Integrating Genetic Services into Public Health - Guidance for State and Territorial Programs
Technical Assistance

• Serve in an advisory role for states and territories with or applying for planning grants
Technical Assistance (cont.)

• Assist states and territories with integration of existing MCH genetics resources with other public health programs and linkage with health care delivery systems

• Develop guidance for state and territorial genetics planning

• Create and support expert review teams and review process
Developing Guidance for State Genetics Planning

- Build on strengths of MCH Genetics
- Create a tool for integrating genetics into other public health divisions including chronic disease, environmental, and occupational health
Guidance for States and Territories

• Derives its constructs from Maternal and Child Health Bureau and Institute of Medicine models which are familiar to public health practitioners

• Sets forth a process for developing a plan to integrate genetics into health systems
Infrastructure Building Services

- Assessment
- Information Systems Development
- Applied Research
- Policy Development
- Legal Framework and Regulatory Infrastructure
Infrastructure Building Services (cont.)

• **Assurance:**
  
  – System of Integrated Genetic Services
  – Funding for Genetic Services
  – Training and Education of Health Professionals
  – Evaluation of the Genetic Services System
Population-based Services

- **Screening throughout the life cycle:**
  - Preconception (e.g. Teratogens)
  - Prenatal (e.g. Rh incompatibility)
  - Newborn Screening (e.g. PKU, Sickle Cell), Newborn Hearing Screening
  - Childhood (e.g. Family History)
  - Adulthood (e.g. Cholesterol)

- **Public Education**
IOM FUNCTIONS WITHIN THE MCHB PYRAMID

- Assessment
- Assurance
- Policy Development
- Direct Health Services
- Population-Based Services
- Infrastructure Building Services

Enabling Services

National Newborn Screening and Genetics Resource Center
Austin, Texas USA

NNSGRC
Enabling Services

Examples:

Transportation, Translation, Outreach, Respite Care, Purchase of Health Insurance, Case Management, Health Education, Family Support Services, Coordination with Medicaid and WIC
IOM FUNCTIONS WITHIN THE MCHB PYRAMID

- Address
- Assurance
- Direct Health Services
- Enabling Services
- Population-Based Services
- Infrastructure Building Services

Policy Development
Direct Health Services

• Examples:

Basic Health and CSHCN Services, Medical Home, Direct Genetic Services, Genetic Counseling, Medical Food, Chronic Diseases (e.g. Cancer, Diabetes, Cardiovascular Disease), Transplants for Metabolic Patients
Guidance Document

Community Genetics
2001;4:175-196

Integrating Genetic Services into Public Health—Guidance for State and Territorial Programs from the National Newborn Screening and Genetics Resource Center (NNSGRC)

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Key Words
Public health - Genetics - Guidance - Policy - Assessment - Assurance

Introduction

During the last decade, there have been many advances in genetics, most resulting from mapping the human genome through the Human Genome Project and other research initiatives. Research in the next decade will bring an understanding of genetic/biologic risk and protective factors, and a description of the influence of the environment on genetic variation. Tests will continue to be developed to identify individuals with genetic disorders and asymptomatic individuals with a genetic predisposition to a particular disorder(s).

* On behalf of the Genetics Advisory Committee of the National Newborn Screening and Genetics Resource Center (NNSGRC) for a complete listing of current program members contributing to this paper.

This expanded knowledge base in genetic medicine is happening, and will continue to have, an impact on public health policy and service delivery, as well as on health care and social service practice. To optimize the impact of this scientific knowledge, advances in genetics will need to be integrated into public health activities. Although the ability to incorporate genetic medicine into public health and health care practice depends ultimately on the capacity to achieve equal access to health care and social services, optimal health also depends on the ability to utilize the latest scientific knowledge in health care practice—in this case, genetic medicine or knowledge about disease causation, illness management, and health promotion.

Unraveling the interaction between genetics, environment, and behavior will require partnerships between the public health and health care communities. Genetic medicine may offer new tools for both individual and community assessment that are useful for long-term primary care and public health activities. For example, by identifying asymptomatic persons at increased risk for acquiring certain disease(s) (clinical assessment), health care
Availability and Use of Guidance Document

- Published in Fourth Quarter of 2001
- Was used to design a self-assessment tool (using PacNoRGG document as model) and a template for reviewers to use when visiting and providing technical assistance to state programs.
- Reprints available on request from NNSGRC Office
- .pdf version available at NNSGRD website http://genes-r-us.uthscsa.edu
Internet Resources for State Genetics Planning

• NNSGRC website at http://genes-r-us.uthscsa.edu has links and online tools for state genetics planning
  – State genetics plans
  – Assessment instruments
  – Proceedings from national meetings
  – Genetics Educational Materials (GEM) database
Advances in genetics provide an opportunity for improved understanding of both health and disease. The challenge is to translate this knowledge and technology into services that benefit the individual and the public.