JD, Clinical Professor, University of Washington; Frank Papatheofonis, MD, MPH, PhD, President and CEO, Aequitas; Paul Billings, MD, PhD, FACP, FACMG, Vice President of Laboratory Corporation of America Holdings (LabCorp); and Robert Wanerman, JD, Senior Counsel, Epstein, Becker, and Green

Presented at: National NIH-CDC-HRSA conference on access to testing for rare disorders.
Washington, D.C. September 2005

▪ **Economic analyses of human genetics services: A systematic review**

Authors: Josh Carlson, Nora Henrikson, David Veenstra, Scott Ramsey

Published in: *Genetics in Medicine*. 2005 Oct;7(8):519-523.

Presented at: International Society for Pharmacoeconomics and Outcomes Research
Washington, D.C. May 2005

International Health Economics Association
Barcelona, Spain July 2005

Genetic Services Policy Project
<http://depts.washington.edu/genpol>