

Introduction

EACH YEAR, 4 million U.S. infants are screened to detect genetic conditions that threaten their lives and long-term health. Newborn metabolic (heelstick) screening is a public health activity that has been conducted for the past three decades and is universally accepted because of its profound impact on the health of newborns. However, new issues and challenges related to newborn screening programs and providing care to children with special healthcare needs are now emerging because of recent trends in diagnostic capability, technology, society, and the healthcare system.

Among them:

- a revolution in biotechnology, dramatically increasing the number of tests that can be performed;
- an explosion of new information technology, making it possible to provide comprehensive, integrated information to a child's medical home;
- an increase in population mobility. Families relocate, change employers and insurers, and change healthcare providers with increasing frequency, resulting in records scattered among different providers, offices, and clinics, and even across states.
- increasing numbers of children who are uninsured or underinsured. Children and families often lack coverage for or access to specific services
- new and growing partnerships between private sector and public sector healthcare organizations and providers;
- pressures to contain costs, even in the face of new tests and treatments that offer promise; and
- ethical, legal and social questions associated with all of these changes, including the need to balance the population's health with individuals' rights and to assure families that their privacy is fully protected.

Recognizing these challenges will have a significant impact on newborn screening programs. At the request of the Health Resources and Services Administration (HRSA), the American Academy of Pediatrics (AAP) convened a National Task Force on Newborn Screening, representing a broad base of perspectives. The August 2000 report from the Task Force outlines a national agenda for strengthening state newborn screening programs (Task Force, 2000).

The report includes four key recommendations, the first of which was a recommendation for action to develop the public health infrastructure and integrate newborn screening systems with the healthcare delivery system. The report stresses the importance of placing newborn screening programs within adequate public health infrastructure, which includes collaboration of federal agencies; development of standards; appropriate evaluation and monitoring of program performance; informed and involved health professionals and the public; and coordination and integration of program activities including information and services, through public-private, federal-state, and intrastate partnerships.

The report lists programs with information that logically can be integrated: those that screen infants for other health and developmental risks (prenatal screening and follow-up, newborn hearing screening, WIC, outreach, case management and home visiting programs); programs for infants with or at risk for special healthcare needs (high risk infant follow-up programs, early intervention programs, and state genetics services pro-

gram); and registry and data programs that include infants (vital records, immunization registries, birth defects).

But it goes on to say:

Publicly funded infant and child health programs often operate independently of one another. The resulting duplication of effort can increase costs, burden families and healthcare professionals, and create redundancy in data management systems.

Improved coordination and integration of information systems is needed. (Task Force, 2000. p403).

Addressing the challenges associated with integrating information and information systems, the report suggests two strategies: assess the status of state newborn screening systems, including information on the capacity to manage and integrate information at each state of the system, and more broadly, the relationships among newborn screening program, especially immunization registries; and support program integration models.

In accordance with these strategies to develop the public health infrastructure that will improve service delivery to children within a medical home, the report specifically notes the need for a national process to share and promote best practices in information integration models.

In October 2001, the Genetic Services Branch, Maternal and Child Health Bureau, Health Services and Resources Administration (GSB/MCHB) contracted with the Center for Innovation in Health Information Systems (Center for Innovation) to identify and describe best practices leading

to the integration of newborn metabolic screening programs with other public health programs and their information systems. Because of its previous experience with All Kids Count, the Center for Innovation was uniquely qualified for this work. The All Kids Count Program, funded by the Robert Wood Johnson Foundation since 1992, had spent eight years assisting state and local health departments in developing and implementing immunization registries. In 2000, All Kids Count broadened its focus to address integration immunization registries with other early childhood health information systems, including newborn metabolic and hearing screening systems.

The Center for Innovation was asked by GSB/MCHB to identify and describe best practices in integration among seven of their SPRANS planning grantees. SPRANS grants were awarded to states to assist them in developing state genetics plans and integrated data collection and service systems for the purpose of enhancing early intervention services. By 2000, grants had been awarded to 17 states: Alaska, Arizona, Colorado, Hawaii, Indiana, Iowa, Kentucky, Massachusetts, Michigan, Mississippi, Missouri, Oklahoma, Oregon, Rhode Island, Texas, Utah, and Wisconsin. The Center for Innovation reviewed the proposals from these grantees to determine which states were in the process of planning, developing or implementing an integration initiative. Seven states were chosen for two-day site visits: Colorado, Iowa, Michigan, Missouri, Oregon, Rhode Island, and Utah.

The Center for Innovation organized the two-day site visits around nine key elements considered critical to the success of an information systems integration project. The key elements are not technical but rather are crosscutting organizational considerations that are critical to success for an integrated project regardless of its scope or focus.

The nine key elements are:

- leadership;
- project governance;
- project management;
- stakeholder involvement;
- organizational and technical strategy;
- technical support and coordination;
- financial support and management;
- policy support; and
- evaluation

Center for Innovation staff identified these through review of health information systems management literature and by drawing from their experience with All Kids Count over the last decade.

The site visits were focused on identifying and understanding what factors, from the grantees' perspective, were important for planning and implementation of the integration effort underway within their states. Site visits were structured to gather consistent information across sites, yet allow flexibility in dealing with the unique nature of each grantee.

The seven sites offered a wide range of experiences. One had more than a decade of experience at developing a state-wide integrated information system to support many public health systems. Others are in the very early stages of their work and have not yet formulated a master plan for future integration efforts. Yet despite the variability of the sites, the key elements critical to success proved valid across all.

This Sourcebook contains a description of each of the key elements and what are considered best practices in their implementation. It gives examples of best practices of each of the elements as demonstrated by five of the seven SPRANS grantee states visited: Colorado, Iowa, Michigan, Oregon, and Rhode Island. Through in-depth case studies of the two remaining states, Utah and Missouri, it describes how the key elements were implemented through two very different approaches. And, it presents five lessons learned – over-arching conclusions that we believe states and government agencies should bear in mind as they consider implementing health information systems integration projects.

This *Sourcebook* provides guidance to other states in planning, developing, and implementing the integration of their newborn screening systems with other early childhood health programs and their information systems.