

**HERITABLE DISORDERS, NEWBORN
SCREENING AND
HEALTH CARE REFORM**

*A White Paper written by
the U.S. Secretary of Health and Human Services'
Advisory Committee on Heritable Disorders in Newborns and
Children*

March 2010

EXECUTIVE SUMMARY

This White Paper provides a unique opportunity to reflect on how well one important segment of our public health system, newborn screening, functions within the current health care scheme, to identify gaps, and propose ways in which health reform might improve the quality and efficiency of public health programs overall for the benefit of the families that they serve.

Nearly all of the 4 million infants born in the United States annually undergo newborn screening for heritable disorders, which is an important line of defense against preventable disease following birth. State newborn screening programs function within the broader health care delivery system, which require the health management of children over time and multidirectional communication among parents, public health officials, medical sub-specialists, and the primary care physician. The delivery of newborn screening and ongoing follow-up services across the United States remains substantially variable depending on place of birth. The reasons behind this disparity—issues related to public financing, payment systems, administrative inefficiencies and insurance coverage—mirror problems cited in ongoing discussions among policymakers about the need for systemic improvements to the entire U.S. public health system.

Health care reform in the U.S. requires further federal commitment and guidance. In the case of newborn screening, there are multiple barriers to system improvement that necessitate the support and leadership of the federal government. Lack of stable, reliable funding prevents half of the states from providing support services beyond minimal

education efforts, screening, diagnosis (in the case of a confirmed positive result), and initial confirmation of treatment. Lack of national budget guidelines has led states to establish different billing and payment practices for the cost of screening services. This has created a labyrinth of billing and payment practices that echo the inefficiencies of transactions within the broader U.S. health care system. Financial incentives fail to promote the medical home model of care, a tool that particularly benefits families of children diagnosed with a disorder as a result of newborn screening and the various providers delivering services to them (e.g., medical management, occupational therapy and education). The use of electronic health records (EHR) would reduce administrative burdens, facilitate delivery of patient-centric, coordinated care, improve the ability of states to track and follow-up patients long-term and provide better data for evaluation and research. Finally, there are many financial hardships for families of children with a disorder identified through newborn screening. Health reforms should eliminate pre-existing condition exclusions and lifetime benefit caps and ensure adequate coverage of medically necessary foods.

In order to assist states deliver the minimum standard of service and care, the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) intends to form a workgroup to develop national guidance on public health budgets for newborn screening systems. Proposed national guidance will highlight budget alternatives that may better serve the needs of particular states, incorporate the flexibility in funding design that states may require, and identify areas that the federal government may target for additional support.

To address the multiple barriers to newborn screening system improvement, the SACHDNC makes the following recommendations to the Secretary of the Department of Health and Human Services:

1. Encourage the Centers for Medicare and Medicaid Services to convene an expert panel to examine coding changes to streamline the billing process for newborn screening services and to put forth recommendations that enhance the standardization of health care transactions.
2. Encourage the Centers for Medicare and Medicaid Services to develop and pilot a payment method for an integrated system of care coordination through the medical home framework for children diagnosed with heritable and congenital disorders as a result of screening.
3. Encourage the adoption and further definition of the Newborn Screening Use Case within the Department's health information exchange endeavors, specifically encouraging the Centers for Medicare and Medicaid Services to make use of the Newborn Screening Use Case when defining "meaningful use" of Electronic Health Records and the Office of the National Coordinator for Health Information Technology to further facilitate the adoption of the Newborn Screening Use Case.
4. Support, as allowable, the closure of gaps in insurance coverage for medical foods and foods modified to be low in protein, as recommended by the Committee in April, 2009.

INTRODUCTION

Nearly all of the 4 million infants born in the United States annually undergo newborn screening for heritable disorders, an important line of defense against preventable disease following birth. State public health departments, U.S. Territories, and the District of Columbia universally operate newborn screening programs for conditions that may cause disability or death absent appropriate treatment. These programs function within a broader health care delivery system that traverses state public health departments. Processes within the system require the health management of children over time and multidirectional communication among parents, public health officials, medical sub-specialists, and the primary care physician. Despite more than four decades of impressive growth and refinement in this field, the core components of newborn screening systems— education, screening, diagnosis, short and long-term follow-up, management and treatment and quality assurance services —still vary substantially depending on place of birth.¹ The reasons behind the uneven delivery of newborn screening and ongoing follow-up services across the United States—issues related to public financing, payment systems, administrative inefficiencies and insurance coverage—mirror problems often cited in ongoing discussions among policymakers about the need for health care reform in the United States.

This backdrop provides a unique opportunity to not only reflect on how well one important segment of our public health system, newborn screening, functions within the current health care scheme, but also to identify gaps and propose ways in which health

reform might improve the quality and efficiency of public health programs overall for the benefit of the families that they serve.

BACKGROUND

Historical perspective of public financing of the newborn screening system

States have maintained responsibility for the oversight and execution of newborn screening programs, and their ability to address the six core components of the newborn screening system has hinged primarily on funding. The Government Accountability Office reported the most recent information available on the overall cost of newborn screening—over \$120 million in state fiscal year (FY) 2001 or approximately \$30 per baby.²

The expansion of newborn screening panels for heritable and congenital disorders, driven largely by recommendations from the Committee and efforts of consumer and advocacy groups to promote their adoption, has dramatically decreased the differences among state screening panels. Most states screen for the Committee's currently recommended uniform screening panel of 29 conditions. The Newborn Screening Saves Lives Act of 2008 authorizes support to states with grants of \$15 to \$16 million annually for FY 2009 – FY 2013 to implement screening recommended by the Committee, improve screening or counseling, educate patients and providers or coordinate treatment.³ To date approximately \$10 million have been appropriated annually to implement this Act, with approximately \$5 million awarded to states.

Current State of public financing of the newborn screening system

The growing demand for newborn screening services has led states to increasingly rely on fees to compensate for program expenses.^{4,5} As of July 2009, with the exception of Kansas, New York, Pennsylvania and the District of Columbia, all newborn screening programs charge a fee for services to raise revenues.⁶ In most cases, fees cover laboratory costs and typically the cost of second screens in states where second screens are performed. However, the extent to which these monies cover the cost of education of providers, specimen collectors and the public as well as the follow-up, diagnosis and treatment screen positive infants varies.⁷ Maternal and Child Health Title V Block Grant funds, state appropriations and general revenues, and approximately \$10 million in annual federal funding constitute other sources of financing.⁸ However, in half of the states, this combination of funding streams is insufficient to support services beyond minimal education efforts, screening, diagnosis (in the case of a confirmed positive result), and initial confirmation of treatment.⁹

Public health departments often cannot provide comprehensive services that include long-term follow-up and monitoring of health outcomes to ensure or provide appropriate medical care, perform evaluations or conduct research. At the level of patient care, these inequities may result in confusion among children and families who move from one state (with a more comprehensive program) to another where the annual follow-up to assess their medical needs and provide feedback that they are accustomed to is no longer available. Along with ongoing contact, the time, effort and care that the prior state of residence invested in these patients are lost.

OPPORTUNITIES TO ENHANCE HEALTH CARE

REFORM EFFORTS

Existing efforts to reform the health system present a unique opportunity to simultaneously reduce current inefficiencies and disparities in state newborn screening programs.

Public Health Budgets

National guidance on developing public health budgets for newborn screening systems that takes into account: (1) the flexibility in funding design that states require to maintain support for newborn screening programs; and (2) areas where additional federal support may be necessary, particularly if states are being encouraged to expand services in that domain, may help to minimize geographical disparities and highlight budget alternatives that may better serve the needs of a particular state program.¹⁰

For example, a survey of state newborn screening programs with responses from 47 states found no correlation between the newborn screening fee amount and the number of mandated tests.¹¹ Some commentators on health reform have suggested that improvement of our public health system overall requires further federal commitment, including “a stable and reliable funding for core public health functions such as immunization and screening.”¹² With respect to newborn screening, stable funding to fill gaps in the system would help every state to provide a minimum standard of education,

screening, diagnosis, follow-up, management and treatment and quality assurance services to all families across the country.

Coding and Billing

Obtaining payment for services that are available and reimbursement for costs incurred by purchasers of specimen collection kits also presents a challenge. In the absence of CPT codes issued by the American Medical Association for newborn screening, states established different billing and payment practices for the cost of screening services, which have risen with the adoption of tandem mass spectrometry.¹³ Experts have proposed coding changes to streamline the billing process, which may reduce administrative burdens for newborn screening programs, providers and third-party payers.¹⁴ Some states bill insurance and Medicaid directly while others bill hospitals.¹⁵ Third party payers usually cover the cost of screening although no national requirement exists, and state Medicaid reimbursement rates vary.¹⁶ Third party payers cannot easily accommodate newborn screening rate increases, particularly if they occur during a pre-defined contract period.¹⁷ In addition, in most states, health care facilities must order a supply of collection kits from the newborn screening program for submission of dried blood spot specimens to the state-designated laboratory, and physicians' offices and outpatient laboratories also need kits readily available if a second screen is required.¹⁸ Although a few states bill for kits periodically, facilities that conduct screening purchase and are billed for kits in advance and cannot recoup their expenses until after the birth of a child.¹⁹

Payment

The labyrinth of billing and payment for newborn screening echoes the inefficiencies of transactions within the broader U.S. health care system. For example, methods for setting payment policies differ even among federally administered public programs, including, Medicare, the Civilian Health and Medical Program of the Uniformed Services, and the Federal Employees Health Benefits Program.²⁰ According to the Commonwealth Fund, the cost of insurance administration, or claims administration and negotiation of provider payment rates, in the U.S. health care system totaled approximately \$156 billion in 2007—a figure that is expected to reach \$315 billion by 2018 absent reform.²¹ In 2007, federal and state maternal and child health programs responsible for newborn screening spent 4 million and 160 million respectively on administrative costs.²²

Organizations such as the National Academy of Public Administration and the National Academy of Social Insurance have recommended enhancing the standardization of health care transactions to reduce administrative costs, a proposal in keeping with the President Obama's belief that comprehensive health reform should reduce long-term growth of health care costs for businesses and government.^{23,24} Changes to the billing and payment system for health care in the U.S. also may lessen administrative burdens shouldered by providers and patients.

Integrated System of Care Coordination - Medical Home

Incentives to promote the medical home model of care, such as reimbursement for care coordination, may minimize redundancies and prevent errors that occur because of lack of communication between primary care providers and specialists. Some analysts have suggested, and the Centers for Medicare and Medicaid Services have piloted bundled payments to medical professionals treating the same patient for a particular condition to promote care coordination and instill performance incentives and shared accountability for health outcomes into the system.^{25,26}

In the case of the more than 10 million children with special health care needs in the United States,²⁷ including those diagnosed with a disorder as a result of newborn screening, collaboration among the various health care providers delivering services such as medical management, occupational therapy and education may simplify the health care process for both caregivers and medical professionals. Encouraging the adoption of and providing the resources necessary to support a national standard of service and care for children identified with disorders through the newborn screening system that applies to all states and territories may help facilitate bundled payment approaches by clarifying the roles of providers, the public health community and others in service and care delivery.

“Meaningful Use,” Electronic Health Records and Exchange of Electronic Information

The inclusion of \$19 billion of Medicare and Medicaid financial incentives for the adoption of certified electronic health records in the American Recovery and

Reinvestment Act earlier this year demonstrates the important role of knowledge sharing in reforming health care. In order to qualify for these incentive payments, eligible individuals and entities must demonstrate “meaningful use” of certified electronic health record technologies, which has yet to be defined.

From the perspective of state public health departments, a definition of meaningful use that includes bidirectional exchange of data between public health departments and private providers that would allow them to receive required screening and immunization information is optimal.²⁸ A 2007 survey by The Commonwealth Fund and the National Governors’ Association found that of the 42 states responding, nine reported that the public health department served as the lead agency for the state’s e-health activities.²⁹

Realizing the potential cost savings from the implementation of electronic health records, however, necessitates an up front investment to develop the technological infrastructure. Although four states surveyed received Transformation Grants from CMS for e-health activities in the amount of \$2.8 to \$11.7 million combined for two fiscal years, 26 states reported funding as most significant barrier to accomplishing e-health priorities.³⁰

Continued federal support for the development of the U.S. e-health infrastructure is necessary to develop adequate communication between counties, states and regions.

For state newborn screening programs, the potential return on investment in health information technology includes not only enhanced delivery of patient-centric, coordinated care but also improved ability to track and follow-up patients long-term, and better data for evaluation and research. Because newborn screening is among the first

encounters where health professionals begin to compile medical information about an individual, it is a prime area for introducing electronic health records. Newborn screening also necessitates the sharing of information among different stakeholders in the system—the birthing facility, screening laboratory, public health department, pediatrician, parents, and, if necessary, specialists. Incorporating integrated electronic medical records that allow health information exchange presents the opportunity to create the foundation for electronic health information exchange between individuals and the public health system from birth onward.

Like all health information, the usability of electronically exchanged newborn screening information depends on standardized format for data sharing. To support the generation and exchange of electronic information related to newborn screening, the American Health Information Community’s Personalized Healthcare Workgroup subgroup on newborn screening developed a “Newborn Screening Detailed Use Case” and a “Newborn Screening Use Case Coding and Terminology Guide,” which were released by the Department of Health and Human Services Office of the National Coordinator for Health Information Technology on December 31, 2008.³¹ It has been since proposed that eventually newborn screening and birth parameters should comprise the initial content in a standard national child health record.³²

The National Institutes of Health and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD) also are engaged in efforts to promote the electronic exchange of newborn screening information. NICHD has established the

National Newborn Screening Translation Research Network to “build a research infrastructure that is large and potentially national in size and scope to facilitate the introduction of new screening tests and treatments in a research mode to gain knowledge as quickly as possible.”³³ The American College of Medical Genetics (ACMG), which was awarded a \$13.5 million contract in September 2008 to serve as the network’s coordinating center, is working toward the development of a virtual repository of residual and dried blood spots and informatics and communication systems.³⁴ The ACMG also serves as the coordinating center for HRSA funded Regional Genetic and Newborn Screening Services Collaborative Groups. As the establishment of the collaborative groups and the network progresses, cooperative efforts across the network and regional collaborative groups may provide an early example of how, as many policymakers hope, reform through the development of the national health information infrastructure and health information exchange can improve patient outcomes through faster translation of research findings into clinical practice and incorporation of knowledge from clinical care experiences, in turn, to research.

Uninsured or Inadequately Insured Children with Special Health Care Needs

For the estimated 48 million uninsured—a figure expected to rise to 61 million or more by 2020 absent changes to the system—and 25 million underinsured Americans today,³⁵ advances in health information technology may have little impact on their ability to access and receive quality health care unless adequate and continuous coverage becomes available to them. The population of uninsured or inadequately insured included approximately 3.8 million Children with Special Health Care Needs (CSHCN), according

to a 2005-2006 national survey, despite the Health Resources and Services Administration Maternal and Child Health Bureau's goal (set forth in 1997) that all children with special health care needs should have continuous private or public health insurance coverage.^{36,37}

The fact that lack of or inadequacy of insurance coverage remains a significant problem, over a decade later, among families with CSHCN stands as a testament to the monumental challenge policymakers face. The federal government's grant announcement of up to \$40 million available to help reach families whose children qualify but are not yet enrolled in state Medicaid and Children's Health Insurance Programs (CHIP) may provide relief for some,³⁸ but the 2005-2006 national survey of CSHCN revealed that about 2/3 of children with special health care needs with insurance coverage had inadequate coverage.¹ Pre-existing condition exclusions, lifetime benefit caps, and gaps in coverage that these and other American families experience can result in extreme financial hardship, a concern reflected in the Obama administration's belief that "comprehensive health reform should (among other things) protect families from bankruptcy or debt because of health care costs."³⁹

Insurance Coverage for Medical Foods

The terms of coverage details, as referenced in current major health reform proposals, do not alleviate the financial burdens incurred for medical management experienced by the

¹ In the survey and in Newacheck et al. (see endnotes) adequacy of coverage is measured as the composite whether health insurance benefits usually or always met the child's needs; whether non-covered charges were usually or always considered reasonable; and whether the insurance usually or always allowed the child to see the providers thought to be needed by the parents.

individuals and families of children with heritable disorders identified through newborn screening. As noted in an April 2009 letter from the Advisory Committee on Heritable Disorders in Newborns and Children to the then Acting Secretary of Health and Human Services Charles E. Johnson, “health care reform does not address the gaps in coverage for items that are a vital component of medical management but which are typically not included as ‘medical’ services.”⁴⁰ The Committee also remarked that insurance coverage of the medical foods and foods modified to be low in protein, that are essential for the treatment and management of many disorders screened for under the panel of conditions recommended by the Committee, may be limited or unavailable depending on the state of residence or type of plan.

Although over half of states require health insurance coverage for medical foods, these policies often establish caps on benefits, limit coverage to certain disorders, set age limits, or define medical foods in a narrow fashion that may not provide for all of the patient’s needs. Under such circumstances, even families living in states with mandates and whose insurance falls under the scope of the law may still annually pay hundreds or thousands of dollars beyond the cost of feeding a normal infant or child for necessary medical foods. Furthermore, approximately 60% of Americans have employer-sponsored health plans that are self-insured and, therefore, exempt from state law under the Employees Retirement Income Security Act.⁴¹

Since the Committee’s April 2009 letter, legislation has been introduced in Congress that would alleviate some of these concerns and allow the Secretary of HHS to determine

minimum yearly coverage requirements [for necessary medical foods] for all health insurance plans, as currently written.⁴² The passage of this legislation could also improve the ability of states to follow-up with patients long-term. The Committee's report *Long-Term Follow-up After Diagnosis Resulting from Newborn Screening* explains that variable and often incomplete health insurance benefits magnify the difficulties of long-term follow-up, which already involves interactions between many different types of providers.⁴³

CONCLUSIONS and RECOMMENDATIONS

The impact of the lack of financing of care for the uninsured and underinsured, and other hallmarks of the present U. S. health care system such as unequal access, inefficient care delivery and fragmentation are clearly visible from the perspective of newborn screening programs.⁴⁴ Minimum standards or national guidelines on several issues related to newborn screening, including the development of public health budgets, billing and payment practices, mechanisms to reduce administrative costs and health insurance benefits, may help states to provide a fully comprehensive set of services that affected families require. Although these barriers to system improvement are well understood in the newborn screening community, their removal relies on the consideration of these factors as a part of current overall health reform efforts.

The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children intends to form a workgroup to develop national guidance on public health budgets for newborn screening systems. The SACHDNC will collaborate with appropriate

governmental and non-governmental stakeholders in the development of the national guidance. Proposed national guidance will be based on the minimum recommended standard of service and care for each of the six core components of the newborn screening system and long-term follow-up outlined by the Committee⁴⁵ and the American Academy of Pediatrics⁴⁶ (AAP) — 1) education, 2) screening, 3) diagnosis, 4) follow-up, 5) management and treatment and 6) quality assurance services. The guidance will highlight budget alternatives that may better serve the needs of a particular state program, incorporate the flexibility in funding design that states may require, and identify areas that the federal government may target for additional support to help states deliver the minimum standard of service and care for long-term follow-up and the newborn screening system set forth by the Committee⁴⁷ and AAP.⁴⁸

Stewardship from the Secretary of the Department of Health and Human Services to take steps to remove existing barriers impacting state newborn screening programs would expedite change for the benefit of families of children with heritable disorders and the nationwide public health community. The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children, therefore, makes the following recommendations to the Secretary to address these concerns:

1. Encourage the Centers for Medicare and Medicaid Services to convene an expert panel to examine coding changes to streamline the billing process for newborn screening services and to put forth recommendations that enhance the standardization of health care transactions.
2. Encourage the Centers for Medicare and Medicaid Services to develop and pilot a payment method for an integrated system of care coordination through the medical home framework for children diagnosed with heritable and congenital disorders as a result of screening.

3. Encourage the adoption and further definition of the Newborn Screening Use Case within the Department's health information exchange endeavors, specifically encouraging the Centers for Medicare and Medicaid Services to make use of the Newborn Screening Use Case when defining "meaningful use" of Electronic Health Records and the Office of the National Coordinator for Health Information Technology to further facilitate the adoption of the Newborn Screening Use Case.
4. Support, as allowable, the closure of gaps in insurance coverage for medical foods and foods modified to be low in protein, as recommended by the Committee in April, 2009.

¹ Bradford L. Therrell, Donna Williams, Kay Johnson, Michele A. Lloyd-Puryear, Marie Y. Mann, and Lauren Raskin Ramos, “Financing Newborn Screening: Sources, Issues and Future Considerations.” *J Public Health Management Practice* 2007 Mar-Apr; 13(2): 207-213.

² General Accounting Office, *Newborn Screening: Characteristics of State Programs*. Washington, DC: General Accounting Office, 2003.

³ P.L. 110-204.

⁴ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations.”

⁵ Kay Johnson, Michele A. Lloyd-Puryear, Marie Y. Mann, Lauren Raskin Ramos and Bradford L. Therrell, “Financing State Newborn Screening Programs: Sources and Uses of Funds,” *Pediatrics* 2006; 117(5 Pt 2): S270-S279.

⁶ National Newborn Screening and Genetics Resource Center (NNSGRC), National Newborn Screening Information System, www2.uthscsa.edu/nnsis; accessed on July 20, 2009.

⁷ Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), Summary of the 18th Meeting, May 12, 2009. Available at www.hrsa.gov/heritabledisorderscommittee/meetings/2009may/default.htm.

⁸ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations.”

⁹ NNSGRC, National Newborn Screening Information System.

¹⁰ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations.”

¹¹ ACHDNC, Summary of the 18th Meeting.

¹² Jeffrey Levi, Sherry Kaiman, Chrissie Juliano and Laura M. Segal, *Blueprint for America’s Health: Preventing Epidemics. Protecting People*. Washington, DC: Trust for America’s Health, 2008.

¹³ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations.”

¹⁴ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations.”

¹⁵ ACHDNC, Summary of the 18th Meeting.

¹⁶ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations;” GAO, *Newborn Screening: Characteristics of State Programs*; and ACHDNC, Summary of the 18th Meeting.

¹⁷ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations.”

¹⁸ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations.”

¹⁹ Therrell, Bradford L. et al., “Financing Newborn Screening: Sources, Issues and Future Considerations.”

-
- ²⁰ The Commonwealth Fund Commission on a High Performance Health System, *The Path to a High Performance U.S. Health System: A 2020 Vision and the Policies to Pave the Way*. New York: The Commonwealth Fund, February 2009.
- ²¹ The Commonwealth Fund Commission on a High Performance Health System, *The Path to a High Performance U.S. Health System*.
- ²² S. R. Collins, R. Nuzum, S. Rustgi, S. Mika, C. Schoen, and K. Davis, *How Health Care Reform Can Lower the Costs of Insurance Administration*. New York: The Commonwealth Fund, July 2009.
- ²³ National Academy of Social Insurance and National Academy of Public Administration, *Report of the Study Panel on Administrative Issues in Expanding Access to Health Care: Administrative Solutions in Health Reform*. Princeton: The Robert Wood Johnson Foundation, July 2009.
- ²⁴ The White House, www.whitehouse.gov/issues/health_care, accessed on July 31, 2009.
- ²⁵ The Commonwealth Fund Commission on a High Performance Health System, *The Path to a High Performance U.S. Health System*.
- ²⁶ Physician News Digest, www.physiciansnews.com/bundled-payment-reform-models, accessed on July 31, 2009.
- ²⁷ U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. *The National Survey of Children with Special Health Care Needs Chartbook 2005–2006*. Rockville, Maryland: U.S. Department of Health and Human Services, 2007.
- ²⁸ National Committee on Vital Health Statistics Executive Committee Meeting, Hearing on “Meaningful Use” of Health Information Technology, April 29, 2009. Transcript available at www.ncvhs.hhs.gov/090429tr.htm.
- ²⁹ V. K. Smith, K. Gifford, S. Kramer et al., *State E-Health Activities in 2007: Findings From a State Survey*. New York: The Commonwealth Fund, February 2008.
- ³⁰ Smith, V.K. et al, *State E-Health Activities in 2007*.
- ³¹ Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), Summary of the 17th Meeting, February 26, 2009. Available at www.hrsa.gov/heritabledisorderscommittee/meetings/2009february/default.htm.
- ³² ACHDNC, Summary of the 17th Meeting.
- ³³ ACHDNC, Summary of the 17th Meeting.
- ³⁴ ACHDNC, Summary of the 17th Meeting.
- ³⁵ The Commonwealth Fund Commission on a High Performance Health System, *The Path to a High Performance U.S. Health System*.
- ³⁶ 2005-2006 National Survey of Children with Special Health Care Needs
- ³⁷ Paul W. Newacheck,, Amy J. Houtrow, Diane L. Romm, Karen Kuhlthau, Sheila R. Bloom, Jeanne M. Van Cleave and James Perrin, “The Future of Health Insurance for Children with Special Health Care Needs.” *Pediatrics* 2009; 123:e940-e947.
- ³⁸ Department of Health and Human Services, “Secretary Sebelius Announces Availability of \$40 Million in Grants to Help Insure More Children.” News Release, July 6, 2009. Available at www.hhs.gov/news.
- ³⁹ The White House, www.whitehouse.gov/issues/health_care: accessed on July 31, 2009.

⁴⁰ Howell, Rodney R., Chairperson, Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children, Letter to the Acting Secretary of Health and Human Services, The Honorable Charles E. Johnson. April 7, 2009.

⁴¹ Secretary’s Advisory Committee on Heritable Disorders in Newborns and Children (ACHDNC), Summary of the Meeting of the Medical Foods Workgroup of the Subcommittee on Follow-up and Treatment, June 2, 2008.

⁴² Medical Foods Equity Act of 2009, S. 2766, 111th Congress, 1st Sess. (2009).

⁴³ Kemper, Alex R. et al., “Long-term follow-up after diagnosis resulting from newborn screening.”

⁴⁴ The Commonwealth Fund Commission on a High Performance Health System, *The Path to a High Performance U.S. Health System*.

⁴⁵ Kemper, Alex R. et al. , “Long-term follow-up after diagnosis resulting from newborn screening.”

⁴⁶ AAP Task Force Report, “Serving the Family from Birth to the Medical Home — Newborn Screening: A Blueprint for the Future.”

⁴⁷ Kemper, Alex R. et al. , “Long-term follow-up after diagnosis resulting from newborn screening.”

⁴⁸ AAP Task Force Report, “Serving the Family from Birth to the Medical Home — Newborn Screening: A Blueprint for the Future.”