

# Genetics Activities in Public Programs: A Baseline Inventory

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<sup>1</sup> GSPP is a collaborative effort between the Washington State Department of Health, University of Washington, and Fred Hutchinson Cancer Research Center. It is supported by Projects # U35MC02601 and # U35MC02602 from the Maternal and Child Health Bureau (Title V, Social Security Act), #11223, Health Resources and Services Administration, Department of Health and Human Services

# Overview

## ■ Findings

- Program Content
- Program Organization
- Program Funding
- Reimbursement of Direct Services

## ■ Data Sources

## ■ Questions and Comments

# Objectives

- To provide a description of state genetics programs and services
- To examine similarities and variation between states in delivery of genetic services in public programs

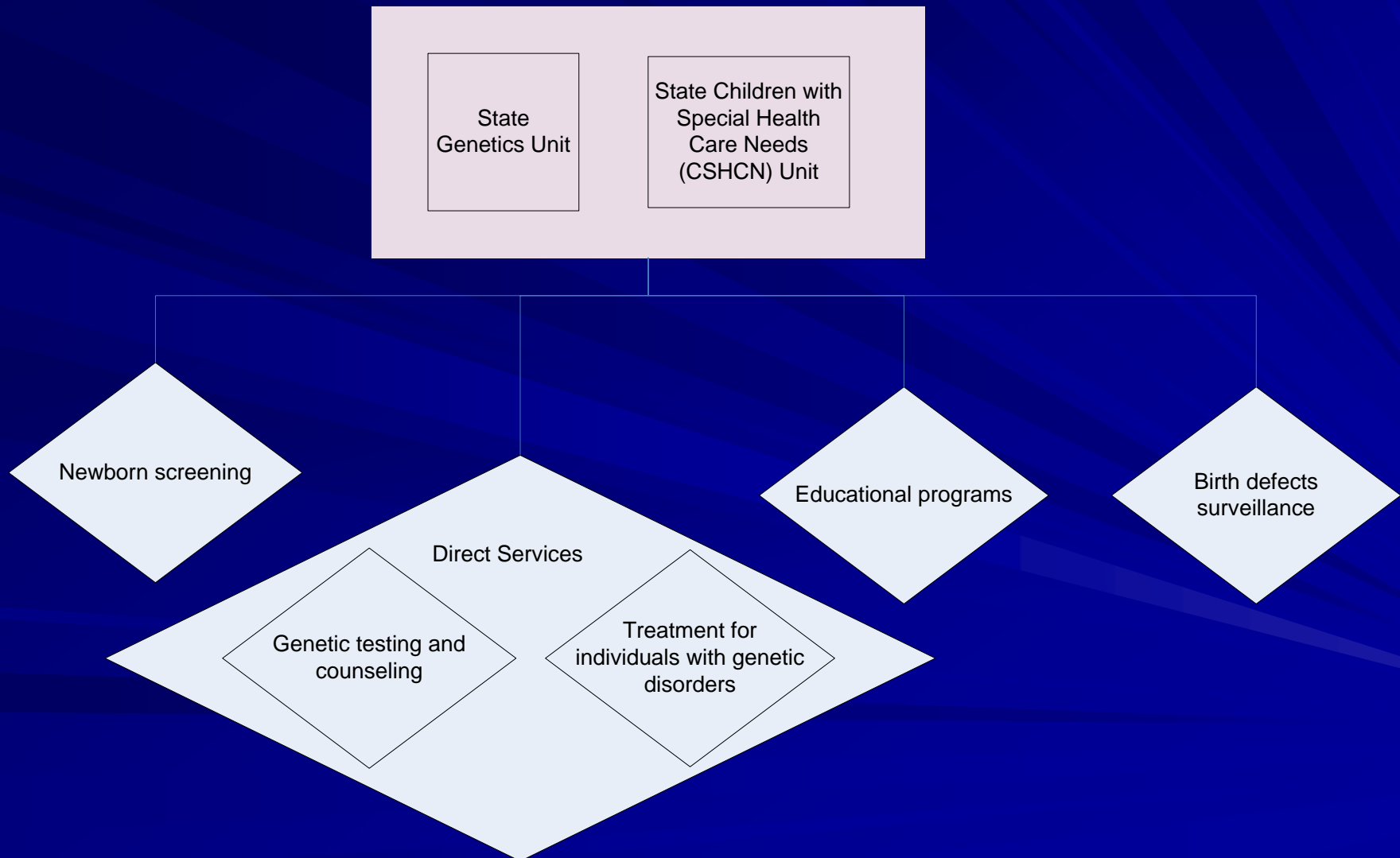
# Findings

- Genetics activities in public programs vary:
  - Program content
  - Organizational structure
  - Funding sources

# Program Content

- Five categories of state genetics activities:
  1. Newborn screening
  2. Testing and counseling
  3. Treatment programs for individuals with genetic disorders
  4. Educational programs
  5. Birth defects surveillance activities

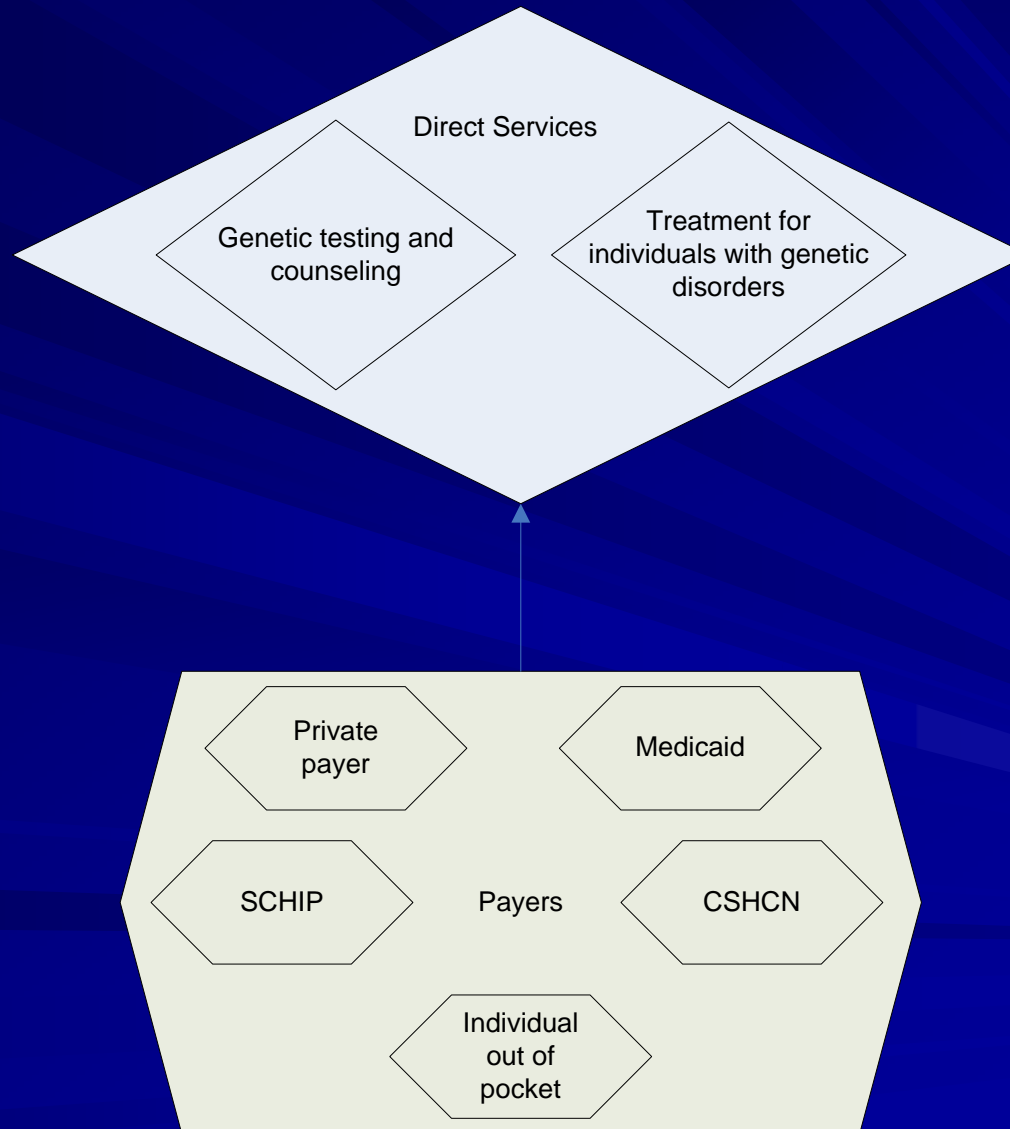
# Program Organization



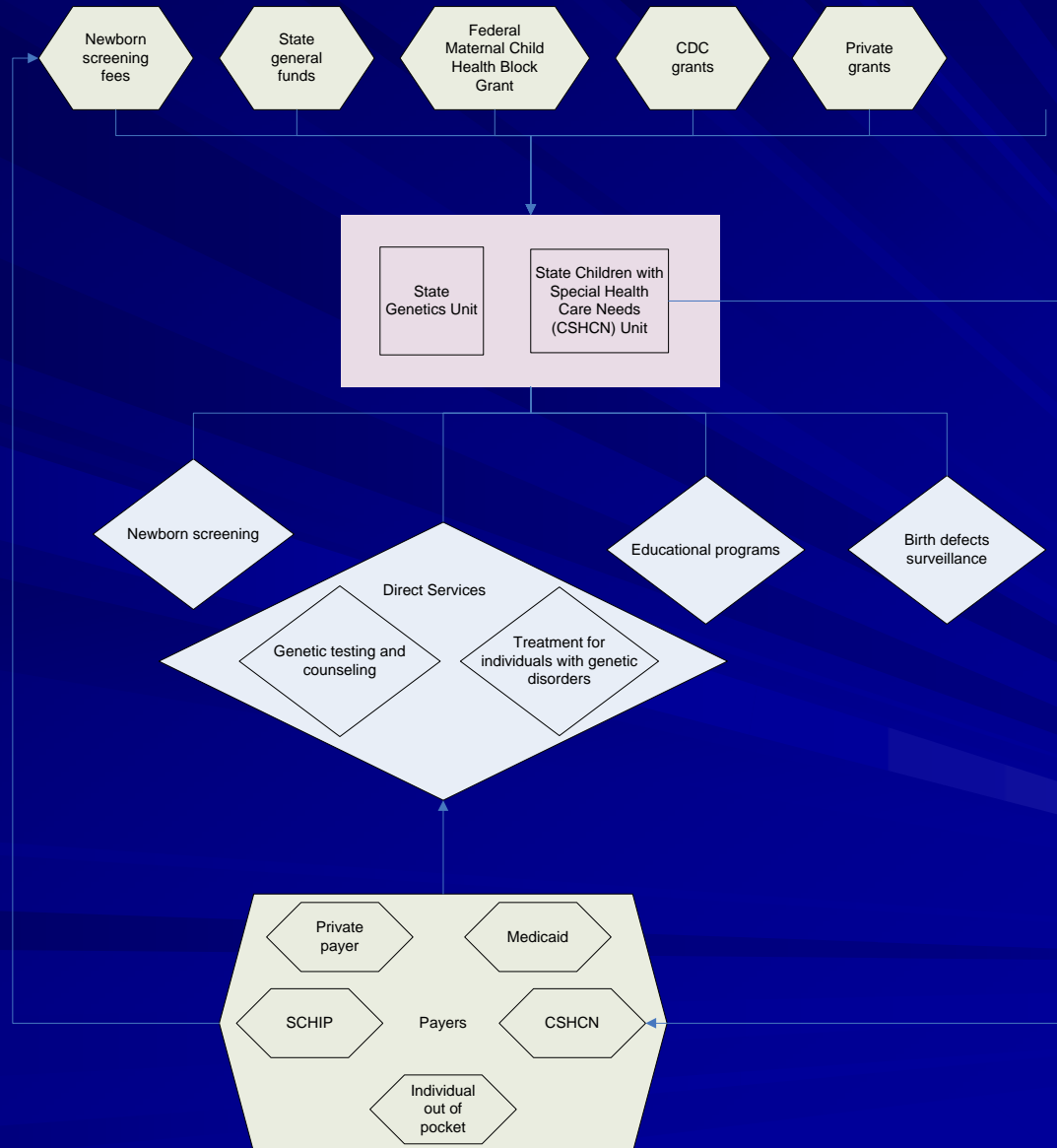
# Funding Sources

- States utilize an array of public and private funding sources
  - Newborn screening fees
  - State general fund
  - Federal Maternal Child Health Block (MCH) grant
  - CDC grants
  - Private grants
  - Other

# Reimbursement of Direct Services



# Funding, Administration, Program, and Reimbursement Structure



# Data Sources

- State Web sites, state agency reports, and association reports
  - Limited in description (particularly Web sources)
  - No trends over time
  - Unpublished
  - Fragmented access

# Data Sources

- No published expenditure data about the costs and reimbursement for genetic services
- General database resources may allow comparisons between private and public sector genetic services utilization and expenditures
  - California Hospital Discharge dataset
  - Medical Expenditure Panel Survey
  - Healthcare Cost and Utilization Project
  - National Ambulatory Medical Care Survey, and the National Hospital Ambulatory Medical Care Survey

# Data Sources

- Information from State Children with Special Health Care Needs (CSHCN) sections
  - Program services
  - Number of clients served
  - Service utilization
  - Expenditures
- Ability to identify individuals with genetic disorders from other CSHCN?

# Questions and Comments