

# Evolution of a Child Health Profile Initiative

Deborah S. Linzer, Michele A. Lloyd-Puryear, Marie Mann, and Michael D. Kogan

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While information technology has proliferated and advanced dramatically in the last 10 years, the application of information technology to health care policy and delivery has not been well coordinated either among public health agencies or between the public and private health sectors. In 1998, the Genetic Services Branch, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources and Services Administration (HRSA/MCHB) began an initiative to help facilitate assessment and prompt provision of appropriate services to improve the health of children. Twenty-five state public health programs received grants to improve integration of newborn screening and genetic services systems with other maternal and child health systems. All Kids Count—a program of the Public Health Informatics Institute—completed a qualitative assessment of state programs that were funded to develop plans for integration. The results are being translated into a business/policy case addressing the need for integration, a description of essential functions that such systems support, ultimately system requirements, and measures for evaluation. HRSA/MCHB's partnership with All Kids Count continues with a project to develop a community of practice to assist programs in moving their integrated child health information systems forward.

**KEY WORDS:** delivery of health care, health services administration, newborn infant screening, public health informatics

Newborn screening for disorders leading to catastrophic health consequences has been a concern of public health departments since the early 1960s. State-based screening programs spread rapidly when it was shown that screening newborns universally for inborn errors of metabolism could reduce the frequency of or prevent

mental retardation and reduce the financial burden to the family and to society. Over the ensuing years, state public health newborn screening systems have been successful in creating efficient disease prevention and service delivery systems for thousands of newborns identified annually with heritable disorders.

Inherent to the success of newborn screening as a public health prevention program is a system of services that are comprehensive and coordinated. This system must consist of education, testing, follow-up, diagnosis, treatment/management, and evaluation activities. The critical junctures between public health's responsibilities and the community-based health care delivery system with which they coordinate must be linked seamlessly without duplication of effort.

The coordination and linkage of services remains a major challenge that has been compounded by recent advances in diagnostic capability, technology, the growing impact of consumer advocacy, changing demographics, and changes in the health care system. While newborn screening remains state-based, roles and responsibilities for state public health programs and practicing clinicians vary widely. Publicly funded infant and child health programs often operate independently of one another, which leads to fragmented services.

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Statements and opinions in this article are those of the authors and not necessarily those of the Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau.

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Newborn screening programs should be in close communication with other stakeholders in the system to include: parents and guardians of screened infants; prenatal care providers; health professionals at the birthing facilities, medical homes, and subspecialty clinics; and service providers at state agencies and community programs, such as early intervention specialists, audiologists, and nutritionists.

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Most importantly, the communication between the state newborn screening program and the infant's medical home should increase the likelihood that every newborn receives appropriate services. All infants identified through newborn screening must receive timely diagnosis and access to care and treatment, if warranted. Newborn screening programs should be in close communication with other stakeholders in the system to include: parents and guardians of screened infants; prenatal care providers; health professionals at the birthing facilities, medical homes, and subspecialty clinics; and service providers at state agencies and community programs, such as early intervention specialists, audiologists, and nutritionists. Collaboration, cooperation, and coordination among these stakeholders should ensure the timely follow-up and handling of screening results and appropriate management of identified infants, as well as the accumulation of relevant data to assess the effectiveness of the system.

Public health information system infrastructure must be developed to support this communication process in such a way as to ensure: (1) minimal duplication of data tracking between programs that serve the same population, (2) rapid follow-up coupled with efficient and effective delivery of medical as well as ancillary and social services, (3) adequate privacy protection, and (4) appropriate outcome data for system evaluation and improvement. The collection and analysis of short- and long-term data, while maintaining strict adherence to privacy and confidentiality principles, should provide information on which to base program changes, policy development, and system improvement. Without outcome data, it is impossible to accurately assess the program's performance. Outcome data also provide a mechanism for documenting that identified children in the system are receiving needed services in a timely way. Further, such information will allow an enhanced understanding of the clinical history of conditions included in screening panels.

Two recent surveys funded by the Genetic Services Branch in the Division of Services for Children with Special Health Needs of the Maternal and Child Health

Bureau, Health Resources and Services Administration (HRSA/MCHB) highlighted a system gap in the exchange of information between public health newborn screening programs and clinical care. Communication between the medical home and these public health programs was haphazard and not organized; infants were potentially not screened or lost to follow-up if screened positive. Results from these surveys indicated that there is a need for augmented communication systems to connect the primary care pediatrician directly with the state newborn screening system to enhance the timely retrieval of screen-positive results, access follow-up test results, and provide documentation for all test results, both positive and negative.

Kim et al<sup>1</sup> found that roles and responsibilities for the state public health program and private pediatrician vary by state. The state newborn screening program does not always include pediatricians in its newborn screening communication process. Most programs had no process or procedure to ensure a medical home or determine who holds the primary responsibility of informing parents about the newborn screening program, leaving the process to chance.

Desposito et al<sup>2</sup> found that 31% of pediatricians were notified of screen-positive results more than 10 days after testing was completed. Although the majority of these patients received treatment and follow-up by the birthing center or the state newborn screening follow-up team in a timely manner, communication with the primary care pediatrician was less than optimal. Communication of screen-negative results was also less than optimal: 26% of pediatricians were not routinely notified of results. Although most pediatricians surveyed made an effort to track down the missing results of newborns in their practice, 28% of pediatricians interpreted the lack of a reporting as a negative result.

The lack of an integrative approach to communication practices between public health programs and between public and private stakeholders is illustrative of the point made by the Institute of Medicine<sup>3,4</sup> that the current care delivery system in the United States consists of silos, often lacking even rudimentary information capabilities to exchange patient information, coordinate care across settings and multiple providers, and ensure continuity of care over time. The resulting duplication of effort can increase costs, burden families and health care professionals, and create redundancy in data management systems.<sup>5</sup>

The current system of categorical programs for child health is no different. Publicly funded infant and child health programs often operate independently of one another, requiring the collection of duplicative information, and leading to fragmented services. Efforts to facilitate the data sharing between public programs and clinical care should improve the coordination

of care for all children identified through newborn screening.

### ● **Role of the Maternal and Child Health Bureau**

In 1998, HRSA/MCHB began developing new initiatives to enhance and strengthen state-based newborn screening programs. To date, 25 state public health programs have received funding through grant support to improve the coordination and integration of newborn screening and genetic services systems with other maternal and child health systems. In addition, All Kids Count—a program of the Public Health Informatics Institute supported by The Robert Wood Johnson Foundation—has been funded to complete a qualitative assessment of these projects. The results are being translated into a rationale or business case addressing the need for integration.

With a commitment to reduce fragmentation and gaps in newborn screening systems, HRSA/MCHB's funded programs are structured to expand and strengthen newborn screening systems and promote their linkage to medical homes, early intervention, and family-to-family support programs<sup>6</sup> through the Maternal and Child Health Services Block Grant Act ("Title V")<sup>7</sup> and the Child Health Act of 2000.<sup>8</sup>

Federal maternal and child health (MCH) programs, with roots going back nearly a century, have been the primary federal entities with major responsibility for promoting and improving the health of our nation's women, children, and families.<sup>9,10</sup> This federal commitment can be traced first to the Children's Bureau (established in 1912) and then through Title V of the Social Security Act of 1935,<sup>10</sup> which authorized the Maternal and Child Health Services programs and provided a foundation and structure for helping to ensure the health of American mothers and children.

Today, HRSA/MCHB administers a broad range of programs that address the needs of the nation's families, the largest of which is the Maternal and Child Health Services Block Grant,<sup>9</sup> which includes the State Formula Grants, Special Projects of Regional and National Significance (SPRANS), and Community Integrated Service Systems (CISS). HRSA/MCHB also funds the Early Hearing Detection and Intervention (EHDI) program.<sup>11</sup>

HRSA/MCHB is the federal entity with the most responsibility for newborn screening system development. Historically, the federal MCH programs played a critical role in establishing public health newborn screening systems by recognizing that screening, short-term follow-up, diagnosis, management/treatment, and evaluation, with education and quality assurance,

are integral to all components of the system.<sup>12,13</sup> It is important to note that the responsibility for the design and implementation of genetic services and newborn screening systems has always resided within the states and territories.

### ● **Newborn Screening Task Force**

In 1998, at the request of HRSA/MCHB, the American Academy of Pediatrics (AAP) convened a Task Force on Newborn Screening (Task Force) to examine the many issues that had arisen around state newborn screening programs.<sup>5</sup> (Note: The Newborn Screening Task Force was co-sponsored by the Agency for Healthcare Research and Quality [formerly the Agency for Health Care Policy and Research], the Genetic Alliance [formerly the Alliance of Genetic Support Groups], the Association of Maternal and Child Health Programs, the Association of Public Health Laboratories, the Association of State and Territorial Health Officials, the Centers for Disease Control and Prevention [CDC], and the National Institutes of Health.) After reviewing some of the challenges facing these programs, the Task Force put forth a national agenda for action and a series of recommendations to strengthen newborn screening systems and proposed changes to meet the immediate technological and programmatic challenges facing these programs.

The Task Force recognized that effective newborn screening systems require an adequate public health infrastructure and must be integrated with the health care delivery system to be effective. The Task Force also recognized that public health agencies must ensure adequate infrastructure and policies for surveillance and research related to newborn screening. Furthermore, they recommended that grants from HRSA/MCHB "facilitate and foster the involvement of newborn screening systems in infrastructure development activities in states."<sup>5</sup> The Task Force noted that "such grants should encourage states to consider integration of heel-stick programs with a core set of other newborn programs, including birth registration, immunization, newborn hearing screening, and possibly the WIC (Women, Infants, and Children) program," recognizing that "improved coordination and integration of child health information systems is needed."<sup>5</sup>

### ● **Child Health Profile**

Newborn screening programs rest on an implied partnership between state public health programs and the community-based systems of care that provides direct services to children and their families to ensure that the results of newborn screens are shared with the

child's medical home for appropriate care, treatment, and long-term follow-up. How to deliver the necessary information to the medical home and families in a real-time manner, to the appropriate subspecialist to ensure rapid confirmation and diagnosis, as well as gain support of this effort within public health agencies were identified as first tasks in the development of the HRSA/MCHB child health information system initiative.

Based on the premise that newborn screening data are useful to public health agencies and to pediatricians with respect to the individual child in their practice, the concept of a community-based "child health profile" was developed. This integrative approach allows: population-based and program specific data to be used by public health programs for such efforts as needs assessments; personal health data access, as necessary, by providers for treatment and by families for their children; and the use of public health and other relevant data through data exchange to optimize the delivery of care.<sup>14</sup>

HRSA/MCHB envisions that by coordinating programs and integrating their information systems with the support of recent innovations in technology, information will be captured in a timely manner to support decision making at the point of health care service delivery and support program needs. The development of a child health profile by state public health programs for every child within their jurisdiction has become a reality.

More recently, the child health profile has been described as an online electronic system (ie, Electronic Health Record [EHR]) for storing, sharing, using, and evaluating child-health information such as newborn metabolic and hearing screening results.<sup>14</sup>

## ● Genetic Services Program Initiatives: From Planning to Implementation

### **SPRANS state development grants for newborn screening efforts and infrastructure development**

The concept of a child health profile as integral to the integration of child health information systems began through a series of 3 strategic planning meetings<sup>15</sup> that were convened in November 1999, in Arlington, Virginia. The attendees were to consider how HRSA/MCHB should meet the challenges and opportunities posed by the recent recommendations of the Task Force. Participants in these meetings were urged to put the emphasis on how best to integrate genetic services into existing programs, not to build new separate, free-standing entities. The report from the Task Force offered many opportunities to address the adequacy of the infrastructure to support quality newborn

screening programs and whether the current systems for data collection and analysis were sufficient. The desired outcome of the meetings was to collectively build strategies for implementation of the Task Force recommendations.

Invited participants represented leaders in the field of genetic services, newborn screening, information technology, public health, family members, and representatives from several states. Participants gave the highest priority to federal funding for state genetic and newborn screening activities that included flexible funding for infrastructure development, grants for information systems development, and state genetic services plans.

Through a competitive process, 7 states—Arizona, Colorado, Iowa, Massachusetts, Missouri, Rhode Island, and Wisconsin—were funded in 1999 in the first round of SPRANS State Development Grants for Newborn Screening Efforts and Infrastructure Development to develop state genetic services plans that included programs in newborn screening and other early identification and prevention measures, and collaborative efforts with primary care providers. The idea was to set a framework for genetic services infrastructure and partnerships among state public health programs, primary care providers, the genetic services community, and service consumers.

These programs were to develop a community-based child health profile and identify a mechanism for integrating surveillance data within public health agencies. Specifically, these grants were expected to facilitate the development or update of the state's genetic services plan, linkage of early identification to early intervention, and linkage of newborn dried blood-spot screening programs to birth defects surveillance, hearing screening programs, and immunization registries. In addition, they were intended to pave the way for an increased role for MCH programs in genetic services policy. The programs were to further the ability of public health agencies to conduct surveillance, look critically at health services data, and improve the monitoring of systems and outcomes.

In 2000 and 2001, state public health programs located in the following 15 states received development grants: Alaska, Connecticut, Hawaii, Indiana, Kentucky, Michigan, Mississippi, Minnesota, Nebraska, North Carolina, Oklahoma, Oregon, Tennessee, Texas, and Utah. For this grant activity, HRSA/MCHB increased the emphasis on the creation of a plan for an integrated child health information system within the construct of the state genetic services plan.

Each of the subsequent years that this state development initiative was funded brought clarity and increased focus to HRSA/MCHB's expectation of what should be included in a state's genetic services plan: (1)

the planning activity for the integration of child health information systems and programs, (2) collaborative efforts with Title V MCH and Children With Special Health Care Needs (CSHCN) State Agency Directors, (3) the creation of a child health profile, (4) issues of informed consent, confidentiality, and access to medical records, and (5) an assessment of what programs would need to implement their plan (ie, infrastructure, personnel, legislation, funding, etc.).

To fulfill their obligation to describe the states' genetic services planning process and to document the extent the process had occurred amongst these states, HRSA/MCHB invited All Kids Count to work with them to identify and describe the best practices of 7 newborn screening programs and their planning efforts to integrate. These 7 state-based programs—Colorado, Iowa, Michigan, Missouri, and Oregon—were selected from the 22 states that had received development grants.

Two products were produced as a result of this effort: *Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems: A Sourcebook for Planning and Development*<sup>16</sup> (see Wild et al, *Key Elements for Successful Integrated Health Information Systems: Lessons From the States*, in this supplement) and the companion document, *Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems: A Tool for Assessment and Planning*<sup>17</sup> (see Wild and Fehrenbach, *Assessing Organizational Readiness and Capacity for Developing an Integrated Child Health Information System*, in this supplement).

### **Implementation of state genetic services plans for the integration of programs and their information systems**

Beginning in 2001 and over the course of 3 consecutive grant cycles, 16 state public health programs received grant funding, through a competitive process, to implement their state genetic services plans to integrate genetic services (including newborn dried blood-spot screening programs and their information systems) into existing state CSHCN systems of care. This activity furthered the implementation of the Task Force's recommendation to "facilitate and foster the involvement of newborn screening systems in infrastructure development activities in states."<sup>5</sup> The first 11 state public health programs to be funded to implement their plan were: the District of Columbia, Hawaii, Indiana, Iowa, Massachusetts, Michigan, Missouri, Oklahoma, Rhode Island, Utah, and Washington State.

These integration projects were to develop effective referral and follow-up strategies through CSHCN systems of care for infants identified through newborn screening to ensure: (1) integration of child health infor-

mation systems, (2) access to medical homes, (3) access to early intervention programs, and (3) family to family support. They were to focus on: (1) process and outcome evaluation, (2) development of standardized data, (3) analysis of the effectiveness of integration with other public health programs and their information systems such as immunization registries, birth defects registries, and newborn hearing screening programs.

The Genetic Services Branch partnered with HRSA/MCHB's Office of Data Information and Management (ODIM) to fund the third and final round of implementation grants to capitalize on each entity's strengths and capacity. Both programs recognized that the increased demand for community-based systems for newborns and children with or at risk for heritable disorders necessitated the development, enhancement, and ongoing support of data systems.

Working with grantees over the previous two funding cycles, it had become quite apparent that the Genetic Services Branch did not have the capacity to address the proliferation of data systems, their increasing complexity, the expectation to communicate with an increasing number of external portals, and the crucial need to meet certain common standards for efficiency of communication and cost-effectiveness of operations.

While program integration and coordination remained the primary goal of this joint funding initiative, the use of data integration as a tool for enhancing program coordination was specified for the first time. MCHB's expectation is that these projects show strong active involvement and partnering between the state MCH, CSHCN and the information technology directors. It is expected that these cooperative agreements will contribute to the formulation of a shared vision of integrated newborn screening service systems to include: (1) public/private partnerships, (2) integration of a wide range of public and private enabling and direct health care services, (3) development of an effective information infrastructure, (4) control of costs, (5) assurance of medical privacy, and (6) ability to respond to requirements for performance measurement. A review of grant documents, meeting summaries,<sup>18</sup> and discussions with grantees offered the following insights with regard to integrated child health information systems. The following insights are in concert with the key elements considered critical to the success of an information systems integration project as described in this supplement by Wild et al in *Key Elements for Successful Integrated Health Information Systems: Lessons from the States*.

1. Technology needs to serve program's needs. In order to be effective, program management staff requires methodological tools to guide how complicated integrated information systems get translated from conception to requirements to design. Strong

methodology will stimulate a rigorous business plan or policy case that incorporates ongoing management and funding concerns.

2. State public health programs have taken a variety of approaches to acquire technical support for their projects. Some have brought in graduate students to handle information technology programming, while others have contracted out their information technology functions.
3. Communication across all stakeholders is critical and state public health programs must find ways to improve communication in spite of scarce resources. Ironically, some grantees have found the shortage of resources can stimulate interest in integration projects because people are naturally working across departments in order to maximize resources.
4. Advisory committees are an important part of the infrastructure for newborn screening systems and can serve as an effective vehicle for communication. A critical part of managing the integration project is identifying multiple levels of stakeholders and advocates for the effort and engaging them in decision making.
5. Community-based health care providers have particular needs that must be met by child health information systems, to include:
  - Systems should enable the timely follow-up by the health care provider of the screen-positive newborn for confirmatory testing.<sup>2</sup>
  - Systems should be simple and quick to use, not require a significant investment in hardware/software and integrate well with existing office systems.
  - Systems must be technology neutral and deliver necessary information at the time it is needed in a manner acceptable to the user.
6. Programs continue to struggle to ensure that families have input throughout this process. Families appear to generally support information sharing for their child's benefit. They require reassurance that the information is secure and they need to know by whom it will be accessed. Parents want their child's information in a single place where they control access and want to avoid having to provide the same data over and over again. Families involved as stakeholders can use information gleaned from data as a powerful advocacy tool with which to approach legislators about data integration issues.
7. Data can be used by multiple programs for multiple purposes while maintaining the privacy of a child's personal data as required by the Health Insurance Portability and Accountability Act of 1996 (HIPAA)<sup>19</sup> and the Family Educational and Privacy Rights Act of 1974 (FERPA).<sup>20</sup>
8. The location of the integration efforts within a state public health program can make a significant difference in how well the efforts are received. The manager of the integration project is a critical player and must remain in constant contact with programs. Successful management also requires determining the value of the effort and conveying that value to the users of the system. Varied expertise is required to carry out the effort, and no one unit can operate in isolation from another. Most of the grantees had support from high-level officials and had high interest in integration across related programs.
9. Even though grantees had documented organizational and technical strategies in their program goals and objectives as part of their application and incorporated them into a high-level planning process, many felt their organizational strategy was incomplete, and others felt it was a constant work in progress.
10. State public health programs are exercising creativity to seek funding to support their efforts. One grantee noted that they have a line item from the state's general fund to support newborn screening fees. Another grantee is using bioterrorism dollars to help fund its data system arguing that birth defects, as a notifiable public health condition, can serve as a pilot for notifiable contagious diseases used in a bioterrorist attack. A third grantee is partnering with its mental health and substance abuse programs working on fetal alcohol issues to tap into resources from the federal Substance Abuse and Mental Health Services Administration. The grantees agreed that regardless of the funding source, to ensure continuous funding they must cultivate a range of people within the state public health agency who will be champions for child health information systems and the need for related data.
11. Grantees who have been working for more than a year to implement an integrated system were asked to share a salient piece of advice gleaned from their experience for the consideration of those just beginning the integration process; their advice included the following:
  - Be aware of the importance of follow-up care and care coordination.
  - Know that everything takes longer than planned.
  - Communicate broadly among team members, stakeholders, contractors, and others to keep the process on track.
  - Realize that integration is not only integration of data, but of services, education, outreach, and the voices of stakeholders.

- Use parental input to ensure the most accurate data are in the child health information system.
- Appreciate the value of having an epidemiologist on the staff of the newborn screening program.
- Go for “low-hanging fruit,” that is, isolate an aspect of the program that can be improved and implemented in a quick time period to demonstrate success and cultivate buy-in for the effort at the earliest stages.
- Address “bugs” in the system as they arise, even at the risk of slowing overall project implementation.
- Be aware that setting priorities is not simple and requires a variety of strategies that reflect the state’s strategic health priorities and operational realities.
- Evaluate the program critically to improve data quality, process efficiencies, and program effectiveness.

### **Business/policy case**

In 2001, it became apparent that it was necessary to build a business case for the private sector and a policy case for the public sector to garner funding and ongoing support for the integration of newborn dried blood-spot screening programs with other related child health programs and the health care delivery system.

To accomplish this task, HRSA/MCHB partnered with All Kids Count to build on the completed qualitative assessment of the previously described 7 newborn screening programs and their planning efforts to integrate. The results are being translated into a framework for integration, a rationale or business case addressing the need for integration, a logical description of essential functions that such systems must support, ultimately a set of system requirements that will guide state programs in developing such systems, and measures that will inform programs if the system is supporting its intended improvements in child health. “Principles and Core Functions of Integrated Child Health Information Systems”<sup>21</sup> has been completed and published in this supplement by Hinman et al.

### **Community of practice**

State public health programs that are integrating information systems serving newborn screening programs with other child health information systems across public health, personal health, and health care provider sectors are among the pioneers in this area. Currently, however, across the nation, these programs are working separately without many opportunities to share knowl-

edge. In Spring 2004, All Kids Count was funded to foster and support a “community of practice” to concentrate the experiences of those involved in the development and use of integrated child health information systems to advance this vision.

This learning community, comprising those on the leading edge of integrated child health information systems development, will assist participants in moving their systems forward. The community of practice will be formed as a collaboration of state public health agency projects committed to integrating two or more of their child health information systems, such as screening for inherited and congenital disorders, immunizations, and vital registration.

It is expected that community members will have executive-level commitment to this process. They will share a common goal of exchanging health information not only with other public health programs, but also with insurers and community health care providers. Members will consider the impact of public health information systems on community-based health care providers to be an important aspect of their system integration efforts.

### **● Conclusion**

The availability of a child health profile for use at the point of service delivery is not easy to achieve. While information technology has proliferated and advanced dramatically in the last 10 years, the application of information technology to health care policy and delivery has not been well coordinated either among public health agencies or between public and private health sectors. Health information systems in the private sector are increasingly exchanging data with other private sector systems to increase efficiencies and quality of care, but they rarely exchange data with the public health sector, which has population-based information.

The restructuring of the public/private health care delivery system needs to include, as an integral component at the state level, the development, enhancement, and ongoing support of integrated newborn screening service systems. Ultimately, these integrated systems should facilitate and support: education for the consumer and general public; appropriate and coordinated sample collection; laboratory testing; follow-up, diagnosis, and timely treatment; tracking of outcomes; and, ultimately, linkage to a medical home. This process should result in a decrease of morbidity, mortality, disability, and attendant health care costs.

The integration and coordination of programs that serve infants and families across private and public health dimensions should make possible the development of a child health profile to facilitate the capture

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and analysis of health care information on every child. Sound and well-planned integrated child health information systems will facilitate assessment and prompt provision of appropriate services to ensure an optimal healthy start for all children and improve the health of children.

The Newborn Screening Task Force recommended that state public health agencies retain oversight control over newborn screening programs. With this oversight, comes the responsibility of ensuring the timely reporting of all newborn screening results to families and the infant's pediatric health care professional. In turn, pediatric health care professionals need to work with their state newborn screening programs to define their roles and responsibilities and determine communication policies and procedures that outline and provide an infrastructure for that communication.

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