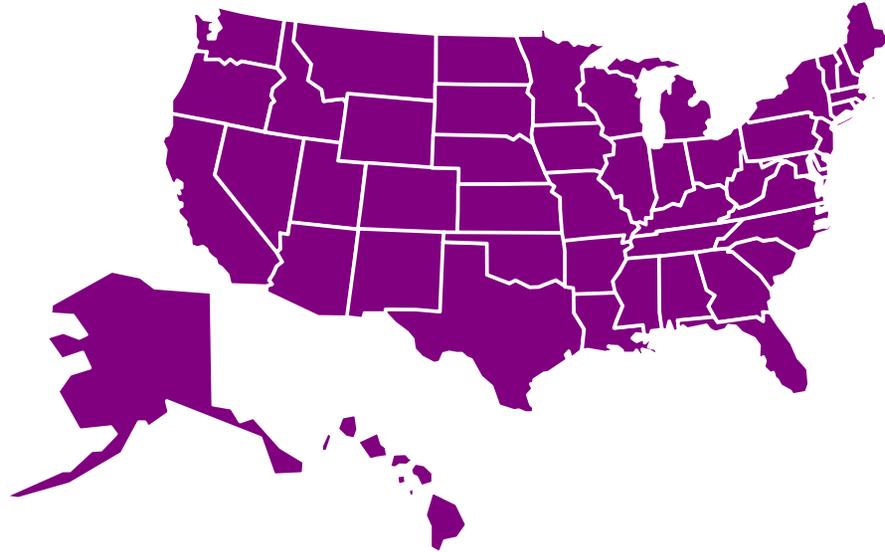


# Integrating Genetic Services into Public Health - Guidance for State and Territorial Programs



# Technical Assistance

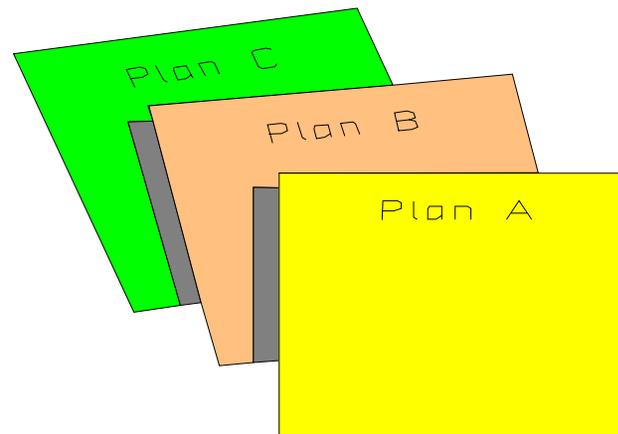
- Serve in an advisory role for states and territories with or applying for planning grants

## 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

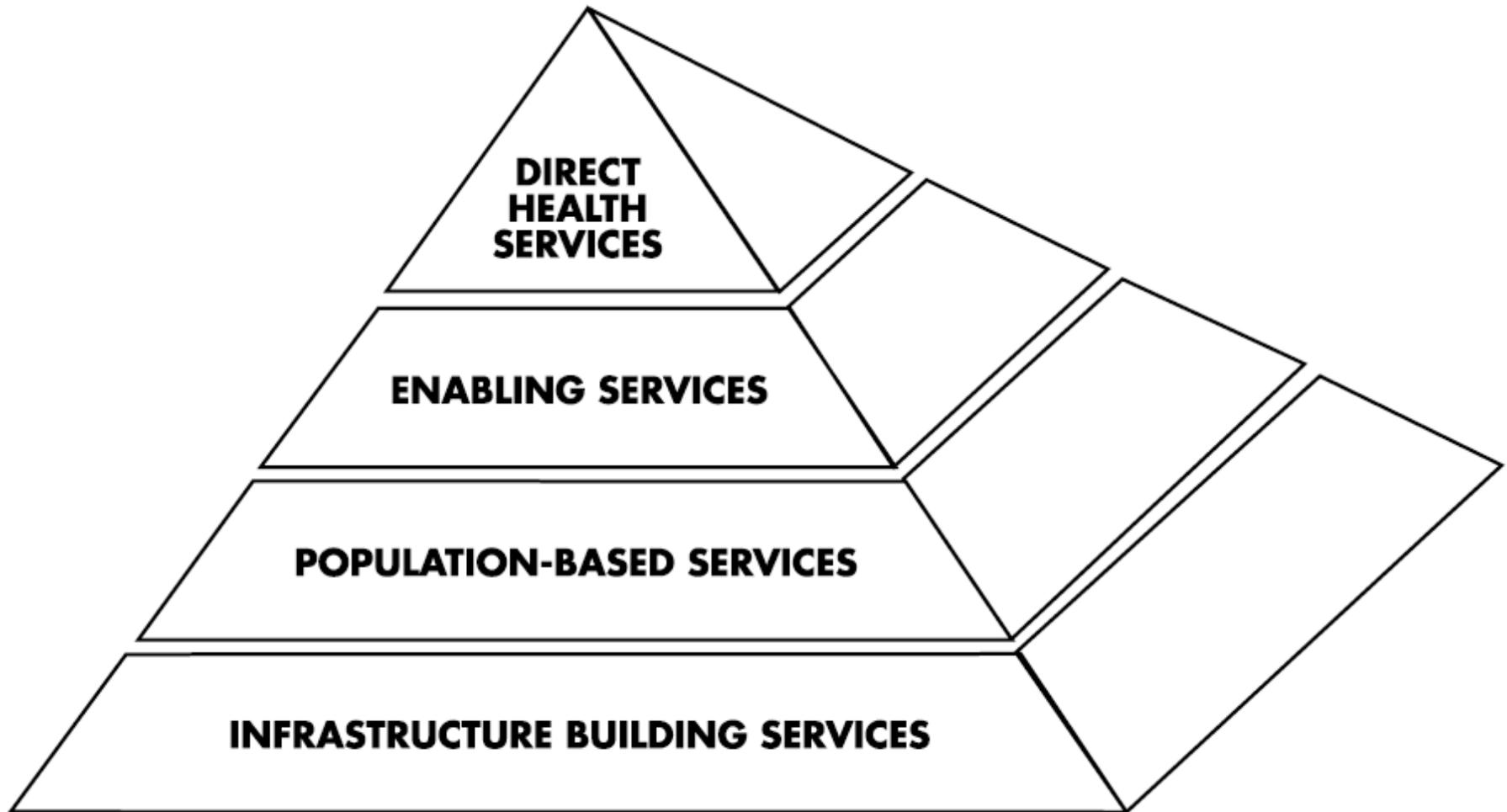




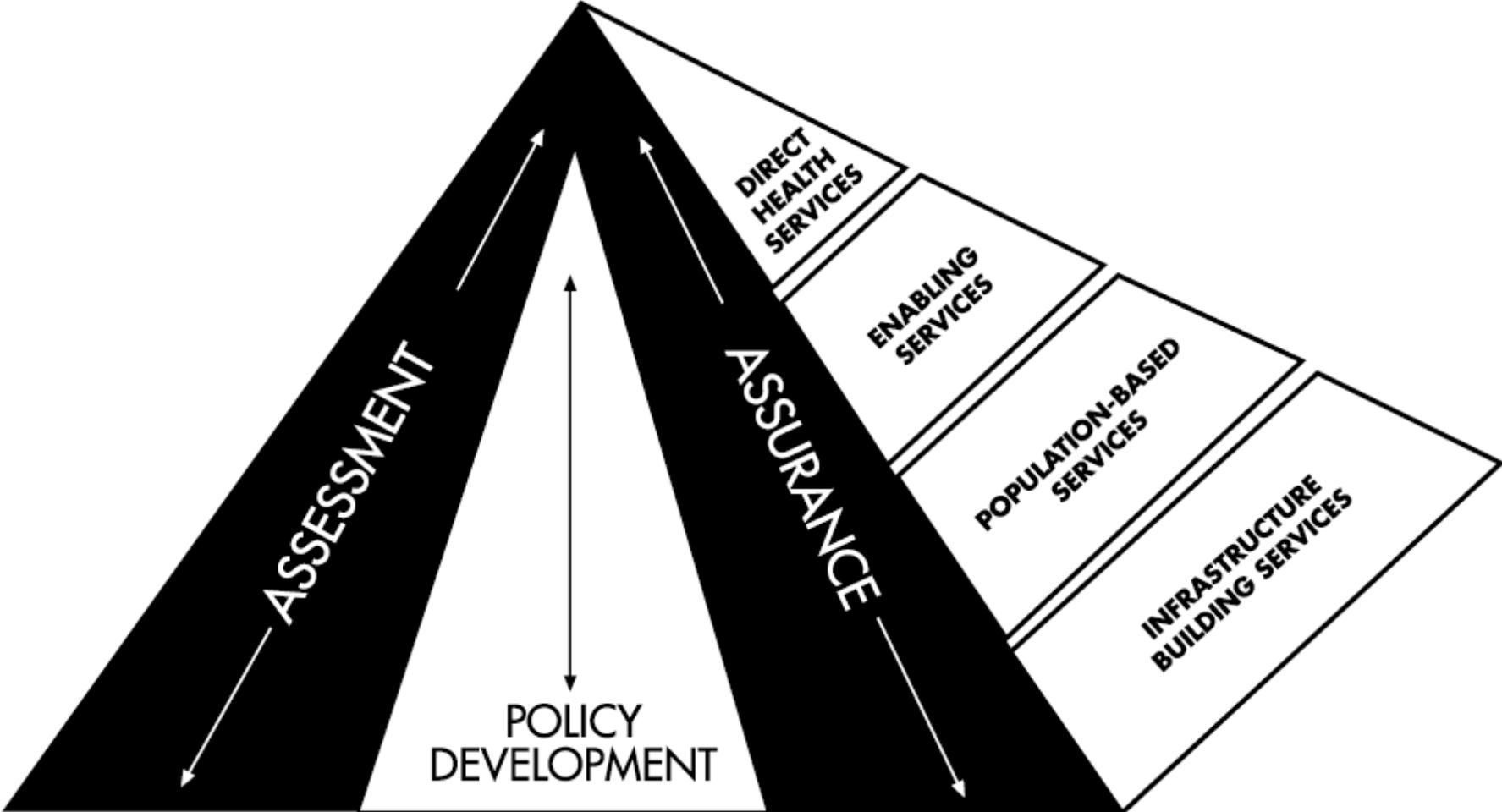
# Guidance for States and Territories

- 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

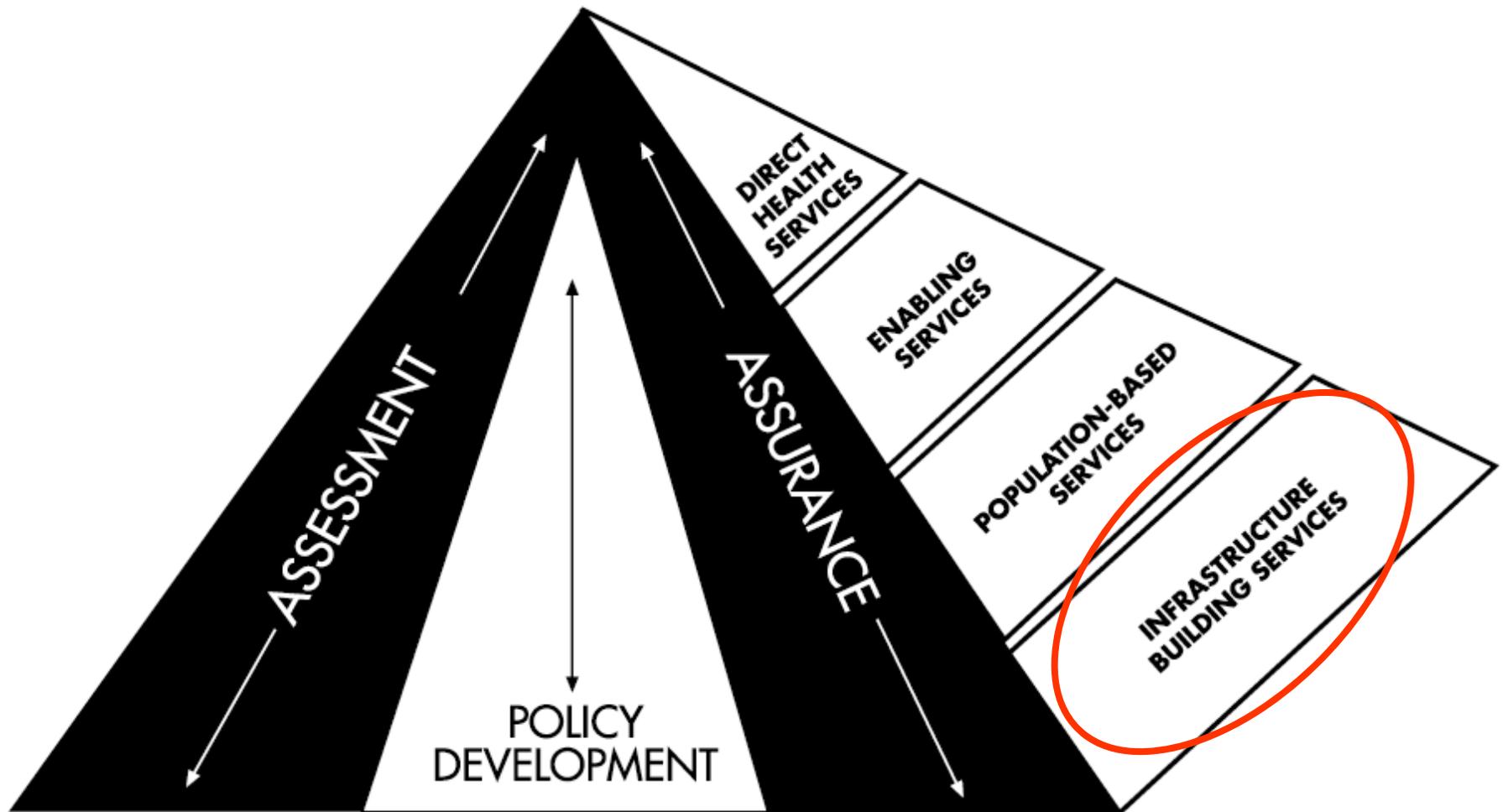
# MCHB PYRAMID



# IOM FUNCTIONS WITHIN THE MCHB PYRAMID



# IOM FUNCTIONS WITHIN THE MCHB PYRAMID



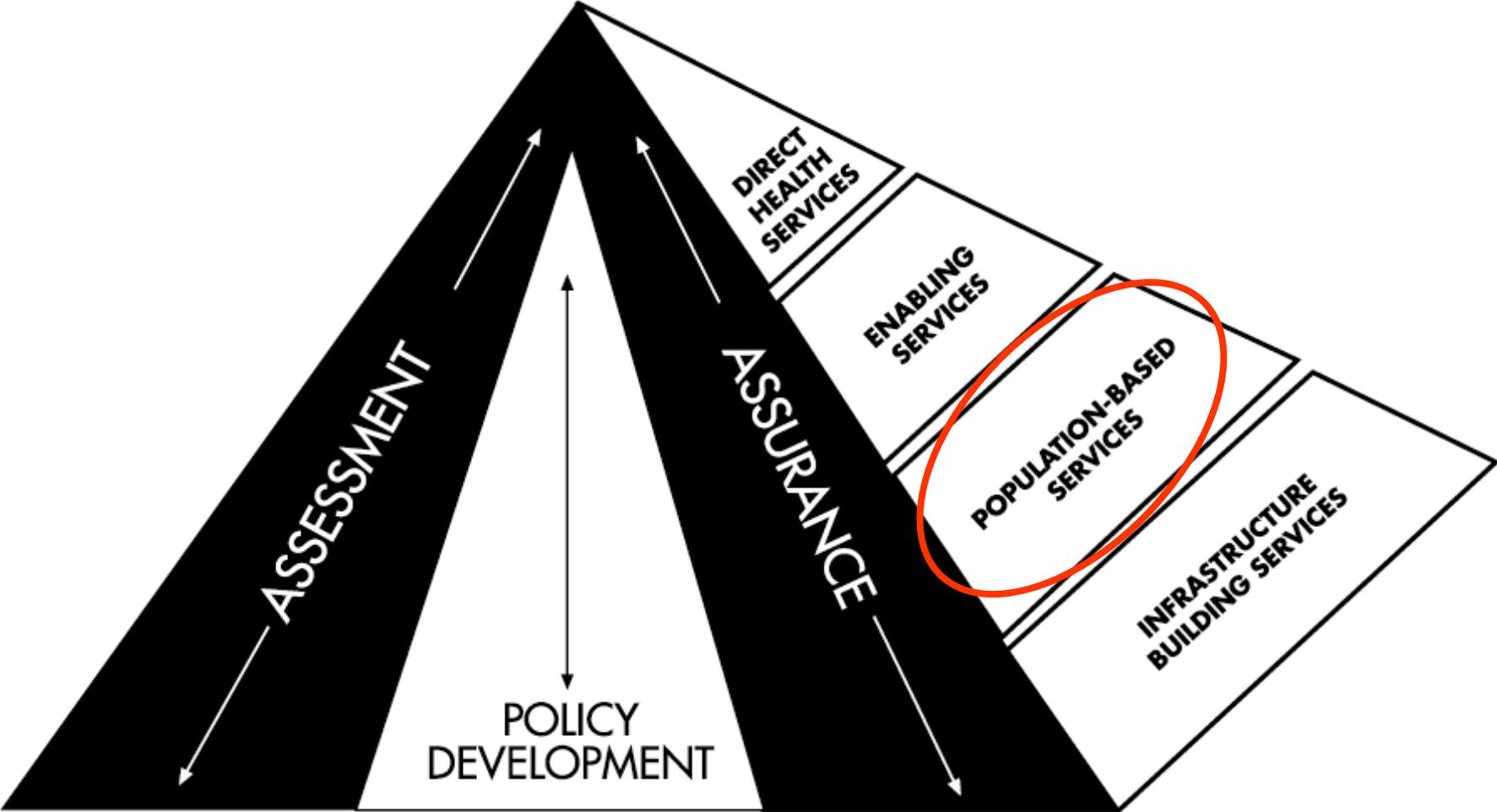
# Infrastructure Building Services

- **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

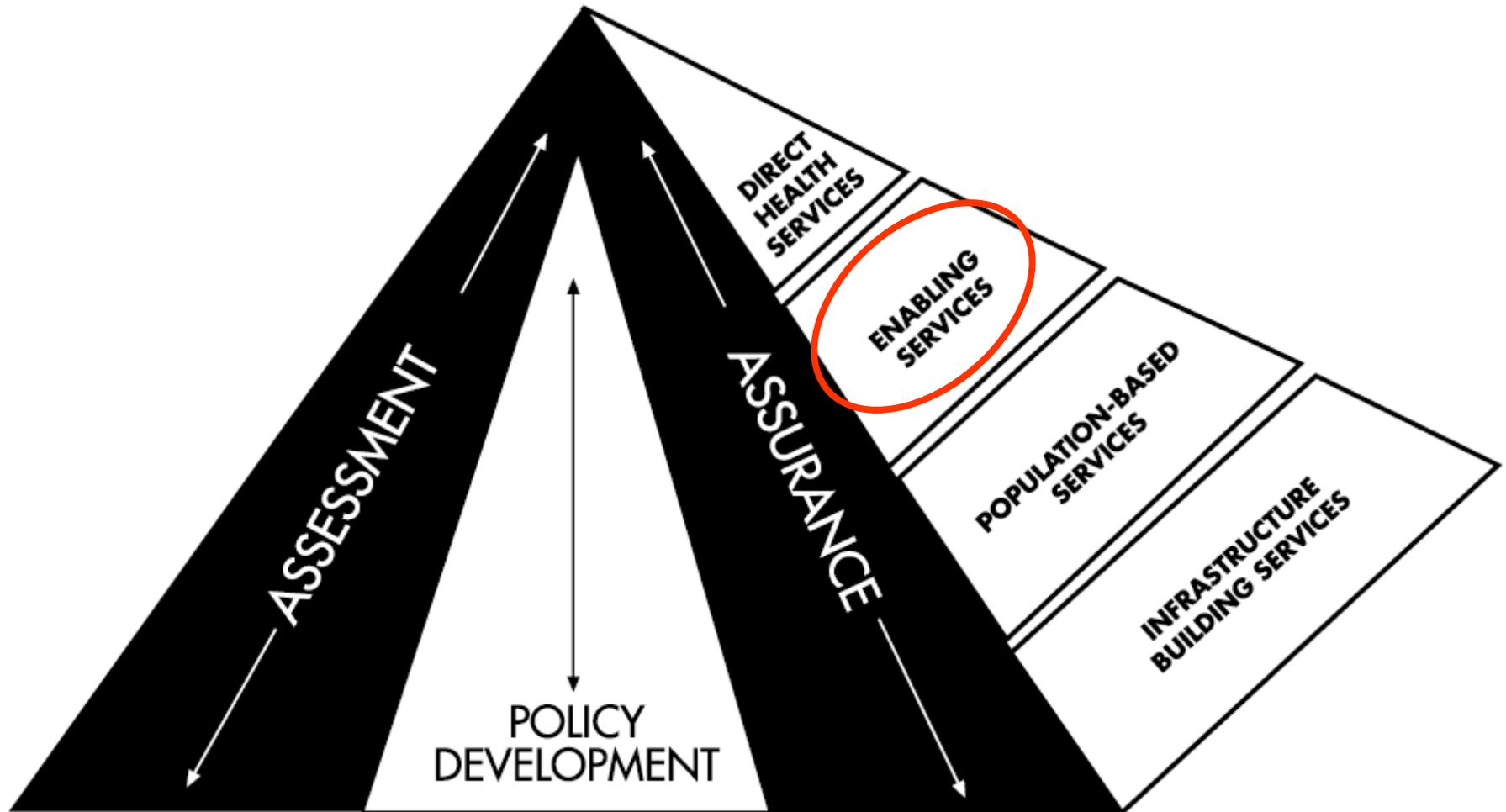
# IOM FUNCTIONS WITHIN THE MCHB PYRAMID



## **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

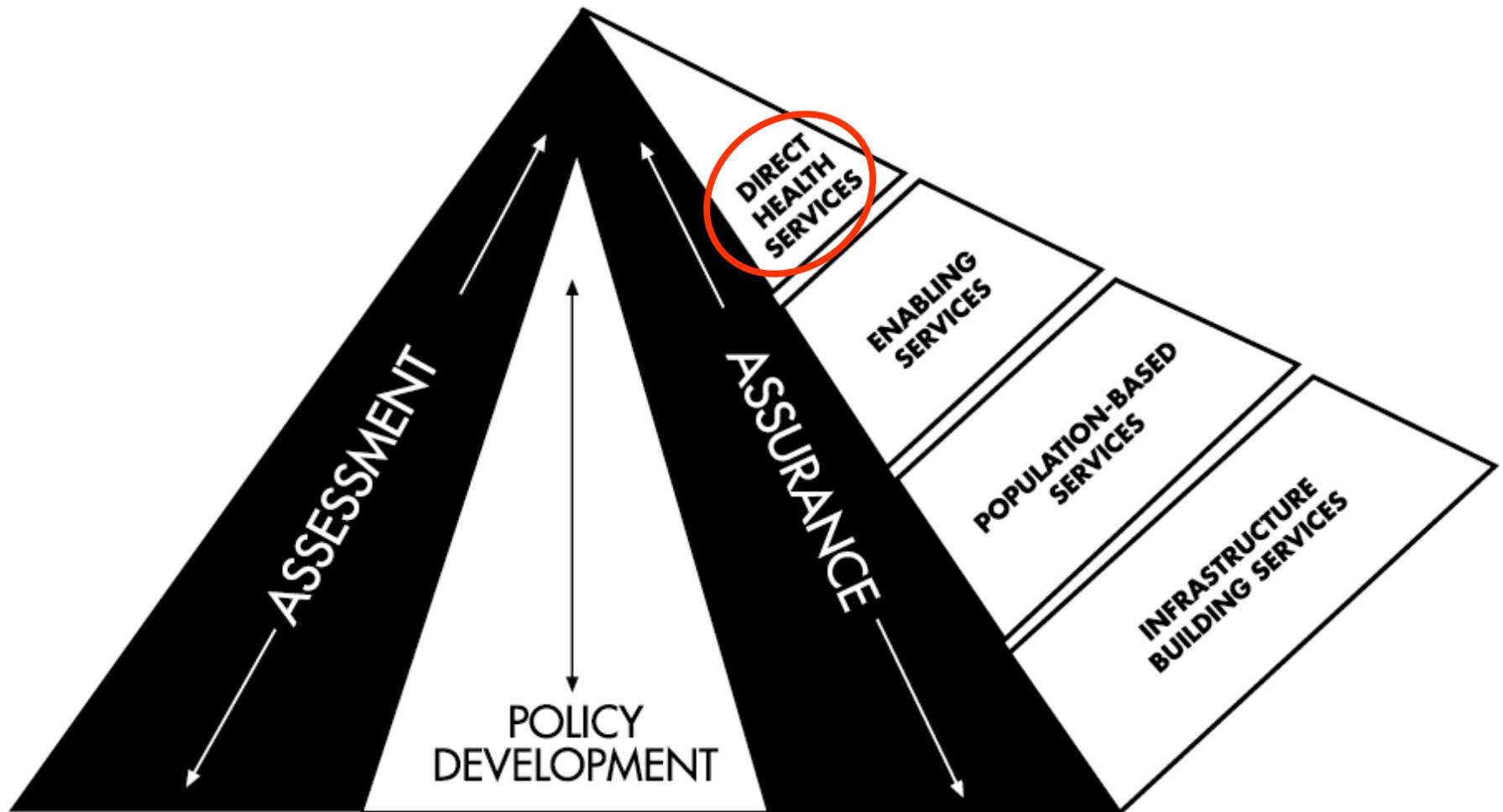


# **Enabling Services**

## **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

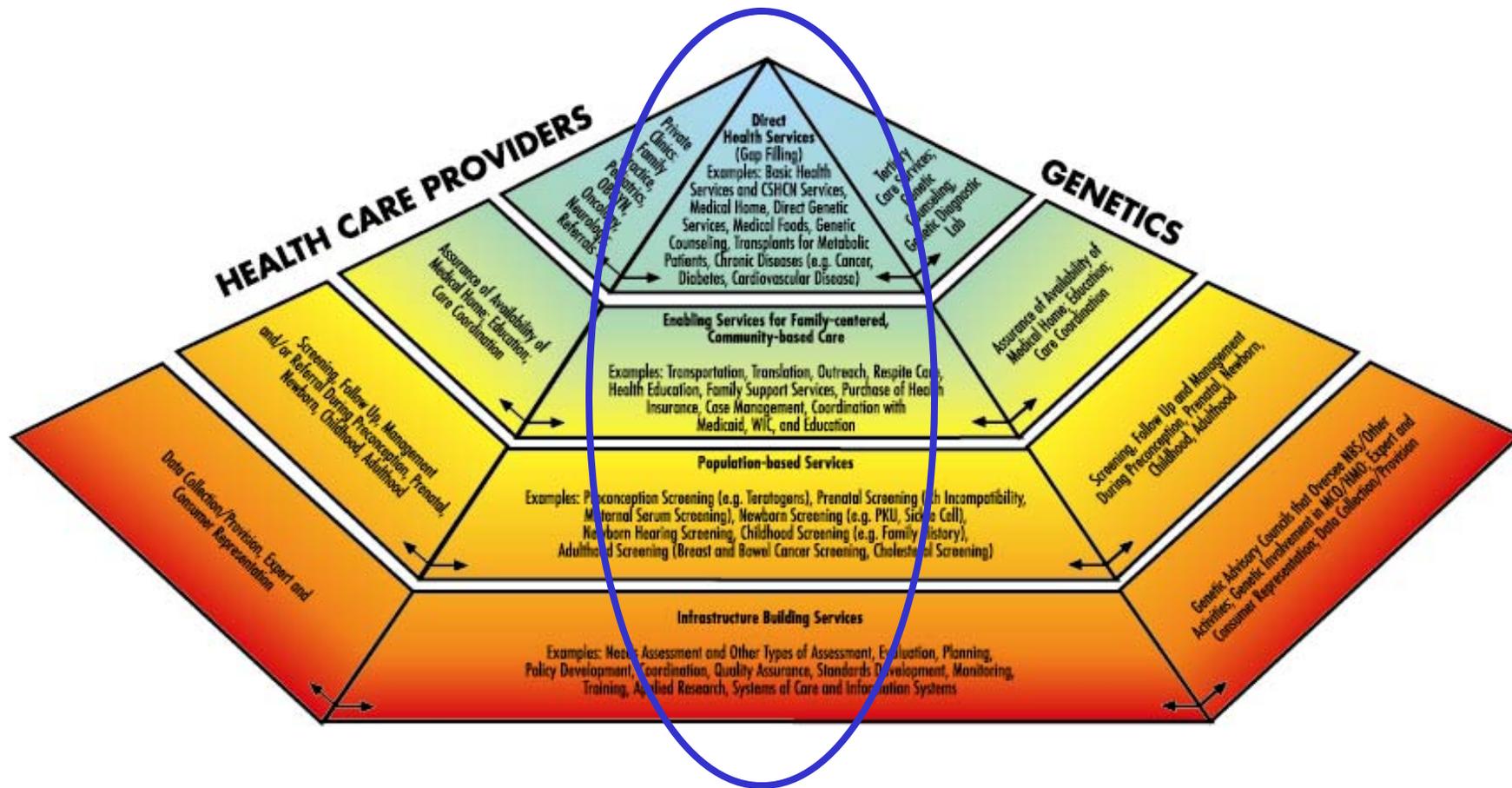


## **Direct Health Services**

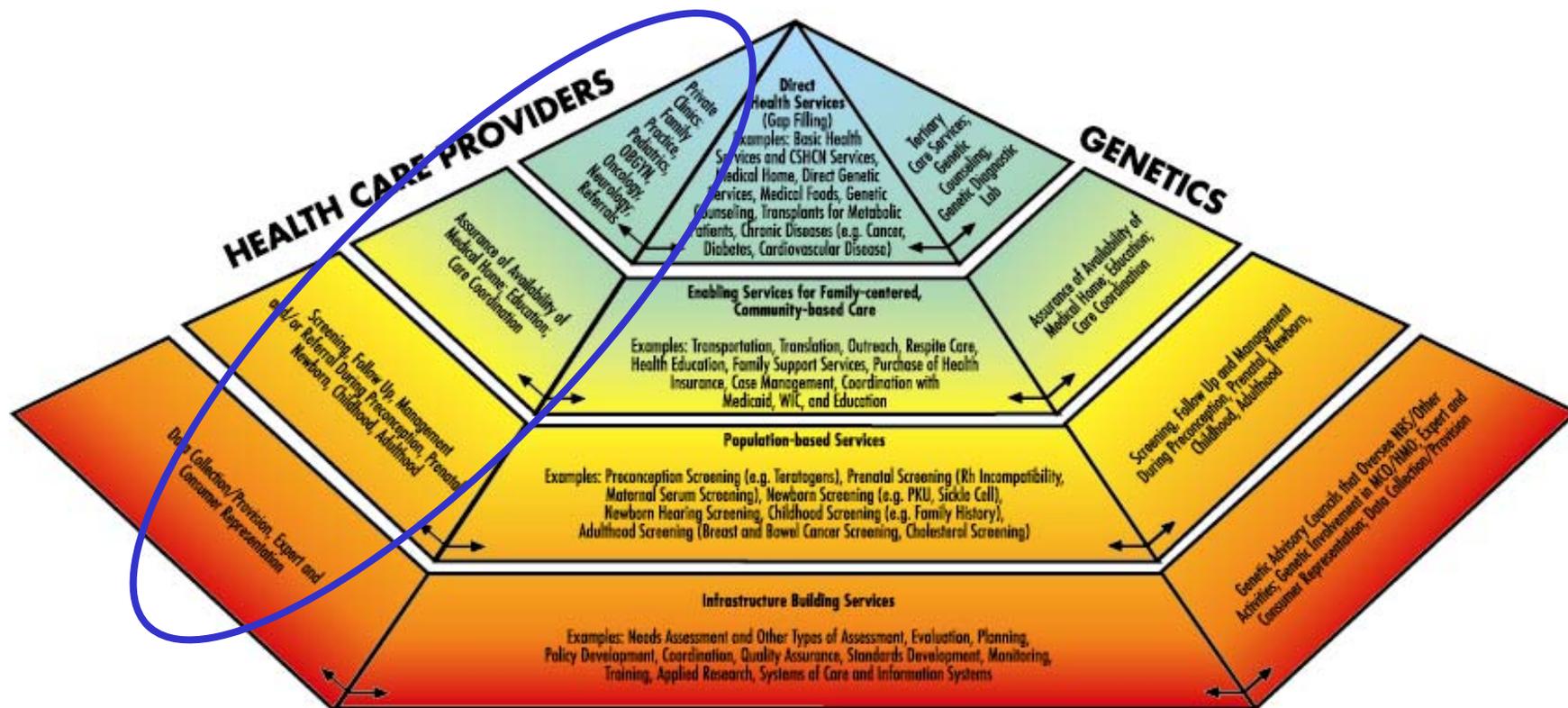
- **Examples:**

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

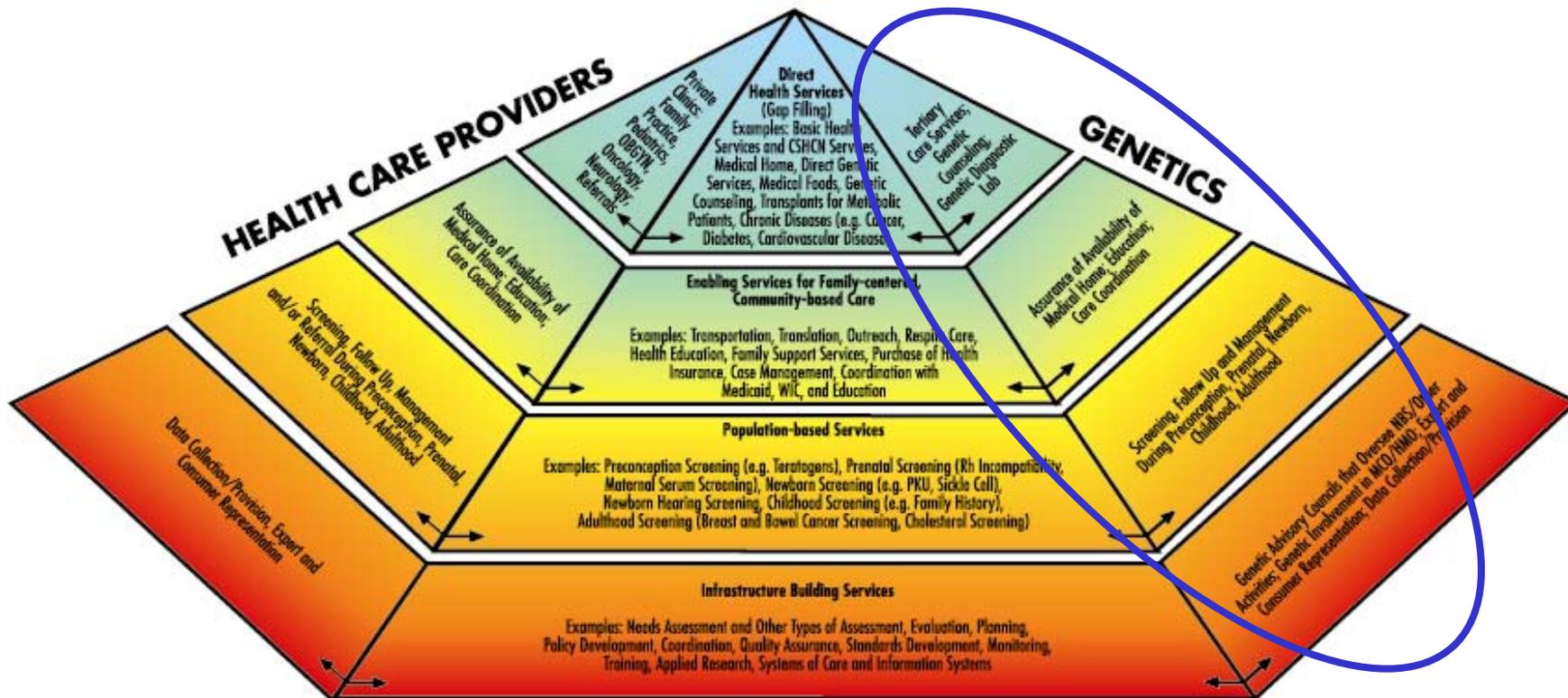
# THE MCHB/GENETICS PYRAMID



# THE MCHB/GENETICS PYRAMID



# THE MCHB/GENETICS PYRAMID



# Guidance Document

Community Genetics  
2001;4:175-196

## Report

Community  
Genetics

Community Genet 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)

Edited by: Celia I. Kaye<sup>a</sup> Renata Laxova<sup>b</sup> Judith E. Livingston<sup>a,f</sup>  
Michele A. Lloyd-Puryear<sup>c</sup> Marie Mann<sup>c</sup> Edward R.B. McCabe<sup>d,e</sup>  
Bradford L. Therrell<sup>g,1</sup>

<sup>a</sup>Department of Pediatrics, University of Texas Health Science Center at San Antonio, San Antonio, Tex.,  
<sup>b</sup>Department of Pediatrics and Medical Genetics, University of Wisconsin, Madison, Wis.,  
<sup>c</sup>Maternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Md.,  
<sup>d</sup>Department of Pediatrics, UCLA School of Medicine, Los Angeles, Calif., <sup>e</sup>Center for the Society,  
the Individual and Genetics, UCLA, Los Angeles, Calif., <sup>f</sup>National Newborn Screening and  
Genetics Resource Center, Austin, Tex., USA

#### Key Words

Public health · Genetics · Guidance · Policy ·  
Assessment · Assurance

#### Introduction

During the past 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 both individuals with genetic disorders and asymptomatic individuals with a genetic predisposition to (a) particular disorder(s).

This expanded knowledge base in genetic medicine is having, and will continue to have, an impact on public health policy and service delivery, as well as on health care and social services 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 genes, 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 integrating primary care and public health activities. For example, by identifying asymptomatic persons at increased risk for acquiring certain disease(s) (clinical assessment), health care

<sup>1</sup> On behalf of the Genetics Advisory Committee of the National Newborn Screening and Genetics Resource Center (see Appendix B for a complete listing of committee members contributing to this paper).

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Fax +41 61 306 12 34  
E-Mail karger@karger.ch  
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Bradford L. Therrell, PhD  
National Newborn Screening and Genetics Resource Center  
1912 West Anderson Lane, Suite 210  
Austin, TX 78757 (USA)  
Tel. +1 512 454 6419, Fax +1 512 454 6509, E-Mail therrell@utscusa.edu



# 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.

