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Newborn Health Screenings

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Every year, thousands of infants are born with serious genetic disorders that can be identified by testing just a few drops of blood. State newborn screening programs test about 4 million infants annually for genetic disorders and other health problems that are not apparent at birth. Early detection of many disorders can not only prevent disabilities, additional health problems or death, they may also save states and families money by avoiding high medical costs and using other state services.

Did You Know?

- Newborn screening first started when a screen was developed for phenylketonuria (PKU) in the 1960s. Today, screening is available for more than 60 conditions.
- Each year, about 12,500 infants are diagnosed with a core condition on the Uniform Newborn Screening Panel.
- Early detection of genetic disorders can save money for states and families.

Newborn screening also detects conditions such as hearing, hormonal and blood disorders. By the time symptoms for these conditions appear, they often are irreversible and can lead to severe health problems, developmental disabilities, mental retardation or even death. To identify most of these problems soon after birth, blood samples are collected from newborns through a small heel-prick—typically before the baby leaves the hospital. According to a 2003 study by the Government Accountability Office, states spend an average of $30 per infant on screening. Early detection and treatment of newborn conditions, however, often can prevent future state costs for medical, educational and support services.

Although states determine newborn screening requirements, they often rely on national recommendations. In 2006, the U.S. Department of Health and Human Services (HHS) developed the Uniform Newborn Screening Panel, a list of tests based on recommendations by the American College of Medical Genetics and supported by the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. Today, the recommended panel consists of 31 core and 26 secondary conditions. Guidelines for selecting core conditions consider the tests' ability to detect the condition soon after birth, the availability of an effective test, and the benefits of early detection and treatment. Secondary conditions are disorders that may be detected through further examination of core condition screening results.

State Action

Each state determines the disorders required for screening, appropriates funding sources for the programs and designs initiatives to educate parents. Currently, all states require screens for at least 26 of the federally recommended core conditions; state testing requirements for secondary conditions range from none to all 26.

Because the federal advisory committee has added recommendations, some states have included these conditions in their requirements. In 2010 and 2011, for example, the committee added screenings for critical congenital heart disease (CCHD) and severe combined immunodeficiency disorder (SCID) to the Uniform Newborn Screening panel. Since 2011, Connecticut, Indiana, Maryland, New Hampshire, New Jersey, Tennessee and West Virginia

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have passed laws requiring newborn screening for CCHD, while a California law requires that the test be offered. During the 2011-2012 legislative session, California, Illinois and Missouri enacted legislation to include screening for SCID. Some other states have required the screens through state agency regulations or other means; a few states are studying or considering the issue.

After testing is complete, some states retain blood samples for research, data collection and birth defect registries to help identify birth defect causes and prevalence. To protect patient privacy, many state laws require that genetic material remain private unless parents give informed consent for the sample to be used for purposes other than screening their child. Some states also regulate how long the samples should be stored—some for only a few weeks, and some indefinitely—and proper disposal methods to ensure genetic information remains private. Finally, laws in many states allow parents to opt out of newborn screening programs entirely if it is against their religious or philosophical beliefs.

Policymakers play important roles in follow-up activities—ensuring additional diagnostic tests or specialty care, providing access to needed treatment and informing parents about services available to children with special health care needs. For example, many states require insurance companies to provide coverage for infant formula specifically designed for metabolic disorders, at an average annual cost of $7,100.

Federal Action

Medicaid covers newborn screening as one of the many services required by the Early Periodic Screening, Diagnosis and Treatment benefit. Under the benefit, states have some flexibility. They are not required to cover all the recommended tests in the Uniform Screening Panel. The benefit requires Medicaid to cover further testing services and medically necessary care for treatable abnormal screening results.

The Patient Protection and Affordable Care Act also expands access to newborn screening by requiring insurance coverage of specified preventive services for children without cost sharing (such as copayments and co-insurance, for example). Under this provision, most private health insurance plans now must cover all newborn screens on the Uniform Screening Panel without cost sharing, even in states that do not require screens for all listed conditions.

NCSL Contacts and Resources

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Insurance Coverage of Medically Necessary Foods and Formula to Treat Disorders Identified Through Newborn Screening

Newborn Genetic and Metabolic Screening State Laws

Newborn Hearing Screening State Laws

Other Resources

Centers for Disease Control and Prevention: Newborn Screening

National Newborn Screening and Genetics Resource Center

Baby's First Test