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Abstract

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Title: Organization, Administration, and Funding of State Genetics Services Programs

Authors: Wang Grace, Roche Amber, Watts Carolyn A, Carlson Rick, Lochner-Doyle Debra,

Purpose: The Genetic Services Policy Project describes the delivery of genetic services via state genetics programs. This review identifies policies and practices that may affect utilization of and access to genetic services. Given the dynamism of the health care system and subsequent effects on state budgets, evaluating state genetics programs gains importance as states critically examine their services.

Methods: We systematically reviewed literature identified through PubMed and the GEMdatabase for information about the delivery of genetic services via state programs.

Results: Analysis of the 18 states with genetics plans or needs assessments showed five categories of state genetics activities: 1) newborn screening; 2) testing and counseling services, ranging from prenatal to adult diagnostic testing; 3) programs providing treatments to individuals with genetic disorders; 4) educational activities; and 5) birth defects surveillance programs. States vary in how they organize and fund care, education, and surveillance activities. Responsibility for these activities generally falls to either state genetics units or children with special health care needs units. Funding to support state genetics activities comes from service-related fees, state and federal governments, and private sources.

Conclusion: States play an important role in delivering health services, including genetic services. Examining state systems and their effect on utilization of genetic services may reveal models for making access to services more equitable and administration more efficient. Changes in state-sponsored and publicly administered genetic service programs could substantially affect providers, payers, and consumers if public services are eliminated or transferred to the private sector. To continue its work in describing genetic services delivery models, the Genetic Services Policy Project plans to collect information from key stakeholders in order to translate genetics research into practice.