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NEWBORN SCREENING

Characteristics of State Programs

GAO Highlights

Highlights of GAO-03-449, a report to Congressional Requesters

Why GAO Did This Study

Each year state newborn screening programs test 4 million newborns for disorders that require early detection and treatment to prevent serious illness or death. GAO was asked to provide the Congress with information on the variations among state newborn screening programs, including information on criteria considered in selecting disorders to include in state programs, education for parents and providers about newborn screening programs, and programs' expenditures and funding sources. To collect this information, GAO surveyed newborn screening programs for genetic and metabolic disorders in all 50 states and the District of Columbia. GAO was also asked to provide information on efforts by the Department of Health and Human Services (HHS) and states to evaluate the quality of newborn screening programs, state laws and regulations that address parental consent for newborn screening, and state laws and regulations that address confidentiality issues.

www.gao.gov/cgi-bin/getrpt?GAO-03-449.

To view the full report, including the scope and methodology, click on the link above. For more information, contact Marjorie Kanof at (202) 512-7119.

What GAO Found

While the number of genetic and metabolic disorders included in state newborn screening programs ranges from 4 to 36, most states screen for 8 or fewer disorders. In deciding which disorders to include, states generally consider similar criteria, such as whether the disorder is treatable. States also consider the cost of screening for additional disorders. HHS's Health Resources and Services Administration is funding an expert group to assist it in developing a recommended set of disorders for which all states should screen and criteria for selecting disorders.

Most state newborn screening programs have similar practices for administering and funding their programs. Almost all states provide education on their newborn screening program for parents and providers, but fewer than one-fourth inform parents of their option to obtain tests for additional disorders not included in the state's program. State programs are primarily funded through fees collected from health care providers, who may receive payments from Medicaid and other third-party payers. Nationwide, fees funded 64 percent of states' 2001 fiscal year program expenditures of over $120 million.

All newborn screening laboratories participate in a quality assurance program offered by HHS's Centers for Disease Control and Prevention, which assists programs in evaluating the quality of their laboratories. All states require newborn screening, and state statutes that govern screening usually do not require parental consent. However, 33 states' newborn screening statutes or regulations allow exemptions from screening for religious reasons, and 13 additional states' newborn screening statutes or regulations allow exemptions for any reason. Newborn screening statutes and regulations in over half the states contain confidentiality provisions, but these provisions are often subject to exceptions.

HHS said that the report presents a thorough summary of state newborn screening programs' current practices.

Disorders Most States Included in Their Newborn Screening Programs as of December 2002

Disorder	Number of states[a]
Phenylketonuria	51
Congenital hypothyroidism	51
Galactosemia	50
Sickle cell diseases	44
Congenital adrenal hyperplasia	32

Source: National Newborn Screening and Genetics Resource Center.

Note: This table does not include states that provide screening for the disorders to selected populations, as part of pilot programs, or by request.

[a]"States" refers to the 50 states and the District of Columbia.