

Genetic Services Policy Project Final Report

Chapter 8: Recommendations

There is consensus among genetic services experts and advocates that the field of genomics holds the potential to advance a more powerful, preventive, and in some cases cost-effective personalized medical care system. One of the goals of the **Genetic Services Policy Project** was to develop a set of policy recommendations to address the barriers to integrating genetic services into the health care delivery system, thereby facilitating the achievement of this potential. In previous chapters, we described the nature of existing genetic services; how, where, and by whom they are delivered; who receives them and who pays for them; the evolution and likely future of genetic services; and policy challenges in their equitable and appropriate delivery. In this chapter, we present our recommendations for public policies that address the barriers to integration that we identified.

Throughout the work of the GSPP, we sought input from our national Advisory Committee. Because committee members work in sectors of the health care industry that are differentially affected by the evolution of genetic services, their input into the final recommendations was particularly valuable. Prior to the final Advisory Committee meeting in May 2007, we circulated a set of federal policy recommendations derived from our research. After lengthy collective and small group discussions at the meeting, we asked members to indicate their sense of the relative priority that should be given to each recommendation. We carefully considered this input from the Advisory Committee as we developed the recommendations and priorities that follow.

Table 1 presents the nine recommendations that we believe have the highest priority for federal government action. We have grouped them into four categories that represent different public policy tools that can be used to influence markets:

- Use the convening/facilitating power of government (C/F),
- Use public insurance programs to model effective genetic services purchasing strategies (PI),
- Use public programs to create opportunities (PP), and
- Use the regulatory power of government to constrain/guide markets (R).

TABLE 1

HIGHEST PRIORITY RECOMMENDATIONS
<i>Convening/Facilitating (C/F)</i>
Convene experts and consumers to create guidelines and recommendations regarding the delivery of genetic services
Facilitate interstate licensure

<i>Modeling Effective Purchasing Strategies Through Public Insurance Programs (PI)</i>
Provide education and decision-making tools regarding genetic services in public insurance programs
Pay for genetic counseling/counselors in public insurance programs
Pay for care coordination and multidisciplinary treatment in public insurance programs
<i>Provide Educational Opportunities Through Public Programs (PP)</i>
Provide public education programs about genetic services for consumers/enrollees
Integrate genetics into educational curricula for current health professional students
Provide public education programs about genetic services (e.g., CME courses) for health care providers
<i>Regulate Genetic Services Markets (R)</i>
Prohibit genetic discrimination

Convene Experts and Consumers to Create Guidelines and Recommendations Regarding the Delivery of Genetic Services. The introduction of genetic services (e.g., genetic tests) often precedes an accepted evidence base to guide their use. Expert opinion can (must) serve as the next best alternative. Thus, the convening function of the federal government can play a central role in the development of standards and guidelines for appropriate use of genetic services. Because the field of genetic services involves values as well as science (e.g., the value of information to guide future health care decision-making), consumers and advocates as well as experts must be included in the discussions.

Facilitate Interstate Licensure. Health professionals often favor licensure programs to protect their professional markets and therefore their economic interests. However, the state-based programs restrict the mobility of genetics professionals, restrict reimbursement of unlicensed professionals (e.g., genetic counselors), and seriously complicate electronic and telephonic consultations across state boundaries. The fast-rising demand for genetic literacy among clinicians, given the shortage of genetic services professionals, especially in rural areas, makes this policy question much more central. While the federal government does not have jurisdiction over this state regulatory function, it can facilitate discussions of mechanisms to provide for interstate licensure.

Modeling Effective Purchasing Strategies Through Public Insurance Programs. The federal government can have a major impact on the delivery of genetic services through effective purchasing strategies in public insurance programs such as Medicaid, Medicare, and the Federal Employees Health Benefits Program. What these programs choose to provide (e.g., education and decision-making tools regarding genetic services) and pay for (e.g., genetic counseling, care coordination, and multidisciplinary care) has not only a direct effect on a large portion of the market, but also influences the behavior of private insurance plans.

Provide Educational Opportunities Through Public Programs. Participants in the health care system can only use genetic services appropriately if they are aware of what services are available and how they can/should be used. The federal government can affect the integration of genetic services through the creation and funding of public programs that educate consumers and providers (current and future) about genetics and genetic services.

Prohibit genetic discrimination. Evidence is mounting that people’s fears about genetic discrimination reduce their willingness to seek genetic services. Opponents of legislation to protect the privacy of genetic information and prohibit discrimination argued that there are few documented cases of discrimination actually occurring. However, for the purpose of increasing the use of genetic services, the evidence is less important than the perception: if people *worry* that results of genetic tests will be used against them, the impact on utilization is the same. To the extent that passage of the Genetic Information Nondiscrimination Act (GINA) will allay these fears, it will contribute to the goal of appropriate genetic services utilization and integration. According to even its supporters, the passage of GINA is an important step in this direction, but one that may need improvement over time.

Table 2 presents additional recommendations that address six issues that arose prominently from our work:

1. How can the federal government promote evidence-based decision making for genetic services?
2. How can the government protect consumers from harms that might arise in genetic services markets?
3. How can the government promote innovation in genetic services and their delivery?
4. How can the government address social and distributional issues around genetic services?
5. How can the government increase the supply of providers with genetic training and expertise?
6. How can the government assure access to genetic services for rural populations?

Again, we grouped these recommendations into the four categories reflecting the policy tools that each one embodies.

TABLE 2

<i>Issue 1: How can the federal government promote evidence-based decision making for genetic services?</i>	
C/F	Encourage research data coordination through NIH
PI	Cover only clinically/cost effective care in public insurance programs
PI	Use data from public purchases to create an evidence base for genetic services research
PP	Fund research on clinical application/utility and cost effectiveness of genetic services
R	Require evidence-based assessment for approval of new technologies

<i>Issue 2: How can the government protect consumers from harms that might arise in genetic services markets?</i>	
C/F	Facilitate interagency (e.g., HRSA, CDC, CMS, NIH) discussions about genetic services delivery and policy
C/F	Evaluate the need for broad regulations regarding direct to consumer advertising and/or retail genetic services
C/F/R	Assure that FTC, FDA, and state attorneys general carry out mission of preventing harm and fraud
R	Regulate “home brew” tests
R	Consider licensing retail genetics companies
<i>Issue 3: How can the government promote innovation in genetic services and their delivery?</i>	
PI	Pay for telemedicine and electronic genetic services in public insurance programs
PI	Integrate genetic services information into electronic medical records in public insurance programs
PI	Reward innovative genetic service delivery models in public insurance programs (e.g., reimbursing telephonic genetic counseling services)
PP	Fund demonstration projects on telegenetics
PP	Fund research on the impact of genetic delivery system innovations
<i>Issue 4: How can the government address social and distributional issues around genetic services?</i>	
C/F	Provide forums for discussion of financial, ethical, legal, social implications (FELSI); assure all voices are at the table
PI	Include genetic services in public programs for low income populations
PI	Provide insurance coverage for children with genetic conditions transitioning into adult services
PP	Fund research on access to genetic services
PP	Fund research on ethical issues related to genetic services
<i>Issue 5: How can the government increase the supply of providers with genetic training and expertise?</i>	
PP	Increase capacity in training pipeline for genetic services specialties
PP/R	Increase genetics content in all medical training

R	Require genetics CME for physician licensure
<i>Issue 6: How can the government assure access to genetic services for rural populations?</i>	
PI	Pay for telemedicine and other electronic genetic services in public insurance programs
PP	Use loan-forgiveness model for rural providers with genetics expertise

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