

The Role of Genetics in the Provision of Essential Public Health Services

States include genetics services among their public health programs, but budget shortfalls raise the question, is genetics an essential part of public health? We used the Essential Services of Public Health consensus statement and data from state genetics plans to analyze states' public health genetics programs.

Public health genetics programs fulfill public health obligations: birth defects surveillance and prevention programs protect against environmental hazards, newborn screening programs prevent injuries, and clinical genetics programs ensure the quality and accessibility of health services. These programs fulfill obligations by providing 4 essential public health services, and they could direct future efforts toward privacy policies, research on communications, and rigorous evaluations. (*Am J Public Health*. 2007;97:620–625. doi: 10.2105/AJPH.2006.087791)

| Grace Wang, MPH, and Carolyn Watts, PhD

IN 2000, THE WHITE HOUSE declared that the sequencing of the human genome, a 13-year effort, was an achievement leading to “new ways to prevent, diagnose, treat and cure disease.”¹ Since that time, the media have continued to fuel public interest in genomics research with headlines about creating designer babies and cracking the code of life.^{2,3} Whereas the goals of the US National Human Genome Research Institute are more limited than those of the White House, the institute has also communicated an ambitious vision, “to improve human health and well-being.”^{4(p836)}

Certain genetics services, most particularly newborn screening and other maternal and child health services, have been part of state public health programs for several decades.^{5–7} As these activities have expanded, researchers and policymakers have weighed in with their views on how genetics might be incorporated more broadly into the public health infrastructure.^{8,9}

Over the same period that states were expanding genetics services, however, states experienced combined budget deficits of almost \$80 billion.¹⁰ Although conditions are improving, spending pressures for public programming continue. Shortages may compel states to respond to the “persistent critique of public health. . . that the field has strayed beyond its natural boundaries”^{11(p1055)} by only engaging in core activities such as infectious disease surveillance or

immunizations. The competition for scarce resources raises the question, is genetics an essential part of public health?

We used the Essential Services of Public Health consensus statement as a benchmark to answer this question. Using information from 19 state genetics plans, we describe the range of public health genetics programs and discuss how they fit within this public health rubric. Our description serves to illuminate the breadth of genetics programs and the contribution of genetics programs to the goals of public health. Finally, we offer perspectives on how public health genetics programs can incorporate the essential services missing from current state activities.

METHODS

We used the Essential Services of Public Health consensus statement to examine public health genetics programs described by 19 state genetics plans. “The consensus statement sets forth a definition intended to: (1) explain what public health is; (2) clarify the essential role of public health in the overall health system; and (3) provide accountability by linking public health performance to health outcomes.”¹² Work group members who developed the public health obligations and essential services described in the consensus statement represented federal government agencies, national associations, and nonprofit organizations. Multiple government agency heads and national

public health organizations have adopted the consensus statement. We compare public health genetics programs to this standard definition and use examples to describe how programs align with this standard.

State genetics plans provide data and formal documentation about the content, administration, and financing of public health genetics programs. Each of the 19 states devised its own process for assessing public health genetics program needs and determining the program priorities that were communicated in the state plans. To reflect the most current information, we included in our analysis all plans that were available to the public and completed between 2000 and 2005. Of the 50 states and the District of Columbia, 22 states had genetics plans. We omitted 3 state plans from review: Hawaii's full plan was not publicly available, Ohio's plan had not been updated since 1998, and Virginia's plan was in development. Our review included plans from Alaska, Arizona, Colorado, Connecticut, Iowa, Indiana, Michigan, Mississippi, Missouri, Nebraska, North Carolina, Oklahoma, Oregon, Rhode Island, Tennessee, Texas, Utah, Washington, and Wisconsin.^{13–31}

OBLIGATIONS OF PUBLIC HEALTH GENETICS PROGRAMS

We focused our analysis on the 3 public health genetics

The Purpose of Public Health

The fundamental obligation of agencies responsible for population-based health is to:

- Prevent epidemics and the spread of disease
- Protect against environmental hazards
- Prevent injuries
- Promote and encourage healthy behaviors and mental health
- Respond to disasters and assist communities in recovery
- Ensure the quality and accessibility of health services

Source: Harrell and Baker.¹²

programs most commonly identified by state plans: birth defects surveillance and prevention programs, newborn screening (NBS) programs, and clinical genetics programs. In reviewing the 19 state genetics plans, we determined whether their programs and activities met 3 of the 6 public health obligations as outlined in the Essential Services of Public Health consensus statement¹² (see the box on this page): birth defects surveillance and prevention programs “protect against environmental hazards,” NBS programs “prevent injuries,” and clinical genetics service programs “assure the quality and accessibility of health services.”

Protect Against Environmental Hazards

Birth defects surveillance and prevention programs protect against environmental hazards by diagnosing and investigating health problems and health hazards in the community. Birth defects surveillance involves epidemiological research and the monitoring of genetic and environmental factors associated with birth defects and genetic disorders. Passive surveillance systems (those that rely on participant reporting) in Connecticut, Indiana, and Michigan as well as the active systems (those that involve direct solicitation of data) in

Iowa and North Carolina use multiple sources of case identification.^{16–19,23} For example, North Carolina’s and Michigan’s monitoring programs link vital records, hospital data, and claims files.^{19,23}

Because some birth defects have multifactorial etiologies that are both genetic and environmental in nature, public health genetics programs sponsor teratogen information services. These services aim to educate the workforce and the public about environmental hazards that affect pregnancy and breastfeeding, such as medications, infectious diseases, substance abuse, and occupational and environmental exposures.

Prevent Injury

State genetics plans indicate that all 19 states conduct NBS, a service intended to prevent injury. NBS prevents injury to the physiology and development of children through early detection of genetic and metabolic disorders. Identifying children who test positive for genetic and metabolic disorders is intended to facilitate early treatment that prevents development of negative and irreversible health outcomes.

States have developed systems to mitigate the repercussions of conditions detected by NBS. NBS programs link families of infants whose screening results are abnormal to health services by

overseeing confirmation testing and notifying providers and families of results. In Colorado, Connecticut, Missouri, Oregon, and Tennessee, case managers identify positive screens and report confirmed cases to primary care providers, often with referral to specialty clinics.^{15,16,21,25,27} In addition to providing basic confirmation and referral, genetic counselors in the North Carolina Genetics Health Care Unit act as liaisons between regional medical genetic centers and the local community to coordinate insurance and financial services, nutrition counseling, and referrals to early childhood programs.²³ In Texas, the NBS program staff contacts the health care providers and guardians of infants with confirmed diagnoses to update an NBS registry to facilitate follow-up and health status monitoring.²⁸

Ensure Health Service Quality and Accessibility

Clinical genetic service programs ensure the quality and accessibility of health services with diagnostic evaluations and confirmatory testing, counseling, case management, consultation, referral, and treatment programs for both children and adults with genetic and inherited disorders. An important mechanism for delivery of clinical genetic services is partnership between universities and government programs, such as federal–state match programs for children with special health care needs. State programs contract with universities to administer specialty genetics clinics. By partnering with universities, state-supported clinics can provide access to board-certified medical geneticists, biochemical geneticists, and other subspecialty providers. Alaska, Arizona, Connecticut, Iowa, Mississippi, Missouri,

Nebraska, Tennessee, Utah, Washington, and Wisconsin all have university-based centers that receive state support and offer services to pediatric and adult populations with genetic and metabolic disorders.^{13,14,16,18,20–22,27,29–31}

States administer outreach specialty genetics clinics to assure entry for families in geographically remote areas into systems of clinical care. Clinics for genetic disorders such as cystic fibrosis, blood disorders, and metabolic disorders are often organized within academic centers that send genetic teams to more remote areas to provide services, as in Arizona, Missouri, Nebraska, and Oregon.^{14,21,22,25} In addition, outreach clinics work with local providers to enhance service provision. Colorado’s 5 outreach clinics accept referrals from community health professionals and schools.¹⁵ Alaska and North Carolina work with local public health nurses and practitioners to help families prepare for appointments and any follow-up services they may need.^{13,23} Finally, outreach to geographically isolated locations is enhanced through telehealth, electronic information and telecommunications technology used to promote health. Nebraska uses telehealth to connect families and health care providers in rural areas to genetics consultants at the University of Nebraska.²²

ESSENTIAL SERVICES OF PUBLIC HEALTH GENETICS PROGRAMS

Public health agencies are charged with providing 10 essential services in addition to the 6 obligations of public health. Our analysis of state genetics plans indicated that, collectively, the 3 most common public health genetics programs (birth defects

TABLE 1—The 3 Most Common State Public Health Genetics Programs, by Provision of Essential Public Health Services

Essential Public Health Services ^a	Genetics Programs		
	NBS	Clinical Genetics ^b	Birth Defects ^c
Monitor health status to identify and solve community health problems			Calculate birth defects rates
Diagnose and investigate health problems and health hazards in the community	Screen newborns before leaving the hospital Process specimens at state labs, often with tandem mass spectrometry		Conduct active and passive surveillance systems monitoring birth defects
Inform, educate, and empower people about health issues	Provide written information for families about NBS	Conduct sickle cell disease outreach efforts	Sponsor folic acid campaigns and teratogen information services
Mobilize community partnerships and action to identify and solve health problems	Partner with universities and advocacy groups to provide services and referrals	Partner with universities and advocacy groups to provide services and referrals	Partner with the March of Dimes for folic acid campaigns
Develop policies and plans that support individual and community health efforts	Change rules and regulations guiding NBS expansion Use advisory committees		
Enforce laws and regulations that protect health and ensure safety	Monitor quality of laboratories used to process NBS specimens		
Link people to needed personal health services and assure the provision of health care when otherwise unavailable	Refer families whose children are identified by screening Provide assistance with dietary formulas	Sponsor outreach clinics and financial assistance for individuals in need	Sponsor teratogen information services
Ensure a competent public and personal health care workforce	Develop presentations and guidelines to health care providers about NBS	Facilitate consultations between genetic specialists and community health care providers	Sponsor continuing medical education from teratogen information services
Evaluate effectiveness, accessibility, and quality of personal and population-based health services	Measure counts of babies screened and conditions detected	Measure counts of individuals served at clinics	
Research for new insights and innovative solutions to health problems			Conduct epidemiological research on birth defects

Note. NBS = newborn screening.

^aServices as defined by Harrell and Baker.¹²

^bClinical genetic service programs ensure the quality and accessibility of health services with diagnostic evaluations and confirmatory testing, counseling, case management, consultation, referral, and treatment programs for both children and adults with genetic and inherited disorders.

^cThe monitoring, surveillance, and prevention of birth defects.

surveillance and prevention programs, NBS programs, and clinical genetics programs) provide 4 of the 10 essential public health services¹² (Table 1): partnering with communities, educating the public, linking people to needed health services, and ensuring a competent workforce.

Education About Community Partnerships and Health

Public health genetics programs mobilize community

partnerships to educate and empower people about health issues. Collaboration with advocacy groups has furthered birth defects education and prevention efforts. Cofunding from community chapters of the March of Dimes has been instrumental to folic acid education campaigns in Alaska, Arizona, Indiana, Michigan, Mississippi, Oregon, Texas, and Wisconsin.^{13,14,17,19,20,25,28,31} Collaborating with the March of Dimes has resulted in targeted media

campaigns for women of child-bearing age as well as provision of health information, such as brochures, at the community level. Oregon’s Women, Infants, and Children program distributes a brochure to encourage clients to increase folic acid consumption.²⁵ Alaska reinforces health promotion messages about folic acid by distributing brochures and posters through primary care providers.¹³ Partnerships between NBS programs, clinical genetics programs,

and advocacy groups provide accessible health information resources at community levels, with particular emphasis on sickle cell disease. Patient organizations in Michigan provide information about genetic services to constituents and refer clients to genetic counseling services.¹⁹ Chapters of the Sickle Cell Disease Association of America join with Arizona, Connecticut, Tennessee, and Texas to develop brochures, educational videos,

films, and presentations about sickle cell anemia and related services.^{14,16,27,28} North Carolina's regional sickle cell centers partner with the association to provide adult screenings and statewide education for schools, churches, and civic groups.²³

Link People to Needed Health Services

The 3 most common public health genetics programs link people to needed health services by ensuring access into the health system for socially disadvantaged people. States link low-income families to needed clinical genetics services through condition-specific programs that pay for services. For example, sickle cell disease programs in Missouri and North Carolina provide financial assistance to eligible adults for outpatient and inpatient services, prescriptions, home medical equipment, emergency care, and service coordination.^{21,23}

Existing government programs provide financial assistance to individuals with genetic conditions. For example, NBS programs in Arizona, Missouri, Nebraska, and Oklahoma help pay for the dietary formulas required to treat newborns with phenylketonuria after they are identified through screening.^{14,21,22,24} Programs for children with special health care needs cover medical and surgical care for eligible individuals, often to age 21. These programs enable families to receive service coordination, care provision training, legal resources, and emotional support. For example, Tennessee's genetic centers coordinate services with primary providers by working with case managers from the children with special health care needs program.²⁷ Arizona uses its

program for children with special health care needs to provide financial assistance to adults with cystic fibrosis and sickle cell anemia.¹⁴

Public health genetics programs also partner with family health programs and early intervention services. Birth defects registries play a role in facilitating access to clinical services for families that have been included in the registry. For example, North Carolina's program directs families to prenatal screening and genetics counseling services as needed.²³ Mississippi identifies children with birth defects so the children can receive assistance from the First Steps Early Intervention Program, Children's Medical Program, and Perinatal High Risk Management program.²⁰

Partnerships across programs, including public insurance programs, are beginning to integrate their data systems to identify clients in need and to streamline services for clients who receive benefits from multiple programs. For example, Colorado reports children identified with genetic disorders through NBS to the program for children with special health care needs for inclusion in the birth defects monitoring and prevention program.¹⁵ Rhode Island enters NBS data into a longitudinal, integrated data system that links 9 maternal and child health service programs.²⁶

Ensure a Competent Health Care Workforce

Public health genetics programs train health care personnel to increase their knowledge and awareness of genetics, genetic services, and available resources. Teratogen information services in Connecticut, Indiana, Michigan, Nebraska, Oregon, Texas, and

Washington all provide information to both health care professionals and the public, often through toll-free phone lines.^{16,17,19,22,25,28,31} Michigan's program also sponsors lectures for the medical community and the public.¹⁹

Continuing medical education projects facilitate the integration of genetics into usual care. Alaska sponsors medical education presentations in 8 cities across the state.¹³ Mississippi, Missouri, and North Carolina have targeted education efforts on sickle cell disease for health professionals.^{20,21,23} For example, Mississippi sponsors meetings with pediatricians, emergency room physicians, and public health physicians about the care and treatment of pain for patients with sickle cell disease.²⁰

States also provide resources for health care professionals to facilitate access to services. NBS programs in Arizona and Oregon provide screening guidelines to hospitals, physicians' offices, and laboratories.^{14,25} Arizona, Missouri, and North Carolina develop and distribute booklets describing clinical genetics services and their locations in the state.^{14,21,23} Finally, states are preparing the workforce for the genetics service needs of diverse populations. Arizona has worked to teach community lay health workers about basic human genetics and to provide Spanish language training to genetics health professionals.¹⁴

GAPS IN SERVICES OF PUBLIC HEALTH GENETICS PROGRAMS

When we examined the list of 10 essential public health

services, we identified gaps in the services of public health genetics programs (Table 1). Future efforts to research communication, to enforce laws and develop policies on privacy, to monitor health status, and to evaluate program effectiveness will strengthen and improve these programs' contributions to public health.

Research for New Insights

The public communications campaigns of public health genetics programs can bolster efforts in the research for new insights and innovative solutions to health problems. Through the work of public health genetics programs and community organizations, researchers and practitioners can learn more about strategies for communicating risk to relevant parties. Although public health institutions have a history of communicating behavioral or infectious disease risk, new methods for conveying inherited risk across diverse populations may require more study.³² Investigations could determine whether approaches developed by the genetics provider community effectively convey risk at the population level outside of clinical settings. Research could inform the development of Web-based resources that teach the public about genetic risk.³³ State public health programs could also capitalize on emerging studies by developing interventions that combine genetic risk information with individual behavior change guidelines.³⁴

Public health genetics programs' communications efforts could also contribute to a second area of research: communication within families. This area may be of particular interest to chronic disease programs that are increasingly incorporating family history and inheritance into activities. For

example, state programs focusing on diabetes, asthma, heart disease, and heritable cancers may consider familial obligation, family involvement in decisionmaking, variation in communications between relatives of different genders, cultural factors affecting familial communication, and perceived salience of family history.^{35–39}

Develop Policies and Enforce Laws

Intergovernmental collaborations by public health genetics programs are an important way for states to enforce laws and to develop policies that support health efforts. Although data integration can improve service delivery, policymakers must consider integration's impact on privacy, confidentiality, and informed consent. As Thomas et al. caution, states delivering genetics services have a duty to protect the privacy of individuals and families affected by genetic disorders.⁴⁰ For states with genetic privacy legislation, practitioners have a role in enforcing these laws by examining their states' data-integration projects. One question resulting from cross-agency collaboration is whether data integration inadvertently reveals the potential carrier status of parents and siblings for conditions such as cystic fibrosis, which many states are considering for NBS. Second, data sharing to facilitate families' access to services requires the inclusion of personal and family identifiers in the data. Strategies for maintaining confidentiality while still enabling service delivery will need to incorporate—and protect—the information that program staffs require. Does the early intervention services program need to know the child's diagnosis or the referring program?

Finally, issues of informed consent arise because families concerned about stigma or genetic discrimination may not welcome automatic referral.⁴¹

Monitor Health Status and Evaluate Effectiveness

With the establishment and growth of public health genetics programs, public health practitioners can improve service delivery by providing 2 related essential services. First, monitoring health status to identify and solve community health problems involves the collection and analysis of information on access, utilization, costs, and outcomes of personal health services. Although some NBS and clinical genetics programs track utilization of services via patient counts, these programs could improve essential services by conducting more extensive and rigorous evaluations. States could conduct long-term evaluations with families to assess whether inclusion of new NBS tests in NBS programs affects clinical and quality-of-life outcomes. Evaluations of clinical genetic services could identify population subgroups that do not access genetics services to determine why not. Researchers could also assess whether care at state-sponsored clinics affects utilization of other health care services, such as hospitalizations. Evaluation plans and data gathering could be developed in conjunction with patient groups to incorporate social values and patient satisfaction with program services.

Second, ongoing evaluation of program effectiveness, accessibility, and quality provides information necessary for allocating resources and reshaping programs. A standard conceptual framework to assess public

health performance allows practitioners to compare and prioritize important traditional and emerging health issues.^{42,43} Comparable measures will enable evaluators and policymakers to contrast genetics with other public health practices, such as vaccination and communicable disease monitoring. Information from well-devised evaluations and cross-program comparisons in combination with data on populations at risk for disease will assist states as they determine how to invest scarce resources for rare disorders, chronic conditions, genetic disease, and nongenetic disease.

CONCLUSION

Our analysis indicates that states' genetics programs do play an essential role in the provision of public health. Information from 19 state genetics plans demonstrates that public health genetics programs fulfill public health obligations and conduct essential services, including mobilizing community partnerships, educating the public, linking people to needed services, and ensuring a competent workforce.

As public health genetics programs grow, they can attend to 5 additional essential services. Future research could provide insight into risk and family communication. Laws and policies could account for confidentiality issues brought about by data integration. Rigorous evaluations could enable the public sector to prioritize nongenetic and genetic issues appropriately when deciding resource allocation.

Certainty among states that their activities in genetics are fundamental to public health becomes increasingly important as legislators and the federal

government turn their attention to genomics.^{44,45} A defined state role helps to clarify the functions of other government sectors in supporting genomics research and regulating genetic services. Ultimately, states' efforts to provide essential services ensure that public health genetics programs continue to make important contributions to public health. ■

About the Authors

The authors are with the Institute for Public Health Genetics, University of Washington, Seattle, and serve on the Genetic Services Policy Project team, a collaboration between the University of Washington and the Washington State Department of Health, Genetic Services Section. Carolyn Watts is also with the Department of Health Services, University of Washington, Seattle.

Requests for reprints should be sent to Dr. Carolyn Watts, Department of Health Services, University of Washington, Box 357660, Seattle, WA 98195 (e-mail: watts@u.washington.edu).

Contributors

G. Wang conceptualized the research question, synthesized analyses, and led the writing. C. Watts originated the study, supervised its implementation, and reviewed article drafts.

Acknowledgments

This article was supported in part by the Maternal and Child Health Bureau, US Department of Health and Human Services (grants U35MC02601 and U35MC02602).

References

1. The White House, Office of the Press Secretary. President Clinton announces the completion of the first survey of the entire human genome: hails public and private efforts leading to this historic achievement. June 26, 2000. Available at: http://www.orml.gov/sci/techresources/Human_Genome/project/clinton1.shtml. Accessed August 22, 2006.
2. Bhattacharya S. Banned "designer baby" is born in UK. June 19, 2003. Available at: <http://www.newscientist.com/article.ns?id=dn3854>. Accessed August 29, 2006.
3. Nova Online. Cracking the code of life. 2001. Available at: <http://www.pbs.org/wgbh/nova/genome/>. Accessed August 22, 2006.
4. Collin FS, Green ED, Guttmacher AE,

- Guyer MS, US National Human Genome Research Institute. A vision for the future of genomics research. *Nature*. 2003;422:835–847.
5. Therrell BL. US newborn screening policy dilemmas for the twenty-first century. *Mol Genet Metab*. 2001;74:64–74.
6. Piper MA, Lindenmayer JM, Lengerich EJ, et al. The role of state public health agencies in genetics and disease prevention: results of a national survey. *Public Health Rep*. 2001;116:22–31.
7. Au S. Survey of nationwide public health genetics activities. 2002. Available at: <http://www.stategeneticscoordinators.org/surveyreport/2001survey-bw.pdf>. Accessed January 11, 2006.
8. Kaye CI, Laxova R, Livingston JE, et al. Integrating genetic services in public health—guidance for state and territorial programs from the National NBS and Genetics Resource Center. *Community Genet*. 2001;4:175–196.
9. Association of State and Territorial Health Officials. Genomics: a guide for public health. 2003. Available at: <http://www.genomicstoolkit.org/moxie/aboutsite/index.shtml>. Accessed January 27, 2006.
10. Boyd D, Wachino V. Is the state fiscal crisis over? A 2004 state budget update. January 2004. Available at: <http://www.kff.org/medicaid/upload/Is-the-State-Fiscal-Crisis-Over-A-2004-State-Budget-Update-Issue-Brief.pdf>. Accessed August 30, 2006.
11. Gostin LO, Powers M. What does social justice require for the public's health? Public health ethics and policy imperatives. *Health Aff (Millwood)*. 2006;25:1053–1060.
12. Harrell JA, Baker EL, Essential Services Workgroup. The essential services of public health. Available at: <http://www.health.gov/phfunctions/public.htm>. Accessed January 16, 2007.
13. Department of Health and Social Services, State of Alaska. Genetics plan for the state of Alaska: findings and recommendations. 2003. Available at: <http://hss.state.ak.us/dhcs/PDF/FinalDraft07-28-03.pdf>. Accessed January 11, 2006.
14. Office of Women's and Children's Health, Arizona Department of Health Services. Genetic health care in Arizona: a plan for the 21st century. 2000. Available at: <http://www.azdhs.gov/phs/owch/pdf/genstatephn.pdf>. Accessed January 11, 2006.
15. Children and Youth with Special Health Care Needs Section, Department of Public Health and Environment. Colorado State genetics services plan. 2002. Available at: <http://www.cdphpe.state.co.us/ps/genetics/geneticsplan.pdf>. Accessed January 11, 2006.
16. Connecticut Department of Public Health, Planning Branch. Connecticut genomics action plan. 2005. Available at: <http://www.dph.state.ct.us/genomics/Documents/gap.pdf>. Accessed January 27, 2006.
17. Genetic Disease Program, Maternal and Child Health Services, Indiana State Department of Health. Genetic services state plan for Indiana. 2002. Available at: http://genes-r-us.uthscsa.edu/resources/genetics/indiana_geneticsplan.pdf. Accessed January 11, 2006.
18. Birth Defects Institute, Iowa Department of Public Health. The state genetics plan for Iowa: a plan of action for the Iowa Department of Public Health. 2001. Available at: <http://www.idph.state.ia.us/genetics/common/pdf/genetioplan.pdf>. Accessed January 11, 2006.
19. Michigan Genetics Advisory Committee, Department of Community Health. Genetics through the life cycle: improving health and preventing disease. 2002. Available at: http://www.michigan.gov/documents/MIgeneticsplanandassessment__118168_7.pdf. Accessed January 11, 2006.
20. Division of Genetic Services, Mississippi State Department of Health. Planning for genetic services in Mississippi. 2003. Available at: http://www.msdh.state.ms.us/msdhsite/_static/resources/758.pdf. Accessed January 11, 2006.
21. Missouri Department of Health and Senior Services. State plan for genetic services in Missouri. Available at: http://genes-r-us.uthscsa.edu/resources/genetics/missouri_geneticsplan.pdf. Accessed January 11, 2006.
22. Department of Health and Human Services. Nebraska's plan for NBS and genetics services. 2003. Available at: <http://www.hhs.state.ne.us/hew/fah/nsp/NewDocs/stateplanPT1.pdf>. Accessed January 11, 2006.
23. North Carolina Department of Health and Human Services, North Carolina Institute for Public Health. State-wide needs assessment for a comprehensive genomics plan. 2003. Available at: <http://www.sph.unc.edu/nccgph/assessment.pdf>. Accessed January 11, 2006.
24. Oklahoma Genetics Advisory Council, Department of Health. Oklahoma State genetics plan. Available at: <http://www.health.state.ok.us/program/gp/osgp/index.html>. Accessed January 11, 2006.
25. Oregon Department of Human Services. Genetics and public health in Oregon: a summary of assessment methods & findings. 2002. Available at: <http://www.oregon.gov/DHS/ph/genetics/plans.shtml>. Accessed January 11, 2006.
26. Rhode Island Department of Health. Rhode Island State genetics plan. 2002. Available at: http://genes-r-us.uthscsa.edu/resources/genetics/rhodeisland_geneticsplan.pdf. Accessed January 11, 2006.
27. Maternal and Child Health, Genetics and NBS, Tennessee Department of Health. Tennessee genetics plan. 2003. Available at: http://www2.state.tn.us/health/Downloads/Genetics_Plan_2003.pdf. Accessed January 11, 2006.
28. Genetics Program, Texas Department of State Health Services. The development of the Texas State genetics plan and a plan for integrated data infrastructure for genetic services. 2002. Available at: http://genes-r-us.uthscsa.edu/resources/genetics/texas_geneticsplan.pdf. Accessed January 11, 2006.
29. Children with Special Health Care Needs, Division of Community and Family Health Services, Utah Department of Health. Utah State genetics plan. 2002. Available at: http://genes-r-us.uthscsa.edu/resources/genetics/utah_geneticsplan.pdf. Accessed January 11, 2006.
30. Washington State Department of Health. Genetic services section plan. 2002–2005. Available at: <http://mchneighborhood.ichp.edu/wagenetics/index.html>. Accessed January 27, 2006.
31. Genetic services plan for Wisconsin. Available at: <http://www.slh.wisc.edu/genetics>. Accessed January 11, 2006.
32. Reynolds PP, Kamei RK, Sundquist J, Khanna N, Palmer EJ, Palmer T. Using the PRACTICE mnemonic to apply cultural competency to genetics in medical education and patient care. *Acad Med*. 2005;80:1107–1113.
33. Bernhardt JM, McClain J, Parrott RL. Online health communication about human genetics: perceptions and preferences of internet users. *Cyberpsychol Behav*. 2004;7:728–733.
34. Sanderson SC, Wardle J. Will genetic testing for complex diseases increase motivation to quit smoking? Anticipated reactions in a survey of smokers. *Health Educ Behav*. 2005;32:640–653.
35. Peterson SK. The role of the family in genetic testing: theoretical perspectives, current knowledge, and future directions. *Health Educ Behav*. 2005;32:627–639.
36. Hallowell N, Ardern-Jones A, Eeles R, et al. Men's decision-making about predictive BRCA1/2 testing: the role of family. *J Genet Couns*. 2005;14:207–217.
37. Patenaude AF, Dorval M, DiGianni LS, Schneider KA, Chittenden A, Garber JE. Sharing BRCA1/2 test results with first-degree relatives: factors predicting who women tell. *J Clin Oncol*. 2006;24:700–706.
38. Mesters I, Ausems M, Eichhorn S, Vasen H. Informing one's family about genetic testing for hereditary non-polyposis colorectal cancer (HNPCC): a retrospective exploratory study. *Fam Cancer*. 2005;4:163–167.
39. Walter FM, Emery J, Braithwaite D, Marteau TM. Lay understanding of familial risk of common chronic diseases: a systematic review and synthesis of qualitative research. *Ann Fam Med*. 2004;2:583–594.
40. Thomas JC, Irwin DE, Zuiker ES, Millikan RC. Genomics and the public health code of ethics. *Am J Public Health*. 2005;95:2139–2143.
41. Wilson J. To know or not to know? Genetic ignorance, autonomy and paternalism. *Bioethics*. 2005;19:492–504.
42. Handler A, Issel M, Turnock B. A conceptual framework to measure performance of the public health system. *Am J Public Health*. 2001;91:1235–1239.
43. Beitsch LM, Brooks RG, Grigg M, Menachemi N. Structure and functions of state public health agencies. *Am J Public Health*. 2006;96:167–172.
44. Obama B. A bill to improve access to and appropriate utilization of valid, reliable and accurate molecular genetic tests by all populations thus helping to secure the promise of personalized medicine for all Americans. S. 3822, 109th Congress, 2nd Session. 2006. Available at: http://frwebgate.access.gpo.gov/cgi-bin/getdoc.cgi?dbname=109_cong_bills&docid=f:s3822is.txt. Accessed September 4, 2006.
45. United States Government Accountability Office. Nutrigenetic testing: tests purchased from four web sites mislead consumers. GAO-06-977T. 2006. Available at: <http://www.gao.gov/new.items/d06977t.pdf>. Accessed September 4, 2006.