

Promotion of the Early Identification of Children with Special Health Needs through Infrastructure Development

Grant Initiative

- Planning grants to support the promotion of the early identification of children with special health needs through infrastructure development.

Objectives

- To develop need assessment for program and informatics integration.
- To develop a framework for State genetic plans and identify the common elements within the State plans.
- To establish a collaborative network of partnerships among the States.

Outcomes

- Develop a community-based child health profile.
- Identify a mechanism for integrating surveillance data within public health agencies.
- Enable public health entities to oversee and track health services within a community.
- Decrease the fragmentation and duplication of the categorical delivery of care.

Post Meeting Products

- To distribute copies of the draft interim State plans one month after the meeting.

Promotion of the Early Identification of Children with Special Health Needs through Infrastructure Development

Agenda Day 1

- 8:30 AM - 8:45 AM** **Welcome & Introductions**
Merle McPherson, MD, MPH
Facilitator: John Reiss, PhD
- 8:45 AM - 9:00 AM** **Charge to the Group**
Michele Lloyd-Puryear, MD, PhD
- 9:00 AM - 9:30 AM** **The Human Genome Project into Practice**
Facilitating the integration of genetic technologies into health care and public health activities.
Bob Fineman, MD, PhD
- 9:30 AM - 10:00 AM** **Integration of Genetics into Public Health**
A Review of the Guidelines for Clinical Genetic Services for the Public's Health
Brad Therrell, PhD
- 10:00 AM - 10:30 AM** **Community-Based Child Health Profile:**
Outlining the essential elements.
Peter Simon, MD, MPH
- 10:45 AM - 11:30 AM** **Health Information Systems:**
Encouraging the linkage of screening programs with other points of early identification through the use of an integrated health information system.
Robb Linkins, PhD, MPH
Martin Wolfson
- 12:00 PM - 5:30 PM** **State Team Meetings**

★ ★ ★

Charge to the Group – Dr. Michele Puryear

Good morning. I would like to add my welcome to you and talk about the work we have planned today. Both HRSA and CDC are interested in genetics issues, particularly incorporating genetic medicine and technology into practice and service. The seven State planning grants represent our commitment to assisting public health agencies and the public.

I have been Chief of the Genetic Services Branch [MCHB-HRSA] for the past one and one-half years. Prior to that time, I was involved in Federal immunization activities. In addition to my service as a Federal employee, I practice in a publicly subsidized, inner-city clinic and see the impact of public health decisions.

At the clinic, I saw problems with missing immunization records and recognized the need for an immunization registry. Later, because of a public health agency reorganization, the clinic was no longer able to receive newborn screening results. The barrier was created when the locality contracted with a private company without safeguards on public health information. The pediatricians no longer had ready access to results. This was a frustrating situation in which I could not practice at the appropriate standard of care. It also was a reminder that agencies must supply a public health perspective to assist communities, consumers, and providers, as well as outside contractors, in fulfilling their roles.

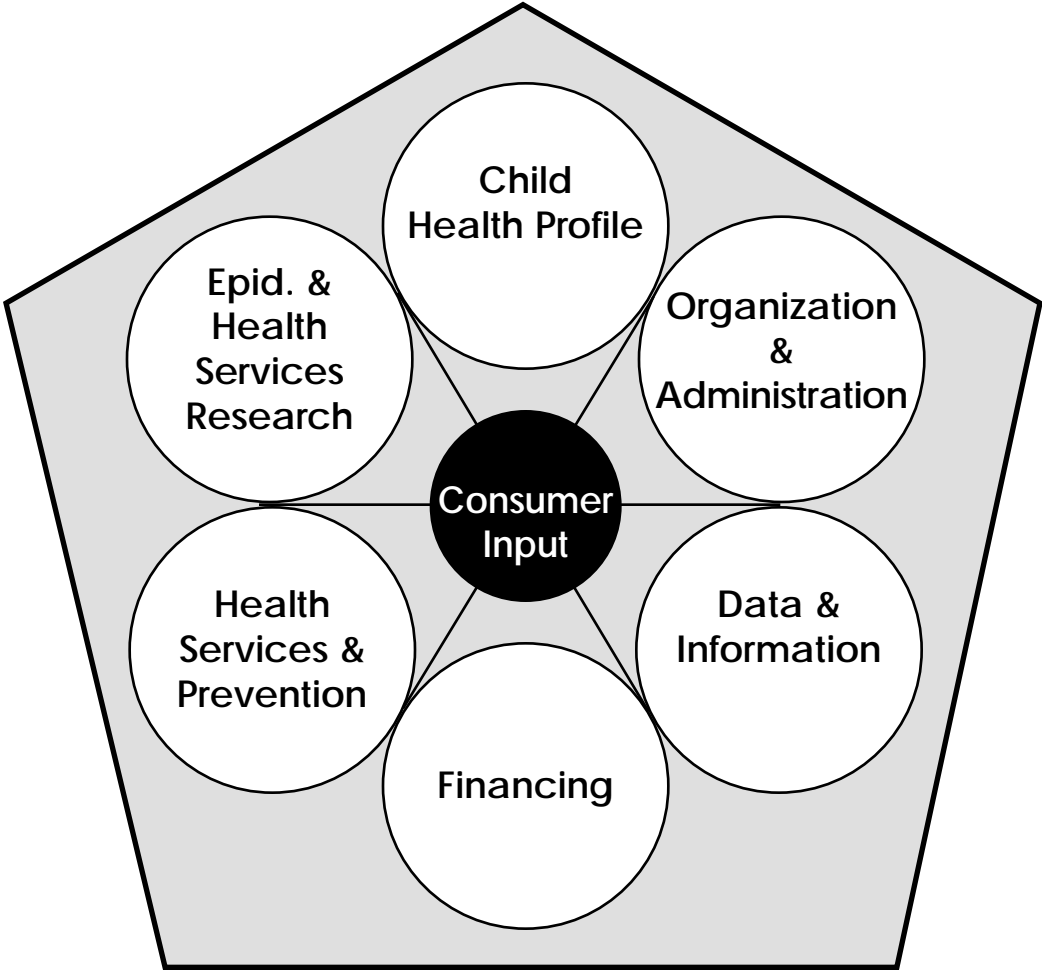
The purpose of our meeting today and tomorrow is to assist you, as grantees, as you develop plans to support the early identification of children with special health needs through infrastructure development. For the development of State genetic plans you will need an integrative approach. The goal of these grants is not to create a separate activity. We hope that MCH expertise and resources can be applied more broadly and that you can link to and encourage interaction among programs for children with special health care needs, immunization, environmental health, chronic disease, and other units of state government. Specifically, these planning grants should facilitate:

- Development or update of the State genetic plan;
- Linkage of early identification to early intervention;
- Focus on linking newborn heelstick screening programs to birth defects surveillance, hearing screening programs, and immunization registries.

There is much work to do. A survey by the Council of State and Territorial Epidemiologists [CSTE] found that newborn screening and genetic activities may not be closely connected to or integrated with MCH programs.

Meeting Two

In response to requests for technical assistance and knowing what you have to share with one another, we have organized the topics of today’s meeting according to the public planning process described in this diagram. Today’s process is represented in the hub of circles. This set of topics can provide a common framework for our discussions. Looking topic by topic at areas of planning, each resource table will provide your State team with information. While all of these topics may not fit reality in your State (Dr. Fox said yesterday “If you’ve seen one health department, you’ve seen one health department.”), we hope you will consider the relevance of each of the seven areas.



The Human Genome Project: Implementation into Practice, Dr. Bob Fineman

[Highlights below. For more information, contact Dr. Fineman. His contact information is listed in the back of this document.]

Washington State has had some success in advancing genetics issues. We also have had challenges with managed care. The State Genetics Advisory Committee has been instrumental to our success. The work of the Advisory Committee, along with the needs assessment and state genetics plan, were essential to having increased reimbursement, strengthened legislation, increased primary care provider education, and guidelines for clinical evaluations.

One might say we used a “used car sales” approach—giving attention to place, price, product, and promotion. These tools were essential to advancing our program goals and to building partnerships at the local, State, and national level. Specifically, we did the following:

- Improved data collection efforts.
- Applied data to identify problems.
- Started a State genetics provider committee.
- Addressed Medicaid reimbursement issues.
- Collaborated with the March of Dimes to secure a grant for primary provider genetic education.
- Added questions to the state Pregnancy Risk Assessment and Surveillance [PRAMS] survey to learn more about prenatal services.

In real estate, it’s “location, location, location.” In public health, it’s “leadership, leadership, leadership.” The ability to lead is critical to the success of our programs. The ability to lead is the ability to create a vision plus the will and wisdom to achieve that vision. The famous football coach Joe Paternak said that the reason he has been able to succeed is taking the team approach. Leadership and taking the team approach can help you succeed in your planning efforts.

To date there has not been enough effort at the Federal, State, or local levels on translating advances in genetics and technology into public health practice and personal action. Federal, State, and local public health agencies need more assistance in the development of expertise to address these problems of systems development. Equity in genetic health care will occur when we spend as much time and effort raising the floor as we have spent raising the ceiling.

Integration of Genetics into Public Health, Dr. Brad Therrell

[Highlights below. For more information, contact Dr. Therrell. His contact information is listed in the back of this document.]

The goal of efforts to integrate genetics into public health is to reduce mortality and morbidity and to alleviate suffering from genetic and congenital disorders. In terms of human disease, genetic factors have a major impact on childhood mortality and morbidity, with knowledge of the impact of adult onset disorders growing rapidly. Genetics play a role on health throughout the life cycle. The prevention potential of medical genetics extends to all branches of medicine in all steps of the life cycle.

Integrating genetics into public health is a new and challenging undertaking. Genetic literacy among the general public is highly related to the success of efforts to integrate genetics into public health. If people do not understand how genetic factors affect their lives, they may not be receptive to genetic services for themselves or support public funding for genetic services. In addition to public misconceptions, certain characteristics of genetic conditions and services present additional challenges. These challenges include the knowledge that:

- Genetic disorders may be rare;
- Medicine treats an individual, not a family;
- Genetic disorders lead to problems not easily discussed;
- Genetic evaluations are complex and require special training;
- Genetic evaluations are time consuming;
- Population screening is usually government controlled;
- Genetic services are often construed as counseling and nonessential;
- Documentation of the benefits of genetic services is incomplete;
- Genetic prenatal screening may be associated with elective abortion and therefore genetic services are perceived as a bad thing.

Community-Based Child Health Profile, Dr. Peter Simon

[Highlights below. For more information, contact Dr. Simon. His contact information is listed in the back of this document.]

KID'S NET is a community-based child health profile in Rhode Island.

Mission:

- To assure that all Rhode Island children receive comprehensive screening/follow-up for public health preventive services; and
- To promote comprehensive prevention and early intervention for children and families in need.

Rhode Island provides no direct public health services; all are provided indirectly and accomplished through the core functions of assessment, assurance, and policy development. This gives added importance to strategic partnerships. State officials, particularly the State public health agency leaders, want to be seen as an essential force in getting kids to school ready to learn. Early success is a predictor of long range achievement in life.

Rationale:

To improve coordination and services.

Altogether, 11 different infant and toddler programs are linked through this initiative. The concept is to use overlapping follow-up and data entry to keep children and families from “falling through the cracks.”

Objectives:

- Continuity to support families;
- Integrated risk response with less duplication;
- Family-focused services;
- Community-based services.

Meeting Two

Structure:

Structure includes: prenatal, universal hospital contact, vital records, WIC, lead, lab, immunization, metabolic/hemoglobinopathy, hearing screening, early intervention, and home visiting.

Organization:

KID'S NET is a data warehouse that relies on transfers of data. Some tracking systems are outside the warehouse and send information. Other data come from official records such as birth certificates, newborn screening records, etc. A central database with a "locator file" is core and comes from birth hospital records (it is downloaded from laptops). This forms the unique file/identifier for that infant. Since January 1997, all live births have been enrolled.

Health Information Systems

Robb Linkins - Immunization Registry Models

Martin Wolfson [See slides by clicking on Mr. Wolfson's name in the Meeting 2 agenda, located at: <http://mchneighborhood.ichp.edu/geneticsmeeting1999/meeting2agenda.htm> – Newborn Screening Models]

★ ★ ★

Promotion of the Early Identification of Children with Special Health Needs through Infrastructure Development

AGENDA Day 2

7:45 AM - 8:45 AM **Working Breakfast**

8:45 AM - 11:00 AM **Reconvene for Large Group Discussion**

Objectives:

1. Outline Essential Elements for State Genetic Resources and Services
2. Needs Assessment for:
 - Data, Information Systems
 - Program Integration Needs
 - Provider Integration via Information Systems
 - Broad PH Participation Including Chronic Disease Integration

Facilitators: Kay Johnson and John Reiss

11:00 AM - 12:00 PM **State Team Session**

12:00 PM - 1:00 PM **Networking Lunch**

1:00 PM - 2:45 PM **Reviewing the Draft State Plans**

Large Group Participation and Discussion; State Representative Presentation of Plan Outline

Objectives:

1. Develop a community-based child health profile.
2. Identify a mechanism for integrating surveillance data and programs within public health agencies.

Facilitator: Kay Johnson

2:45 PM - 3:00 PM **Summary and Adjournment**

Michele Lloyd-Puryear, MD, PhD
Merle McPherson, MD, MPH

★ ★ ★

Core Components of a State Plan for Infrastructure Development and Maintenance – Group Conclusions

Seven State teams worked at each of six resource tables to share and to extend the vision of their planning efforts. The results of this work ultimately will be represented in the State plans developed. Over the next few months, each state will refine the work they accomplished at the meeting. This list summarizes topics discussed on November 2 and 3.

Community-Based Child Health Profile

- Incorporate genetic information for a more comprehensive profile;
- Identify consumer and provider “output” needs;
- Involve WIC and Medicaid viewpoints and resources;
- Create a “virtual” medical home;
- Incorporate early intervention (Part C) program information;
- Examine confidentiality issues;
- Review problems with past efforts and seek remedies;
- Link to existing health data systems;
- Use families to carry the message about value of registry;
- Promote success with media reports.

Organization and Administration

- Develop a cross-cutting work group/task force;
- Establish a state advisory panel;
- Identify organizational resources;
- Determine role for CSHCN program;
- Build a departmental, not just program, approach;
- Raise awareness of executives;
- Use “command and control” tactics and identify lead unit;
- Determine ways to get around categorical grant restrictions;
- Seek buy-in from other agency partners;
- Plan for infrastructure to support child health profile;

Data and Information

- Determine what data are important and why;
- Consider government and private sector performance measures;
- Include both service process and outcome data;
- Map current data systems (show existing and potential linkages);
- Identify resources;
- Build flexibility into data systems;
- Ascertain consumer concerns;
- Seek buy-in from consumers and other users;
- Build in confidentiality and privacy protections;
- Assure data integrity and validity;
- Apply tools now common in other States (e.g., electronic birth certificate);
- Think about application of other tools;
- Distinguish between data system and research data sets.

Epidemiology and Health Services Research

- Involve all stakeholders in developing data and research strategies;
- Study both service process and outcomes;
- Develop consumer satisfaction surveys;
- Develop efficiency/effectiveness studies;
- Consider government and private sector performance measures;
- Consider “results-based accountability” approach;
- Consider Federal reporting requirements and 2010 objectives;
- Build cooperative research agenda (e.g., birth defects surveillance);
- Regulate access to public health data to protect confidentiality;
- Link surveillance to service or research purposes;
- Analyze and report data collected;
- Use previously collected data to improve current programs;
- Identify long-range collaborative questions.

Health Services and Prevention

- Use data to identify problem areas and unmet needs;
- Link services when appropriate;
- Link to medical home provider;
- Close the gap between newborn screening test and infant’s medical home.

Health Services and Prevention *(continued)*

- Improve connections to early intervention (Part C) program;
- Identify and support family networks;
- Consider continuum of care, lifespan issues;
- Address issues related to the transition to adulthood;
- Increase access to genetic services by closing gaps;
- Increase access to genetic services by identifying coverage.

Consumer Involvement

- Include families as full and equal partners;
- Conduct focus groups with consumers;
- Identify issues related to ethnocultural factors;
- Develop strategies to improve cultural competency;
- Submit plan for formal public review and comment;
- Involve consumers in advisory group;
- Formalize list of consumer and organization partners;
- Identify non-traditional partners and develop new partnerships;
- Use electronic tools to share information;
- Acknowledge and respond to diversity of population;
- Provide compensation for consumer time, expenses, and expertise;
- Guarantee mechanisms for consumer input and feedback.

Financing

- Identify financial barriers to access;
- Identify internal and external resources;
- Look for opportunities to match Federal funds with State resources;
- Consider ALL payers;
- Engage the State insurance commission;
- Use Medicaid and children's health insurance program [CHIP] funds;
- Use model contract language [for example see www.gwu.edu/chsrp]
- Maximize the role of the health department in assuring quality of health plans;
- Separate coverage from infrastructure resource needs;
- Identify and use opportunities to combine existing resources (e.g., bioterrorism);
- Inform partners who may advocate for funding and coverage increases;

★ ★ ★