

Genetic Activities in State Public Programs: A Baseline Inventory

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States have an important role in delivering and monitoring health services, including genetic services. Examining the similarities and variations between states may provide information regarding the role, impact and importance of genetic services within public programs. To provide an initial description of public services and programs in the area of genetics, we conducted a search of published and non-published information using PubMed, state and federal agency Web sites, and other Internet-based sources. This paper provides examples from a few states to illustrate the variability in state funded or state coordinated genetics programs. The emerging picture suggests that state delivery systems vary in organizational structure and rely on a wide variety of funding sources. Further, sources of ongoing data about genetic service utilization and expenditures are scarce.

Program Content

State activities in the area of genetics tend to fall within five broad categories: 1) newborn screening,² 2) testing and counseling, 3) treatment programs for individuals with genetic disorders, 4) educational programs, and 5) birth defects surveillance activities.

States may administer programs that offer testing and counseling services, which range from prenatal testing to adult diagnostic testing. For example, California and Iowa have maternal serum alphafetoprotein screening programs to assess the risk of birth defects. Diagnostic testing for children may include hearing screenings of newborns. Many states, such as Georgia and Hawaii, coordinate non-mandated testing and follow-up evaluations. State genetics clinics offer general testing, evaluation, and counseling services to residents. Clinic services in Missouri are provided through contracts with local medical schools. These contracts also provide for outreach services to geographically remote areas.

Treatment programs and direct care programs may also be provided by states for individuals diagnosed with genetic conditions. Children with metabolic disorders identified through screening programs often receive follow-up services at special metabolic disorders clinics. Maryland provides free nutrition services and counseling to families of children with phenylketonuria (PKU) and other metabolic disorders. In addition, many states provide and coordinate direct care to children and adults with genetic disorders, such as sickle cell anemia and hemophilia. Kansas and Missouri residents with sickle cell anemia and hemophilia are eligible for services regardless of age.

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² All states mandate screening of newborns for metabolic disorders, such as phenylketonuria (PKU). Because mandated screening is well-described elsewhere, this effort for the Genetics Services Policy Project focuses on other state activities.

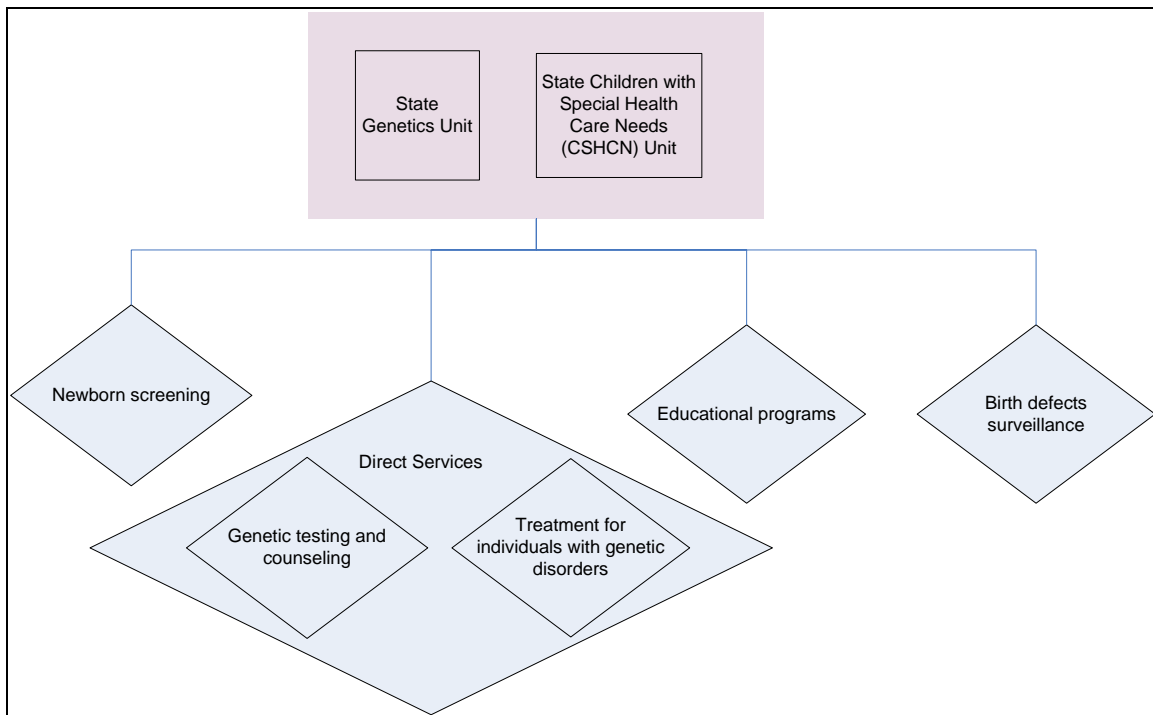
State-sponsored educational activities address a variety of topics. For example, Arizona is developing a human genetics curriculum for health paraprofessionals as well as Spanish language training for delivery of culturally competent care. Indiana’s Genomics Program publishes a state-wide quarterly newsletter and coordinates public speakers and lecturers. The state of Virginia partners with the Medical College of Virginia to administer the Sickle Cell Awareness Program. Washington State is working to increase awareness of the importance of taking family health history.

Forty-two states have birth defects surveillance programs or are currently developing programs.^{i ii} The programs may conduct passive or active surveillance, and are intended to monitor and detect trends in birth defects. Eighteen states explicitly use genetic clinics as a data source for their registries, and seventeen states include genetic diseases in their registries.

Program Organization

States vary in how they organize their care, education, and surveillance activities. In general, responsibility for these activities falls to either one of two sections: state genetics units or children with special health care needs (CSHCN) units. (Figure 1) For example, state genetics sections in Maryland, Mississippi, Ohio, Virginia, and Wyoming have organizational oversight over birth defects surveillance programs whereas CSHCN programs administer the surveillance programs in New Jersey, Pennsylvania, and Wisconsin.

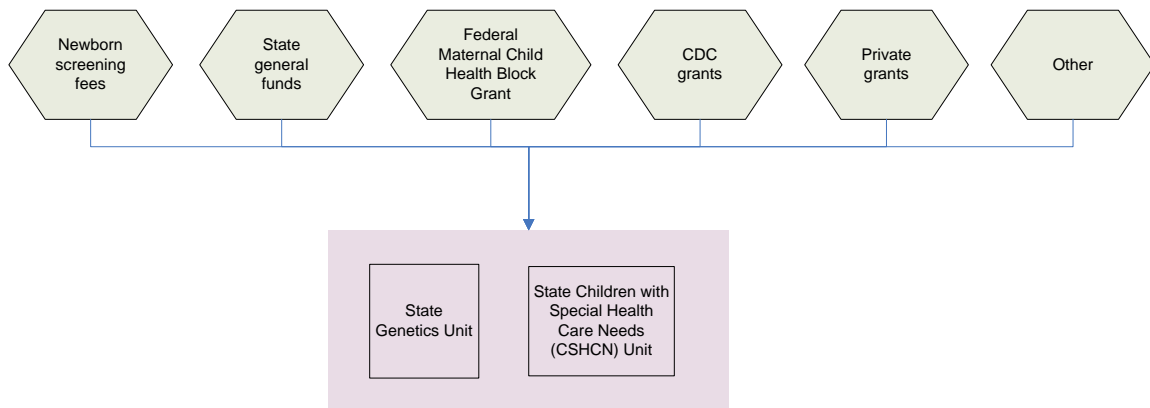
Figure 1. Categories of programs administered by states



Program Funding

To support population level genetics activities, states utilize an array of public and private funding sources. (Figure 2) Revenue from newborn screening fees funds most public genetic activities in Illinois and all services in Michigan. In contrast, Iowa uses general revenue funds to support its programs.ⁱⁱⁱ One substantial source of federal funding that supports population level genetics activity is the Title V Maternal Child Health Block Grant.^{iv} States must provide a three dollar match for every four federal dollars allocated and must use at least 30 percent of funds for services for CSHCN. Title V funds support both population level programs as well as individual level care.

Figure 2. Sources of funding for administrative units.



Reimbursement of Direct Services

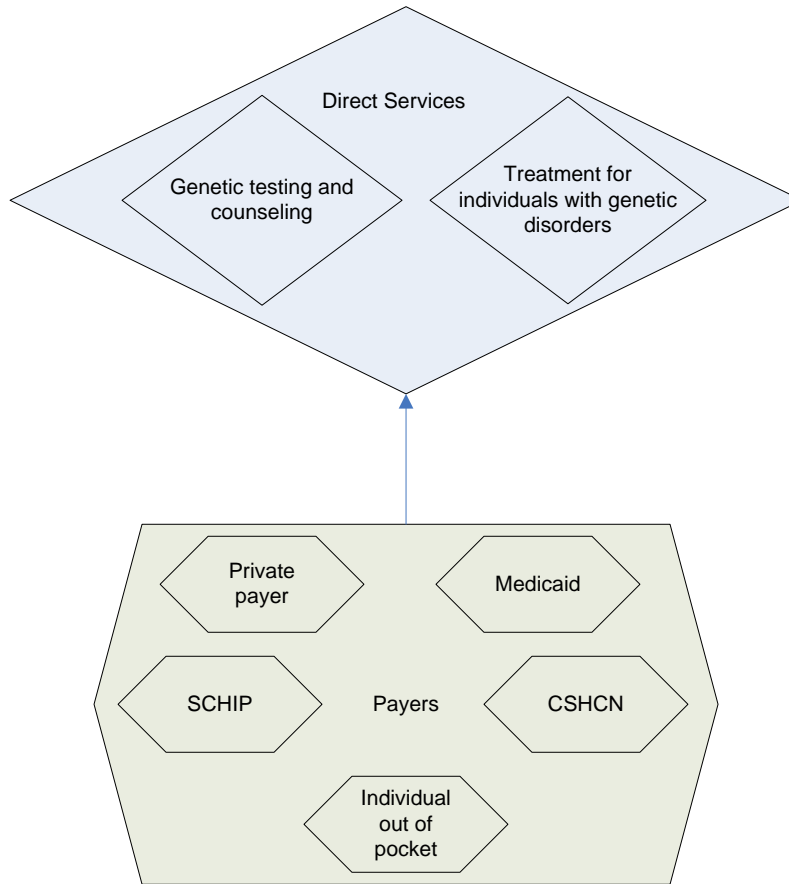
Reimbursement of direct genetic services is derived from a variety of private and public sources. Major sources include: private insurers, Medicaid, State Children's Health Insurance Plans (SCHIP), Children with Special Health Care Needs (CSHCN) Programs, and individual out of pocket payment. (Figure 3)

- Private insurers – Private insurers may determine covered services, rates of reimbursement, and approve specialty referrals within the context of state laws concerning mandated coverage. In Rhode Island, the primary funding source for direct services are private payers.^v
- Medicaid – Medicaid may provide coverage for children and adults with genetic disorders if the service is considered medically necessary. For example, genetic services in Texas are available with Primary Care Physician referral and approval of the Health Maintenance Organization in the Medicaid Managed Care program.^{vi}
- State Children's Health Insurance Plans (SCHIP) – SCHIP may provide coverage for genetic testing and counseling or therapies for children with genetic disorders. However, because each state determines benefits, reimbursable services may differ across states.
- CSHCN Programs – Maternal and Child Health federal block grant funding provides gap-filling health care to almost 1 million individual CSHCN.^{iv} The block grant is often reserved for families that do not have any third-party coverage, Medicaid or SCHIP. Minnesota's services are partially funded through the Minnesota Children with Special Health Care Needs program.ⁱⁱⁱ In Texas, the Chronically Ill and

Disabled Children's Services program provides funding for non-Medicaid individuals (age 0 to 21) affected with genetic disorders.^{vi}

- Individual out-of-pocket – Families may also choose or be required to pay for services directly.
- Other sources – One clinical genetics center in Wisconsin receives funding from 23 different sources including private foundations, contracts with private hospitals, biotechnology companies, various state agencies, and federal agencies.ⁱⁱⁱ

Figure 3. Reimbursement sources for direct services



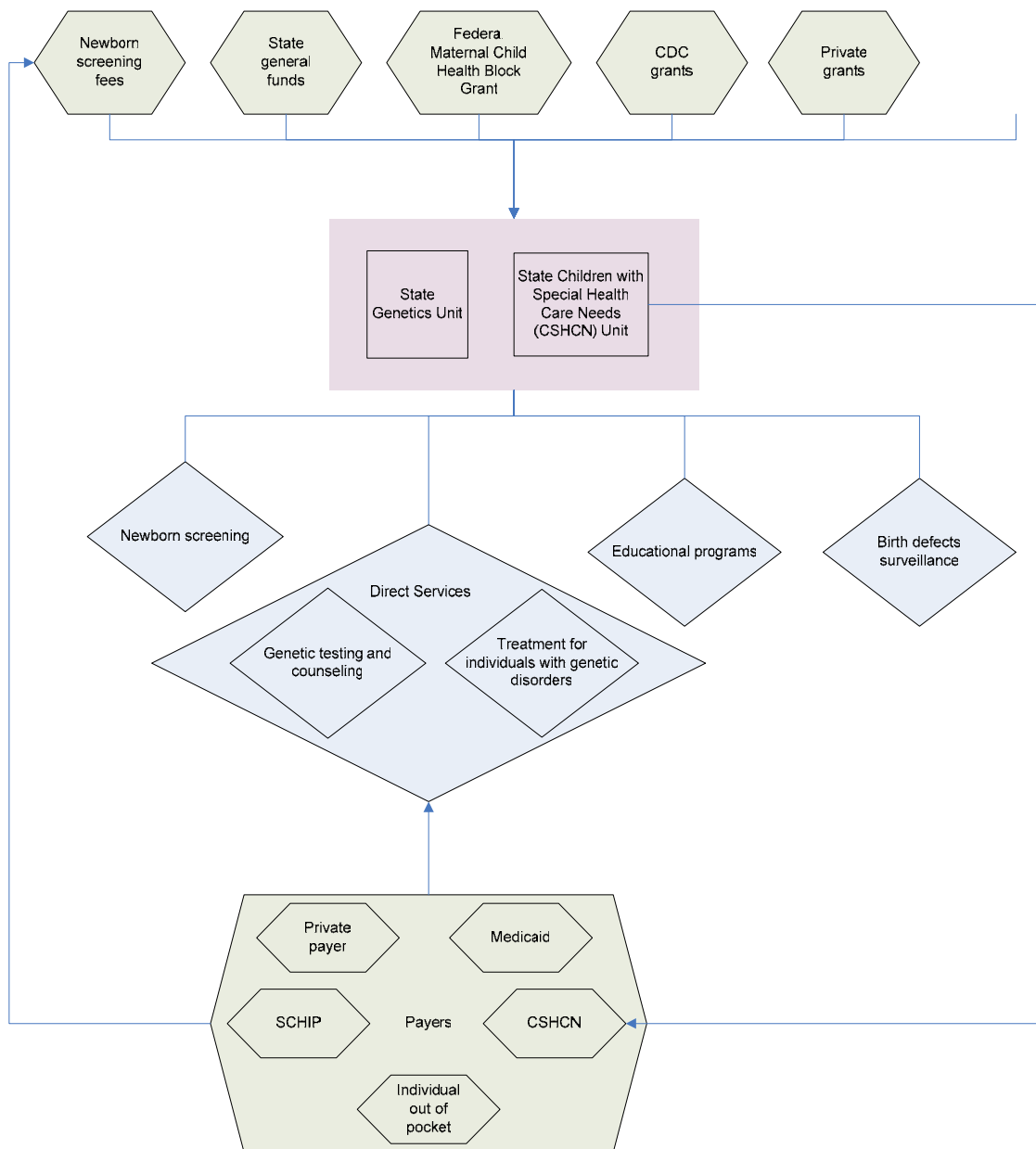
Data Sources

This initial glimpse into what states offer and how states administer and fund their programs (Figure 4) is limited by the sources of information that are available. The lack of published information resulted in extensive use of state Web sites, state agency reports, and association reports for descriptions of genetics activities. While valuable, Web sites may not fully capture the richness and complexity of state programs and public efforts in the area of genetic services. Some states have compiled reports about genetics activities, but the reports are generally intended for internal planning rather than for tracking trends over time. In addition, these sources do not provide ongoing data collection and analysis. As a result, the information has limited utility for generating

comparisons between states. Furthermore, the process of finding and accessing these sources is somewhat fragmented.

Expenditure data about the costs and reimbursement for genetic services specifically have not been published. There are several more general data sources that may contain useful expenditure and utilization information specific to genetic services. Available sources include the California Hospital Discharge dataset,^{vii} the Medical Expenditure Panel Survey,^{viii} the Healthcare Cost and Utilization Project,^{ix} the National Ambulatory Medical Care Survey, and the National Hospital Ambulatory Medical Care Survey.^x These databases may also allow comparisons between private and public sector genetic services utilization and expenditures.

Figure 4. Overall structure of funding, administration, programming, and reimbursement



State CSHCN sections are likely to have valuable information regarding their programs, number of clients served, service utilization, and expenditures. Children with genetic disorders may receive services through these programs as these individuals are often considered a subset of the CSHCN population. However, the nature of federal and state-level definitions may result in an inability to separate individuals with genetics disorders from other CSHCN.

Conclusion

Advances in genetic technologies broaden the population that benefits from genetic services. Increasing integration of these services into clinical practice as well as into publicly funded care systems will result in growing pressure for more and better data. Our work is intended to provide a baseline, albeit imperfect, measure from which service expansion can be evaluated.

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- ^{vii} University of California, San Diego. Social Sciences & Humanities Library. Hospital Patient Discharge Data [California]. 2001; Available from <http://ssdc.ucsd.edu/ssdc/cal00004.html>. Last accessed on April 4, 2005.
- ^{viii} US Department of Health and Human Services. Agency for Healthcare Research and Quality. Medical Panel Expenditure Survey. Available from: <http://www.meps.ahrq.gov>. Last accessed on April 4, 2005.
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- ^x Centers for Disease Control and Prevention. National Center for Health Statistics. Ambulatory Health Care Data. 2005 April 1; <http://www.cdc.gov/nchs/about/major/ahcd/ahcd1.htm>. Last accessed on April 4, 2005.