

# **Fiscal Year 2004 Integration of Newborn Screening & Genetic Service Systems with Other Maternal and Child Health Systems Conference**

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## **Summary of the October 15-16, 2003 Conference**

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## I. Introduction

The Health Resources and Services Administration (HRSA), through Title V of The Social Security Act -- Maternal and Child Health Services Block Grant, and Title XXVI -- Screening For Heritable Disorders, Sec. 2601 Program to Improve the Ability of States to Provide Newborn and Child Screening for Heritable Disorders, is working to expand and strengthen newborn screening systems and promote ongoing screening of children with special health care needs.

At the request of and with funding from the Maternal and Child Health Bureau (MCHB) within HRSA, the American Academy of Pediatrics (AAP) convened a Task Force on Newborn Screening (Task Force) that issued a report in August 2000 examining the many issues that have arisen around State newborn screening programs. After reviewing some of the challenges facing these programs, the Task Force made a recommendation to MCHB to provide States with grants that would help them stimulate development of newborn screening systems that are connected to the medical home and are integrated with other public health systems.

Since 1999, MCHB has provided financial and technical support to 25 state public health programs to integrate newborn screening program activities, including information and services through public-private, federal-state, and intrastate partnerships to ensure that children with special health care needs (CSHCN) identified by newborn screening programs are linked to medical homes to receive ongoing follow-up and appropriate referral to community services. Through the integration of child health information systems, States will be able to maximize resources to improve their efficiency and effectiveness.

Of these 25 state public health programs, 16 have been funded to implement their plans for the integration of their newborn screening and genetic service systems with other maternal & child health systems.

On October 15-16, 2003, HRSA sponsored the third in a series of technical assistance meetings of these State grantees, entitled "Integration of Newborn Screening and Genetic Service Systems with Other Maternal and Child Health Systems." Deborah Linzer, M.S., a Senior Public Health Analyst in MCHB's Genetic Services Branch, noted that the meeting was built around the work generated by the grantees, and designed to bring together States recently awarded grants with more seasoned grantees to discuss the progress they have made thus far and to share lessons learned in their data integration efforts. (A list of participants is included in Appendix A.) Ms. Linzer also observed that the States' projects fit well within the goals of the National Health Information Infrastructure (NHII), a Federal initiative aimed at developing a comprehensive knowledge-based network of interoperable systems of clinical, public health, and personal health information that should improve decision-making by making health information available when and where it is needed.

The Genetic Services Branch envisions that States will be able to develop a child health profile on every child to capture information in a timely manner, support decision-making at the point of service, and support program needs. By integrating information systems so that the information user has access to complete and accurate information about a child, it is anticipated that child

health can be improved. The MCHB is supporting this goal not only by funding 16 States with newborn screening/genetics grants, but also by funding:

- The development of two documents to support States in their work, “Integration of Newborn Screening and Genetic Service Systems with Other Maternal and Child Health Systems: A Sourcebook for Planning and Development” and, the companion document, “A Tool for Assessment and Planning.”
- The creation of the “Framework for Integrating Child Health Information Systems” (Framework) intended to help guide States in their efforts to improve the integration and coordination of public health programs that serve infants and children.
- The National Newborn Screening and Genetics Resource Center.

Ultimately, the Branch hopes that grantees will learn the lessons needed to forge ahead and build systems that ensure an optimal healthy start for children by providing for the assessment and provision of services.

## **II. Grantee Presentations**

Following introductions, the most recent group of States to be awarded grants by HRSA to integrate information and services to improve their newborn screening systems spoke about their initial work and the goals they envision for their States’ information systems.

### **A. Colorado**

Colorado’s grant application focused on two areas: 1) the use of an existing integrated electronic database to improve medical home usage by children with special health care needs (CSHCN), and 2) the opportunity to work with the State’s Genetics Advisory Committee to educate the public and providers about emerging genetic issues. This committee is comprised of a wide range of stakeholders, including public health, attorneys, ethicists, the March of Dimes, families of CSHCN, and geneticists, among others.

Colorado received a grant from the Centers for Disease Control and Prevention (CDC) to develop an electronic data system for the State’s newborn hearing screening program. It is this system that the State hopes to build on, and it is also trying to develop an immunization registry as part of this effort. One of the primary goals of Colorado’s grant is to enhance the assessment and assurance that children screened are followed through to medical care. A final outcome of achieving this goal would be to connect with on-the-ground providers who can, with permission, get the child health profile and pass it back and forth between themselves and subspecialists. Colorado expressed some technical concerns that it is attempting to deal with in the interim, such as:

- Difficulty of access to local case management modules via Citrix (the State’s current infrastructure software);

- Establishing provider access to the system over the Web and getting the word out; and
- Addressing the growing demand for maintenance of the system as it is used by entities outside the State health department.

Some of the questions the State had for other grantees included how to evolve a genetics program nearly from scratch, and how to get legislative support for genetics programs. Colorado also wants to learn from other States how they approach broader issues in genetics not related to newborn screening.

## **B. Georgia**

Having had a CDC grant to track its newborn hearing screening, the State of Georgia realized it needed to be integrating with newborn dried blood spot screening as well. In addition to making the integration of newborn hearing and dried blood spot screening one of its goals under the MCHB grant, Georgia is also seeking to develop and deploy Web-based registration of birth and fetal death events, and create a population-based system by integrating information across newborn screening, birth registration, and Georgia's planned Newborn Surveillance and Tracking Information System.

Georgia has gotten tremendous support on this initiative from the State Director of Public Health, and has set up several advisory committees, comprised of different stakeholders, to provide guidance as it goes forward. These include a Newborn Screening Advisory Committee, a State Advisory Committee on Newborn Hearing Screening, a Birth Defects Surveillance Advisory Committee, and an Integration Project Oversight Committee. The latter of these is a work in progress; the State's representatives are seeking assistance in how to set this up and who should be included on such a committee.

The State team reviewed the child health profile model, which relies upon the public health community and pediatricians to feed patients into Children 1<sup>st</sup>, the State's collaborative system of public health and prevention-based programs and services. As Georgia prepares to improve collaboration and data flow across agencies, it is looking for counsel on how to match algorithms and avoid de-duplication of data, as well as how to ensure stakeholder support from various entities that result in sustainable support for the data integration project. The State is somewhat impeded, however, in having to do this under the direction of the Georgia Technology Authority, which oversees all information technology in the State.

## **C. Minnesota**

As Minnesota aims to integrate State health information and newborn screening service systems into a comprehensive program, it is facing a large number of disconnects across the systems, and leering on the part of many agencies that are unsure about integration. The State has a rich WIC database and vital records system, yet these remain unconnected with newborn screening. Thus, the State's goal is to be able to build a system that allows for the provision of comprehensive follow-up services to 100% of the babies and families identified through

newborn screening. This follow-up includes coordinated care, and giving providers “just in time” information.

Like Georgia, Minnesota has several advisory committees with a wide range of stakeholders, including a newly formed Integrated Newborn Screening Management Team. As the State reexamines its data flow and newborn screening organizational structure, it will also be starting to contract with the Mayo Clinic to do tandem mass spectrometry and allow for a second tier of testing that can better deal with false positives.

The technical concerns, however, are great. These include handling diverse database managers (e.g., Oracle, SQL server, Access), and determining which data are correct and who the data steward is for duplicate data. Minnesota likewise has restrictive data privacy rules, and no common person identifier. Yet the State also sees opportunities in being able to create a common application, reduce the amount of data entry and errors, and share authorized data and provide Web access to information for providers.

#### ***D. Oregon***

Oregon has been ahead of the curve in building an integrated system (FamilyNet) for maternal and child health, having started the process 15 years ago. Currently, the State is building on successes in newborn screening by providing affected children an integrated system of services that identifies them as soon as possible and assists their families as long as needed. This is being done through public/private collaboration, and by providing hospitals, medical homes, public health programs and specialty clinics with direct Web access to an interactive system of communication to promote timely screening and follow-up.

Numerous advisory committees have input into the system, including a legislative group that coordinates activities in each community, and a Council of Local Health Officials that advises about public health services. Oregon has also put together a FamilyNet Steering Committee to continue to advise processes for data flow. The State already has mapped out the programs that flow into FamilyNet, which include newborn screening, early hearing detection, care coordination for children with special needs, a case management program for high-risk children, Healthy Start, and a community connections program for special needs children. Oregon is just starting to map out how the data flow between these groups within the system, but noted an advantage to the system being rooted in maternal and child health, and not solely newborn screening.

In the future, Oregon would like to bring private providers directly into access with FamilyNet. Meanwhile, it grapples with issues that include maintaining data integrity with a legacy system. Oregon asked whether it should market FamilyNet as a data system that combines population-based screening and county-based services. If so, it ponders how to assure families do not reject population-based services over concerns for confidentiality, and if not, how to assure coordination of services without violation of user or family assumptions about data security and confidentiality.

## **E. Tennessee**

The University of Tennessee is the recipient of this grant. The University is collaborating with the State Department of Health to enhance and expand the State's newborn screening program. Tennessee also wants to integrate systems of early identification with early intervention, implement quality assurance and evaluation of service delivery systems, and increase the ability of providers and families to understand and seek appropriate, timely treatment.

Tennessee is one of the first States to receive funding from the Federal Genetics Act in 1985, which has enabled the State to have a long-term Genetics Advisory Committee. With the initial genetics planning grant from MCHB, the State has also formed a Statewide Genetics Coordinating Committee with participation by public health programs, and stakeholders from education, early intervention, Medicaid, and consumer groups. This committee has formed several subcommittees, each dealing with a separate issue relevant to the integration process, such as professional education, ethics, hearing screening, consumer involvement, and financing.

While Tennessee currently has a strong follow-up system, it encounters difficulties because there is no process of getting birth certificates linked to newborn screening, and the State has not yet mandated hearing screening. Tennessee envisions a secure system that will allow for authorized users to receive health profiles as appropriate. The State has just purchased a tandem mass spectrometer, and is interested in getting expanded screening and advice from other States on how to do follow-up. It also would like to know how other States have established criteria for newborn screening and genetic testing, and developed data systems for evaluation, tracking, and integration of newborn screening with other genetic services, as well as MCH and early intervention services.

## **III. Panel Discussion: Voices of Experience**

Eleven grantees who have been working for more than a year to implement integration systems were asked to come to the meeting and share their experiences with the newer grantees, and to help answer some of their questions. What follows is a brief summary of the advice each of these States offered to those just beginning the integration process.

- A few years ago, the **District of Columbia** (DC) paid for a discharge planning expert to gather data on every infant born in DC hospitals. The District has found this helped to bring disparate groups together and made them realize what other programs were important to create linkages with. Currently, the District has a Web-based Oracle system that allows for varying types of security protections, and gives early intervention access to the system to help coordinate follow-up services. The District is challenged with wanting to provide more information to providers outside of government entities and to parents; it also hopes to tag onto the vital records system in the coming months. District representatives emphasized the importance of follow-up care and care coordination, and noted they are also trying hard to integrate more with WIC and immunizations to help improve surveillance of children before they enter school.

- **Hawaii** has focused much of its grant activities on education and implementation of genetics in other health programs. Being able to network prior to getting their grant helped to develop the application, but the State also learned the importance of sending out information to stakeholders after partnerships are in place. Hawaii went to stakeholders to ask for feedback about how best to present information for their use. As a result of the feedback, Hawaii developed a Web site ([www.hawaiigenetics.org](http://www.hawaiigenetics.org)) to provide information. Another Web site, [www.newbornscreening.info](http://www.newbornscreening.info), provides educational materials to providers and consumers about newborn screening. Some of the primary lessons learned by the State included: never underestimate how little people know about genetics; know the basics of many subjects (education, marketing, IT); everything takes longer than planned; and the more successful a project, the busier it gets.
- **Indiana** emphasized the power of communication—among team members, with grant contractors, and other stakeholders—to keep the process on track. Specifically, the State’s representatives said they hold weekly team meetings with grant members, bimonthly meetings of the genetics implementation grant steering committee, quarterly meetings of everyone involved in the grant activities, and semi-annual meetings of Indiana’s Genetics Advisory Committee. These mechanisms have helped the State stay focused even in the absence of a project director for six months. Indiana also found that effective communication with the State health commissioner helped to get a plan to amend the birth defects reporting law, which will now include autism.
- **Iowa**, in its third year of grant funding, has learned that integration is not only integration of data, but of services, education, outreach, and the voices of stakeholders. Even when the data integration effort is stalled, it is important to take advantage of the opportunity to advance in each of these areas. Stakeholders, in particular, play a crucial role. As Iowa learned after notifying families they were in its birth defects registry, sometimes the diagnosis at birth is not correct; therefore having parental input ensures the most accurate data is in the State system. Stakeholders must be involved throughout the process, and States must recognize these stakeholders constantly change. As Iowa moves forward, it is concentrating on putting out more education through a genetics Web site, and giving information on the Health Insurance Portability and Accountability Act (HIPAA) to all hospitals from which Iowa collects birth defects information.
- A shift in programs at **Massachusetts’** Department of Public Health has increased the State’s efforts to assure all programmatic systems are in place to help prevent kids from falling through the cracks. While the State has been impacted significantly by budget cuts, it has found an opportunity in the State reorganization to talk to other agencies previously operating in silos. This improved level of communication is seen as a positive step in improving integration overall, and the State hopes someday to be able to expand its efforts to have a technical assistance and intake triage center.
- **Michigan** added an epidemiologist to its newborn screening program, and found this very beneficial. This individual has begun working with staff to develop algorithms for patient flow from screening to patient management. As the State works on integrating newborn screening with childhood immunization, it has been using the epidemiologist to develop a

longitudinal study of outcomes for children treated for phenylketonuria (PKU) in Michigan, as well as to develop the first annual report on newborn screening to be issued by the State. Finally, Michigan is collaborating with medical directors of follow-up clinics on outcomes and longitudinal assessment of children identified through newborn screening.

- With a nearly 10-year-old integration effort, **Missouri** has seen a wide range of challenges and had several points of advice for States new to the process. One of the first is to go for “low-hanging fruit” in order to demonstrate success in a quick time period and be able to create buy-in for the effort. It’s also important to bring in the programs’ users to help set priorities and make decisions about what will work best within the integrated system. Missouri acknowledged the importance of addressing bugs in the system as they arise, even if this slows down the process. Finally, the State noted that setting priorities is not simple and requires a variety of strategies that need to reflect the realities of the environment in which the State is operating.
- **Oklahoma** emphasized the need for States and project planners to justify everything they develop in order to gain advance support for the initiative. The State said not to be afraid to be the “squeaky wheel”; one way it has been able to move forward on newborn screening expansion efforts is by being vocal and using that to get buy-in from the State Commissioner of Health. Oklahoma also has found success with its Genetics Advisory Council, which has set up a series of committees, each developing action steps and generating energy around those. The State stressed the need for other States to conduct at least short-term follow-up, noting that diagnosis alone is not enough. Oklahoma is looking at more long-term follow-up by bringing on a metabolic coordinator to handle case management and tracking, and by developing long-term outcome measures.
- **Rhode Island** noted that its success has been a result of consistent project governance and stakeholder involvement. As its system, KIDSNET, has evolved, so too did the stakeholders, as the State began bringing in schools and other groups to address children’s issues as they age. One constant stakeholder group, however, has been families. Rhode Island also found that as the project has grown, it has needed to add management, particularly around data management and provider relations. The State cautioned others to not underestimate the amount of technical coordination and support needed, to constantly be scanning the horizon for multiple sources of funding to replace those monies that run out, and to use evaluation to help improve data quantity and quality, and not lose sight of the end product.
- **Utah** stressed the importance of community stakeholders in the process, especially during the planning phase. One of the major hurdles Utah thought would occur were families not agreeing to share data, but when it involved them in the process, it found families amenable to data sharing, but concerned more about misuse of data. Families that represent larger organizations, such as Family Voices, are especially valuable to providing a larger perspective on the process. Utah is currently conducting a survey to assess the best way to approach the educational piece with families and will share this with States in the next year. The State also reminded others to remember there are community groups beyond families that need to be a part of projects as well. Finally, the State promoted the idea of ongoing

education, saying it is working with medical homes to put information in module form out on a Web site to educate providers and others about the conditions being screened for in Utah.

- One of the problems **Washington State** encountered was with coordinating referrals within its Early Hearing Detection and Intervention (EHDI) Program. To handle this, the State decided to hold a summit and bring together a range of stakeholders to this event. The outcomes of the summit extended far beyond getting a better referral system into place—groups met by profession and determined the need to share resources; they also met by geographic area and identified challenges within their regions. Another positive outcome was the decision by the deaf and hard of hearing centers to identify members within those centers to act as mentors or coaches for families with newly identified children. Washington spent a great deal of time in planning the summit, but their level of effort has paid off, and they would recommend the procedure to other States.

Following these remarks, the grantees had the opportunity to ask one another questions about their programs and some of their lessons learned. One person asked the District of Columbia for more information about the discharge planning position. This is a State-funded position, and the District had an agreement with all birthing hospitals to hire a nurse or licensed social worker to see every woman after giving birth and fill in a three-page form with her. The District representatives noted that the position fit into a wider initiative meant to reduce infant mortality, and was not solely concerned with birth defects or newborn screening. The District also has a system wherein those identified in the hospital will receive home visits within 24 hours of their release.

Other States pondered the issue of sustainability of the integration efforts. One resource person noted that all States must realize grant money is time-limited. There is no one answer to seeking additional funding, but some States have looked into getting it from Medicaid; this might be a good place to look for maintenance funding.

One participant asked how States have moved from process to outcome evaluation, and what performance measures they have devised. An individual from Rhode Island said her State has linked performance measures with larger division activities, and been looking across programs for indicators. These have included medical homes, how many children with abnormal screens confirmed are enrolled in early intervention, and how many infants have had all three newborn screening activities completed.

Finally, there was a question of how to reach those providers without Internet access who may not want to have to call up for screening results for all of their patients. Oklahoma has worked around this by having a coordinator for each program to ensure adequate follow-up. This coordinator gets abnormal results and keeps checking with parents and physicians until there is resolution for follow-up; for borderlines and presumptives, the coordinator also schedules a home visit. Colorado has come close to designing a Web-enabled system that will connect immunization and newborn screening information and that allows physicians to sign up and access individual patient data—that way any physician treating a child may be able to access the same information. Others stressed the need to promote the use of personal digital assistants to

ensure Web-enabled systems are accessible to physicians who may only use computers for billing.

#### **IV. The Status of Newborn Screening across the States**

Bradford Therrell, Ph.D., Director of the National Newborn Screening and Genetics Resource Center (NNSGRC) provided an overview of current newborn screening activities across the States, after the States had an opportunity to share their experiences. While all States mandate screening for PKU and hypothyroidism, there is wide variation in the number of other conditions with mandated screening. Roughly half of the States mandate screening for more than eight conditions, and half screen for eight or fewer. A handful of States have mandatory tandem mass spectrometry (MS/MS) screening, and several others have pilot MS/MS projects or optional testing in place.

The criteria for mandated screening originally set forth by Wilson and Junger in 1968, still holds validity today, with most States looking at the degree to which conditions are an important health problem, have accepted treatment, acceptable testing, and the cost of screening is balanced relative to the expense of medical care. The NNSGRC has been compiling 10 years of State data to determine those conditions with the highest incidence rates; currently these are hypothyroidism, sickle cell diseases, and cystic fibrosis. These conditions fall within the nine recommended screened conditions of the March of Dimes, along with hearing screening. HRSA also holds a contract with the American College of Medical Genetics to develop recommendations about model policies and procedures for State newborn screening programs and outline a uniform panel of conditions for screening; the results are expected to be released in June 2004.

Legislation around newborn screening varies across the States as well. Two States have required consent laws, and 17 have privacy provisions. Other States have genetics privacy laws that may or may not relate to newborn screening. All States indicate that they tell physicians about abnormal results, but many States lack policies around the use and disposal of residual samples or delegated responsibilities of physicians related to tracking and follow-up.

The NNSGRC recently conducted a survey with 50 States and DC to determine the level of information provided to parents through brochures of the newborn screening programs. This survey examined distribution of brochures, the content and its description of conditions screened for in the State, discussion of specimen collection and disposal, and discussion of screening results and limitations. Dr. Therrell highlighted some of the results of this survey, adding that this was not intended to tell States what to put in their informational brochures, but to gather baseline information about what States are doing in the area of parent education. Currently, Louisiana State University is looking at these brochures for literacy and other details, and will make recommendations on model parental education materials.

Dr. Therrell also highlighted some of the Federal initiatives related to newborn screening, including HRSA-funded projects to establish regional collaboratives and five demonstration projects to examine genetics service issues. CDC is still involved in newborn screening as well, by providing quality control and consultation and research. Last year, CDC discussed the

feasibility of having a national data bank of samples, and determined this was not appropriate now, but it might be useful to have a central database outlining what each State does around newborn screening. CDC has done surveys on how States are storing samples and now it is comparing these results of these, with a focus on coming up with national policies related to sample storage and disposal.

## **V. Integration of Newborn Screening and Genetic Service Systems with Other Maternal and Child Health Systems:**

- **A Sourcebook for Planning and Development**
- **A Tool for Assessment and Planning**

One of the recommendations set forth by the National Task Force on Newborn Screening was to have a national process to share and promote best practices in information integration models. MCHB thus partnered with All Kids Count/Public Health Information Institute (AKC/PHII) to identify and describe best practices leading to the integration of newborn dried blood spot screening programs with other related child health information systems. Nicole Fehrenbach, M.P.P., a Senior Research and Evaluation Associate at PHII, provided background on two products developed under this effort.

A Sourcebook for Planning and Development provides nine key elements, a list of best practices, two in-depth case studies, and lessons learned from the States. PHII also broke each of the key elements down further into checklist points. Meant to be a companion to the Sourcebook, A Tool for Assessment and Planning builds on the nine key elements and helps project teams to assess their organizational readiness and capacity to undertake and sustain a complex integration project. The Tool is designed to assist project teams in understanding:

- Best practices associated with information systems projects;
- Organizational readiness for the information systems project;
- Additional strategies required to support successful project planning and implementation; and
- Accomplishments and action steps.

Its underlying purpose is to characterize a strategic vision, assess organizational readiness, to determine where teams are in the project cycle, and question data integration needs and strategies.

Ms. Fehrenbach solicited feedback on the Tool from the attendees who have used it, and their comments were generally positive. The State of Tennessee found it a useful way to measure progress on each specific recommendation, and got ideas from the Tool to design questions to share with the State's Chief Medical Officer. Oregon also found it useful in talking to folks about agreements between programs. There was some question as to when States should consider actions "in progress" or "achieved". Ms. Fehrenbach noted that there is no clear standard for what constitutes achievement; States must be able to gauge for themselves when they achieve a step, as the Tool is not meant to be a straight quantitative evaluation instrument.

One thing observed to be missing from the Tool is a more explicitly laid out strategic plan that gets updated frequently, with more incorporation of lessons learned (e.g., that change takes time, let the programs drive the technology). Ms. Fehrenbach also noted that suffused into the Sourcebook—but not in the Tool—is direction on how to use the information. The tendency of many States is, while they wait to perfect the system, not to use the information, but States must realize that using even initial information helps to advance the integration effort.

## **VI. Breakout Sessions**

To encourage more interaction between the States and offer them an opportunity to ask more questions about their successes and challenges, breakout sessions were held around a number of topic areas. These were: leadership and project governance; project management and stakeholder involvement; organizational and technical evaluation; technical support and coordination; financial support and management; and evaluation across all areas. The brief summaries below highlight the major discussion points arising during each breakout session.

### **A. Leadership, Project Governance and Evaluation**

One of the primary questions discussed in this breakout session was the issue of location of the integration activities. The group agreed that where projects are located within a State might make a significant difference in how well the efforts are received. But the group also discussed the influence of budget cuts on projects, and how these may not be as negative an influence as thought. Because of budget cuts, State employees are often forced to do more activities; this can be a bonus for integration projects because people are naturally working across departments in order to maximize resources.

The leadership session also discussed whether the MCHB Title V Healthy People 2010 indicators help the grantees in fulfilling their missions. There were comments on both sides of this issue; some people are using indicators to go to their stakeholders and tell them what they want to do, then explaining why the funds are needed to do it. But other States noted that unless the indicators become Federal law, their States regard them merely as suggestions.

Finally, the group discussed the level of leadership support across the States. Most of the grantees expressed that they had support from high-level officials, and high interest in integration across programs in their regions. Some States cautioned that integration takes time, and an ability to know when to draw attention to and away from the project.

### **B. Project Management, Stakeholder Involvement, and Evaluation**

In this session, the participating States first highlighted some of the ways they have been managing their projects, before discussing their efforts at communicating with stakeholders. Some of the key elements they stressed as being important to the management process included communication, funding, collaboration, and utilization of contractors. The States agreed that the manager of the integration project is a critical player and must liaison with programs. Successful management also requires determining the value of the effort and conveying that to the users.

There was consensus among the group that the most critical piece to managing the integration project is identifying stakeholders and champions for the effort, and getting them to the table during decision-making discussions. Sometimes this involves making special accommodations and creating incentives that will allow them to stay involved, such as flexible meeting times, provision of child care, and payment. Stakeholder involvement is necessary at multiple levels, and one person noted that by examining how much stakeholders know about the process and what is going on is one way to evaluate its success.

Finally, the group discussed the idea of getting data to users, in particular the need to share data with policymakers. It was agreed that this should be done cautiously, but that data really is the most valuable tool in working with legislators and their staff. One way to approach this might be to have consumers who are involved as stakeholders approach legislators about data integration issues.

### **C. *Organizational/Technical Strategy and Evaluation***

This session began with a discussion of articulation and documentation of the organizational and technical strategies. The participants noted that strategies should be already documented in the grant proposal, and in the program goals and objectives, but it is also important to get this documented in the high-level planning process as well. Yet among the States, many felt their organizational strategy was incomplete, and others felt it was a constant work in progress.

Some of the featured strategies occurring among the grantees included:

- Rhode Island developed a “Children’s Cabinet” to meet periodically, and discuss integration strategies to improve coordinated services for children.
- Missouri looked at the functions of its organization and categorical programs, and designed a strategy to work within these while reducing data duplication.
- Two States also channeled money from bioterrorism into strategies to support their MCH programs.

The group also highlighted points to remember in carrying out organizational and technical strategies. First, States need to be patient and capitalize on opportunities when they do happen, such as funding, changes in leadership, or media events to promote the integration efforts. People and relationships matter just as much as organizational structure; territorial issues and poor relationships can undermine even the best organizational strategies. Most of all, technology needs to match the program’s needs. In an integrated effort, technology folks must be on the team, but they cannot drive the project. A lot of different expertise is required to carry out the effort, and no one unit can operate in isolation from another.

#### ***D. Technical Support and Coordination and Evaluation***

In this session, States discussed the variety of approaches they are using to offer technical support to their projects. Some have brought in graduate students to handle IT programming, while others have contracted out their IT functions. All of the States agreed that it is important to invest in individuals through training opportunities and other incentives so that they keep current on industry knowledge and standards.

Regardless of what approach States take, one person expressed the idea that the project leader and database manager should remain consistent. This is especially important given that often, program and information technology staff see applications differently.

The group also discussed a few of the challenges inherent to technical support and coordination. They noted that to sustain the integration effort, each system requires a business plan that incorporates ongoing management and funding concerns. They also urged the creation of information management accountability, wherein those handling IT capabilities must be able to answer inquiries and express what functions are giving back to the programs.

#### ***E. Financial Support and Management, Policy Support, and Evaluation***

The grantees in the financial management breakout session began by talking about their concerns regarding fees for newborn screening, especially as their newborn screening programs get expanded. One State examining the fees in an effort to gauge whether they should be raised; noted that the initial fees were set before there was a lot of information technology to be supported. Washington State noted it has a line item from the State's general fund to support these fees. Other States cautioned that when fees begin to be raised, it may imply to legislators and others that they can be lowered in the future after the integration system is in place.

The States also took the opportunity to discuss creative ways that funding can be sought to support their efforts. Washington State is using bioterrorism money to help fund its data system, with the argument that birth defects, as a notifiable public health condition, can serve as a pilot for notifiable contagious diseases used in a bioterrorist attack. Another State is partnering with its mental health and substance abuse folks working on fetal alcohol issues to tap into resources from the Substance Abuse and Mental Health Services Administration. Several States also mentioned Medicaid as a good revenue source. Oregon has supported its immunization registry by dividing the costs between Medicaid and other groups based on the populations being served. The Medicaid Information Technology Initiative was also cited as a possible place to turn. Finally, as the Social Security Administration gets involved in electronic birth certificates, it too was mentioned as a place States could go to for funding. The grantees agreed, however, that regardless of the funding source, they must create a cross-section of people within the States to become champions for newborn screening and data efforts that will ensure these are continuously funded.

## VII. Pitfalls in Translating Data into Action

Integrating data systems can be a complex procedure that carries significant risks. Several representatives from States involved in data integration activities offered their perspectives and counsel to the grantees regarding these risks and how to anticipate and possibly avoid them.

Richard Urbano, Ph.D., formerly the Assistant Commissioner within Tennessee's Bureau of Health Informatics, reviewed some of the security issues around data. Information—whether in computers or on paper—is subject to theft, alteration, destruction, and neglect. States must remember that all systems have vulnerabilities and anticipate failure; the best way to combat these risks is to develop a multi-layer defense strategy. Such a strategy must aim to mitigate external threats through such means as firewalls, encryption, identification/authentication, partition/specialization, and patches/updates. States must also realize that as more people are given power and access to the system, so too they must attempt to mitigate internal threats by looking at:

- Physical access;
- Backup/recovery;
- Encryption;
- Partition (need and right to know); and
- User identification/authentication.

Dr. Urbano stressed that the most important task for States to do is to test their recovery plans to assure data will not be lost and that security measures are effective. This assessment should include looking at intrusion detection, logging, and analysis.

Leonard Green, Chief of Rhode Island's Office of Vital Records, spoke specifically about security measures within his State's public health child information system, KIDSNET. Numerous programs feed data into KIDSNET, including newborn screening, immunization, early intervention, WIC, vital records, and lead screening, among others. Access to the system is offered to pediatric care providers; staff of affiliated programs, school nurse teachers, and community-based agencies contracted by the Division of Family Health and KIDSNET community-based risk response network members.

KIDSNET is governed by four underlying principles, namely:

- The individual legally responsible for the child should have access to KIDSNET information on that child;
- Licensed health care providers should have access to appropriate information on their patients;

- Health department programs should have access to all program-specific information and shared information for children receiving their services; and
- Family service agencies that have contracts with KIDSNET's risk response/follow-up program should have access to information needed to carry out their functions.

Mr. Green noted that some of the concerns when designing and implementing a program like KIDSNET include connectivity, compatibility of legacy data with new data, interfaces, network performance, quality assurance, standards, and new technology. But one of the most important concerns is confidentiality. As systems become more complex and involve more data sets, there is greater need for more access to these data by different entities. The goal of States should be to ensure that access is provided within parameters that maintain privacy and confidentiality.

To achieve this, States must systematically analyze current confidentiality policies, and existing security and access measures. Each expansion of the system should be evaluated to assure confidentiality principles and procedures remain intact. The grantees should review State and Federal laws, and develop their own written policies and procedures for addressing confidentiality; moreover, instruments for confidentiality agreements must be developed into standard protocols for participation in the system. All participants should be trained in these policies and procedures to maintain the system's integrity. Finally, confidentiality must be part of a dynamic process for continuous quality improvement and incorporation of best practices.

Garland Land, M.P.H., Director of Missouri's Center for Health Information Management and Evaluation, then discussed standards for hardware, software, data, development, and quality assurance. When Missouri started its application in the 1990s, it had no standards for hardware. Later, it developed workstation standards, a department local area network and wide area network, and server standards that now must be met when new equipment is purchased. The challenge of dealing with standards related to hardware and software, Mr. Land noted, are in keeping up with the industry as it changes. Sometimes this becomes an expensive effort and difficult for States to maintain.

One of the problems Missouri encountered when developing data standards was that programs use different terms to refer to essentially the same thing. The State decided to create neutral terms that cut across groups for data entry purposes, then to create some specialization in the model to clarify when these became too generic. As for development standards, Missouri created a development support unit to develop and enforce development standards, handle version control, and develop naming standards related to variables, columns, and tables. The State also developed ROADMAP standards related to all phases of development of an application. But the State found that where it originally had too little control of standards, now it has too much, and it is reviewing these to find a balance.

Missouri also developed progressive levels of quality assurance that test the processes prior to certification. The developer does the bronze test, the silver includes performance testing and standards evaluation, and the gold involves user testing and certification. At the top of the quality assurance mechanism is testing implementation and doing a "dress rehearsal" of the application prior to its release. Throughout all of these developments, Missouri has learned that

standards must undergo constant change, and involve a significant amount of overhead and monitoring.

When asked what is occurring on the national level for standardization of data, Mr. Land highlighted the national vital records reengineering project, which aims to develop a standard for Web-based birth and death systems. Right now, the project is involved with defining the functionality of such a system, but in the future States will be able to use this Web-based model and hopefully include within it elements related to newborn dried blood spot and hearing screening.

Other activities around data and standards development featured by the group included:

- Rhode Island is moving forward on its own Web-based system and is interacting with KIDSNET to see what else can be accomplished in the department using this system.
- The Social Security Administration is pushing a project to access electronic birth certificates for baby boomers as they retire; SSA regional offices are dialing into a URL to access a database on this—but they still need to address security and confidentiality issues.
- The immunization registry community has agreed upon standards for HL7. A public health data consortium is now developing HL7 standards for public health and converting all vital records data into HL7.
- Dr. Therrell urged States to consider linking newborn dried blood spot screening numbers to electronic birth certificates; getting automated data entry from the point of birth seems to help reduce error rates and is a way to get into hospital billing systems.

## **VIII. Principles and Core Functions of Integrated Child Health Information Systems**

In spite of the plethora of child health information system activities in the public and private sectors, a cohesive framework for guiding these integration activities has not been previously developed. To create a cohesive framework, HRSA/MCHB partnered with AKC/PHII to work closely with federal, state, and private sector partners and other critical stakeholders to develop the framework while representatives from national organizations reviewed and informed this effort.

Alan Hinman, M.D., Principal Investigator at PHII observed that the primary means through which PHII has been working to improve child health outcomes is by cultivating the linkage and integration of information systems. This approach includes finding mechanisms to provide a range of information to the user in a simple, comprehensive format, regardless of what the hardware/software looks like.

In May 2003, PHII convened a workgroup of critical stakeholders to gain agreement on what an integrated system should do. The group's goal was to develop a draft "Model of Practice" for

integrating newborn screening systems with other related early childhood health information systems that includes a comprehensive set of core functions, activities, and services.

The group agreed to focus on four information systems: newborn dried blood spot screening, early hearing detection and intervention, immunizations, and vital registration. They also catalogued and reviewed existing program standards and guidelines, existing functional standards, and agreed to rename the “Model of Practice” the “Framework for Integrating Child Health Information Systems.” In addition, the group compared 12 registry core functions for immunization registries to see if these were relevant to the other three information systems (they were), and subsequently developed 19 principles, 22 core functions, and eight desirable functions.

The principles are focused around the following areas:

- Security and confidentiality—including using information only for intended purposes, informing patients and families about the timing of data entry, and assuring access to providers and others based on their roles;
- Technology serving stakeholder needs—the systems must meet the health needs of the people and minimum needs of participating programs;
- Processes for quality assurance and evaluation to ensure accuracy of information and appropriate usage; and
- Financing, with assessment of costs and benefits to users and society.

Among the core functions, an integrated child health information system must assure:

- Security and confidentiality;
- Well established and maintained client records;
- Service functionality;
- Technical functionality; and
- Appropriate reporting.

Finally, Dr. Hinman outlined some of the desirable functions of such a system, including the timing of data entry and report production. Ideally, these systems should:

- Establish a record within two weeks (ideally seven days) of the first visit to any program/provider;
- Track long-term follow-up care into adulthood;
- Record additional information as relevant;

- Identify those who have moved or gone elsewhere within 90 days (ideally 30 days);
- Record whether children are currently linked to a medical home;
- Provide all information on a real-time basis to all authorized users as soon as it is within the system;
- Generate a printed report or electronically transmit information from one system to another as a child moves; and
- Permit users to access and generate aggregate data reports online with identifiable information depending on the user's role.

In a subsequent breakout session, Dr. Hinman talked with representatives from nine grantee States about their current capabilities in meeting some of these core functions. Almost all of the group felt they could protect confidentiality and security, though some were unsure as to whether they could verify the identity of those retrieving information. The majority, too, felt they could maintain an audit trail, but only half anticipated being able to provide a record of those who opted out of screening. Adding a record beyond birth, establishing a record within two weeks, carrying out short-term follow-up, and generating reminder recalls for people late for services are also current capabilities for more than half of the grantees. Fewer than half have the ability to access information at the time of the encounter, and have systems that will include a provider education tool to help impart what the child should be receiving in services.

Reporting was another area with which grantees experienced problems, when compared to the Framework's recommendations. Few systems can generate coverage reports, and only a third of the grantees anticipate being able to produce useful reports. None of the participants thought their systems would be able to identify those who have moved within 90 days, nor do any of them have the capacity for real-time reporting or to electronically transmit information between systems or across States. Yet despite these challenges, the group did not identify a single function within the Framework as being irrelevant to their information systems.

The grantees, however, did suggest the need to re-include the words "model of practice" into the Framework's title or language. They felt legislators who only want to fund best practices often hinder States, and inclusion of the language might build a case for sustainability of the systems to meet these functions. Dr. Hinman noted that at the moment, no one has any proof that integrated systems improve health care, and therefore it is misleading to use the term model of practice. He also outlined some of the next steps in developing integrated child health information systems that may lead to coming up with best practices. These include:

- Agreement on core data sets and information transfer standards;
- Development/use of performance measures;
- Documentation of impact of integrated systems on outcomes;
- Development of information on costs and cost savings; and

- Identification of funding sources to sustain integrated child health information systems.

## **IX. Developing Indicators to Measure Child Health Information Systems Integration**

Now that the PHII has developed the “Framework for Integrating Child Health Information Systems”, they want to assess how States know whether their systems can do these functions. Kristin Saarlal, M.P.H., Deputy Director of the PHII, talked with grantees both within and after the breakout sessions about the purpose of indicators and how to use the information to inform next steps.

Indicators are a way to measure, indicate and point out whether or not a system is meeting its goals and objectives; they may also be called performance measures, targets, and benchmarks. Most indicators have a numerator and a denominator and can be expressed as a percentage. Indicators serve a variety of purposes, including to:

- Track trends;
- Systematically monitor progress toward a common goal;
- Communicate with stakeholders and policymakers on progress; and
- Allow for identification of problem areas in need of intervention and action.

Good indicators provide a combination of process and outcome measures, and are feasible to measure on an ongoing basis. They must be sensitive to change over time, and be valid and reliable.

Ms. Saarlal noted that it is best to use a small number of indicators at first to be able to assemble a representative picture of progress. Using indicators around child health information systems allows States to build a strong policy and business case and to demonstrate progress toward selected core functions. On a broader level, aggregate progress of MCHB grantees can help guide policymaking and program support, thus lending to sustainability of these efforts.

Some of the common questions indicators can be used to answer include:

- Is the information system representative of the population we are trying to serve?
- Do we have timely submission of data into the system by providers of care or services?
- Who is participating in the information system?
- Is the information in the system complete and accurate?
- Can we identify children in need of services?

- Are services having an impact on health outcomes?

Some of the State grantees shared their experiences with developing indicators around integrated systems. Rhode Island is developing performance measures on the percentage of children who have information captured in multiple programs (e.g., newborn screening, immunizations, lead screening). Utah is examining whether all children have the same unique birth identifier across all programs. The State of Oregon is building its evaluation processes at the same time it develops its system, looking at different levels such as risk, data quality, participation in the system, and the management of the infrastructure building process.

Ms. Saarlal reminded the group that stakeholder perspectives are crucial to the integration effort, and indicators must speak to the questions of families, physicians, health plans, health departments, and Federal agencies. Some of the most important questions indicators may answer for these stakeholders are:

- Does the system improve the efficiency of getting information back to the physician and is it preventing children from “falling through the cracks”?
- Are the data confidential and who has access to those data?
- Does the system identify in a timely manner children lost to follow-up or who have died?
- Is the integrated system more efficient than the previous one?
- Are programs and practitioners getting and using the integrated data differently than they used categorical data?

Integrated systems will only work if the programs use information not directly related to their program, Ms. Saarlal added, offering an example of a WIC program asking about a hearing screen in a child identified as not having one. For the major advantages of an integrated system to occur, we must first demonstrate that the system provides something not able to get otherwise, so it is crucial States help build their business cases by examining what makes their integrated systems more complete, efficient, or adds value to their existing programs.

As PHII moves forward, its next step will be to identify a workgroup comprised of representatives from State health departments, family organizations, physician groups, Federal agencies, and evaluation experts to develop a list of indicators. These indicators will then be pilot tested, including methodology to collect and analyze the data. These indicators will be pilot tested with a selected number of States, with revisions made as necessary in an effort to inform recommendations for next steps.

## **X. Community-Based Systems of Care**

The final panel discussion of the two-day conference showcased examples of how grantees are working to achieve appropriate community-based systems for children and youth with special health care needs identified by newborn screening programs and their families.

### **A. *Healthy and Ready to Work (Services Necessary to Transition to Adulthood)—Oklahoma***

Pam King, M.P.A., R.N., Oklahoma's State Genetics Coordinator, reviewed one of Oklahoma's initiatives being supported by an MCHB grant, the "Healthy and Ready to Work Program". This two-part program aims to establish an adult medical home for children identified through newborn screening, and to provide transition services that help them to complete their education and prepare for work and independent living.

The "Healthy and Ready to Work Program" has begun with two pilot projects, one for sickle cell anemia patients, and the other for young adults with cystic fibrosis. Both programs have been working to identify a medical home for these patients, recruit primary care providers and educate them about these conditions, and advocate for pediatric subspecialty rotation and greater exposure to these diseases for residents in internal medicine and family practice. Some of the patients seen in the programs have been able to pursue college-level education and work and live on their own. Additionally, Oklahoma has enrolled 50 primary care physicians in the adult medical home program and witnessed a change in medical school curricula around sickle cell anemia and cystic fibrosis.

One of Ms. King's patients, Shaunté Parker, and her mother, Deborah Parker, spoke about the benefits of the program and their experiences living with sickle cell anemia. The elder Ms. Parker noted that she had to do a "crash course" to learn about the disease when her daughter was diagnosed, because her primary care provider and family knew little about it. She also encountered difficulties in getting insurance benefits for Shaunté's pre-existing condition, and in dealing with the significant absences required from her job when her daughter was hospitalized.

Shaunté Parker spoke about the challenges she has faced throughout her life, but in particular the transition into adult care when she turned 18. Her major difficulty lay in transferring from a pediatric sub-specialist to a primary care physician once her insurance changed, and having to deal with adult providers who are uneducated about her condition and how to treat it. As she noted, patients often know more about their bodies than physicians, but doctors are reluctant to listen to patients and learn from them. She also highlighted the need for people in the genetics community to make a strong effort at going into schools and educating teachers, coaches and nurses about these conditions, and how to support children who have them.

### **B. *Access to Medical Home—Michigan***

George Baker, M.D., Chief Medical Consultant in Michigan's Office of Medical Affairs, spoke about Michigan's process of integrating newborn screening with other maternal and child health systems. One of the State's primary realizations is that programs have been charged to find a medical home for those identified through newborn screening. Thus, Michigan set up a medical home initiative with the goal of providing all CSHCN coordinated, ongoing, comprehensive care within a medical home. Three programs are collaborating to implement this effort: the newborn screening program, EHDI and the children with special health care services division.

One of the major realizations the State had was that when trying to do collaboration, it must acknowledge the special perspectives and opportunities each group brings to the table. Dr. Baker noted that the Division for Children with Special Health Care Services brought a statewide system and mechanisms for payment, systems for care coordination, care plan models and a relationship with the American Academy of Pediatrics. The EHDI program brought well-developed resource material, the “chapter champion” concept, and a model of care emphasizing early intervention and parent to parent support. Finally, newborn screening brought well-established credibility, an urgency of purpose, an established communication system, a subspecialty advisory group model, centers of excellence, and manageable populations.

Dr. Baker noted that Michigan’s vision is to build upon Utah’s medical home model. The ultimate goal will be to have an educational resource available to people who may not have seen disease cases before. Yet one of the State’s remaining challenges is to address the differing definitions of medical home that occur across the region—e.g., managed care organizations believe the assignment of a child to a provider equals a medical home, and Michigan had language in its block grant that indicated a medical home was a child enrolled in managed care.

### **C. Access to Affordable Insurance—Massachusetts**

Cheryl Bushnell, M.S., R.N., Director of Massachusetts’ Division of Special Health Needs, and Ron Benham, Director of the Division of Perinatal and Early Childhood Health, highlighted some of the efforts the State of Massachusetts has taken to legislate action around insuring early intervention. Massachusetts has been working with the health plans in looking at identification and screening of children with special health care needs, and to apply lessons learned about how plans identify these children. One of the State’s ongoing efforts is to figure out how to improve functional and programmatic integration as data between programs is being integrated, and to increase benefits to the populations served by those programs.

Massachusetts’ legislation specifically addresses early intervention coverage, and dictates that for medically necessary early intervention services, private insurance plans are obligated to pay for those services. Mr. Benham observed that early intervention can be a new revenue source, and it’s important to think outside the box for potential revenue sources. While sustainability is an issue in every State, the scope of early intervention allows dollars to leverage other dollars to support a wide range of services. He emphasized that relationships are key to sustaining integration, and it is necessary to include insurance plans as partners as integration efforts move forward.

### **D. Easy-to-Access Community-Based Service Systems—Iowa**

Andy Penziner, M.D., M.S., Program Associate with the Policy & Planning Unit of Iowa’s Child Health Specialty Clinics shared some of his State’s experiences with providing easy-to-access community-based service systems to its population. He began by offering some data on CSHCN. More than two-thirds of Iowans with CSHCN report that services are usually or always organized for easy use, and roughly 12% receive professional help to organize services, or care coordination. Only 2% of Iowans with CSHCN report not being able to receive needed help to

organize services. Yet these statistics cannot automatically be used to state that Iowa is doing well in serving this population.

Dr. Penziner provided an in-depth example of one easy-to-access program, the Birth Defects Registry Notification Program. The program evolved from a priority identified by families during the State's needs assessment process that was part of the development of the State's Genetics Plan. The planning process included family and provider surveys, focus groups, and workgroups. The program also developed its own database used to generate letters and track follow-up, address changes, physician charges, and referrals.

Currently, Iowa is in the process of informing and educating providers about the notification program, having sent out first notices in June 2003. Preliminary results indicate that families have already spoken positively about the program, asking about resources and being connected to services such as Title V, Part C and genetic counseling. Dr. Penziner reminded the grantees that easy-to-access services are a worthy goal but its measurement and interpretation remain a conceptual and methodological challenge. There is a lot more to access than convenient location and hours, and this includes assuring appropriate provider knowledge, and monitoring families' experiences.

#### ***E. Family/Professional Partnerships (Family Participation and Satisfaction)—Indiana***

Donna Olsen, Executive Director of the Indiana Parent Information Network, highlighted how families play an important role in making decisions about integrated systems of care. As the parent of two children with cystic fibrosis, Ms. Olsen learned that it is important not to close doors on children's opportunities based on their diagnoses. The Indiana Parent Information Network was established to support families of CSHCN by providing information, peer support and by building partnerships between families and professionals and communities. The Network has been included as part of Indiana's MCHB grant, having been given the role of talking to physicians about developing medical homes.

Families bring a number of resources to the table, and can be involved in different levels of the system, by providing services through parent to parent programs, parent training and information centers, family to family health information centers, and organizations such as Family Voices that advocate for the needs of CSHCN. Ms. Olsen also reminded the group that in addition to recognizing that families are negotiating all levels of the system, States too must realize the need to work with schools and educate them about CSHCN.

#### ***F. Early and Continuous Screening—Utah***

John Eichwald, M.A., Clinical Administrator with Utah's Children with Special Health Needs Division and the CHARM Administrator, offered an overview of early and continuous screening and the lessons his State has learned in the progress of implementing its integrated program. Screening is an essential tool for identifying CSHCN; according to studies, without screening, 70% of children with developmental disabilities are not identified, compared to 70-80% who are correctly identified when screening occurs. Newborn dried blood spot screening is the mostly

widely used mechanism for screening infants, with 99.3% of neonates undergoing this testing. While States vary in the conditions they screen for, the March of Dimes has identified 10 diseases that it encourages should be screened for all populations.

Initial performance measures indicate that States are steadily working toward meeting their screening goals, with 72.5% of Medicaid enrollees under age one receiving at least one initial periodic screen, and 81.5% receiving prenatal care beginning in the first trimester. Yet there is limited data reporting on continuous screening, and with differing tools, it becomes hard to assess performance.

Mr. Eichwald highlighted the Medical Home Screening and Surveillance Program, a five-year cooperative effort between the American Academy of Pediatrics and the National Center on Birth Defects and Developmental Disabilities aimed at educating physicians about screening, promoting the integration of newborn screening into the medical home, establishing national, State and community partnerships, and promoting the implementation of best practices for developmental screening and surveillance. He stressed that family input has been crucial in getting the program going. Initial discussions with families revealed that access and information about financial status were greater concerns to them than the types of information in a child health profile.

One of the problems Utah has experienced is uniquely identifying babies and getting that information into the data linkage process. Beginning in May 2002, every heelstick kit in the State has come with identifying labels that are now used for newborn dried blood spot, hearing screening and birth certificates. Mr. Eichwald noted that Utah has learned that when newborn data can be reliably shared, it increases the potential for:

- Decreasing redundant data and reporting in hospitals;
- Increasing the accuracy of the data being collected;
- Locating infants missing in screening;
- Identifying infants lost to follow-up;
- Not contacting families with infants who have recently died; and
- Improving the quality of life for newborns.

And while he emphasized the importance of envisioning the future, Mr. Eichwald also reminded States to remember that every integration process gets messy as it gets underway.

## **XI. Wrap-Up**

At the close of the meeting, Ms. Linzer reviewed the next steps the Genetics Services Branch will take to continue to support the efforts highlighted by the States over the two-day conference. These steps include:

- Facilitating the development of a public health and health care infrastructure to enhance and expand newborn screening programs and to improve linkages among them and the State and community systems of care;
- Supporting State and Territorial efforts to coordinate activities among different programs, and integrate child-related public health agency information to support improved coordination, tracking, assessment and evaluation;
- Promoting the linkage of newborn screening programs to medical homes and family support networks;
- Assisting States in their efforts to monitor and evaluate system performance; and
- Engaging in a national process to develop nationally recognized newborn screening standards and policies.

Additionally, Ms. Linzer highlighted the activities HRSA hopes to fund in the coming fiscal year that coincide with these efforts. These activities include the award of a cooperative agreement to support a newborn screening informatics practice network, as well as another cooperative agreement to develop a program evaluation and assessment scheme for quality assessment of State newborn screening programs. In FY 2005, the agency hopes to fund five cooperative agreements with previously funded States with integration efforts to implement the integration Framework and recommendations proposed by the newborn screening expert group. A year later, they also wish to support a national evaluation of newborn screening systems using indicators developed by PHII and the program evaluation and assessment scheme for quality assessment of State newborn screening programs to be developed.

The contract with PHII will continue to finalize the “Framework for Integrating Child Health Information Systems” with agreed upon core elements, functions, and performance measures. Under this contract, PHII will also finalize a discussion paper that supports adoption of the Framework, develop a manuscript of the results of the pilot test of performance measures and recommendations for indicators across the States, and conduct activities to gain consensus and endorsement of the Framework by partners and stakeholders.

Finally, as she thanked the participants for their valuable contributions to the discussions of newborn screening integration efforts, Ms. Linzer urged them to utilize the National Newborn Screening and Genetics Resource Center (at <http://genes-r-us.uthscsa.edu>) for more information on activities across the States, and the Public Health Information Institute (at <http://www.phii.org>) to access the sourcebook and tool highlighted during the meeting.

Appendix A: List of Participants

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U.S. Department of Health and Human Services  
Health Resources and Services Administration  
Maternal and Child Health Bureau

*Presents*

## **Fiscal Year 2004 Integration of Newborn Screening & Genetic Service Systems with Other Maternal and Child Health Systems Conference**

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October 15-16, 2003  
Hilton Crystal City Hotel  
Arlington, VA

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