Creating a Child Health Profile with Integrated Newborn Screening Service Systems

Immunization Registry Conference
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Newborn Screening

“Each year 4 million U.S. infants are screened to detect conditions that threaten their life and long-term health…”
Components of Newborn Screening System

Management:
- Treatment
- Long-term follow-up
- Specimen storage

Screening:
- Newborn initial test
- Analysis of test
- Repeat, as necessary

Diagnosis:
- Assessment by specialist
- Results shared with family

Follow-up:
- Receive results
- Give Physician/family results
- Obtain Diagnostic tests
- Link to diagnosis/treatment

Evaluation:
- Quality assurance
- Outcome evaluation
- Cost effectiveness

Newborn Screening Work Flow

The Medical Home
In the Beginning

- No immunization records
- No lead screen results
- No newborn screen results

In the End

Creating a Child Health Profile

What I Knew and Where the information Was:

Public Health Agency
INBSSS Initiative

Integrated Newborn Screening Service System Initiative

Creating a Child Health Profile

Partners:
- State newborn screening programs
- Primary Care health care providers
- Other federal agencies
- Families
- Immunization registries, birth defect programs, etc. chronic disease
Objectives

1) Promote systems of care to ensure early identification of children with special health needs and genetic conditions;

2) Encourage the linking of State Newborn Screening Programs with systems of care and treatment interventions that are family centered, community based, comprehensive, coordinated, and culturally competent.

Integrate Public Health and Health Services Data

3) Use State Newborn Screening Program and other points of early identification to facilitate the development of national standards for a health information system that would integrate public health and health services data.
Establishment of a State Plan

- Guide officials to best employ health information networks to achieve their program goals,
- In turn, infrastructures to promote close partnerships among State public health programs, primary care providers, the genetics community and service consumers

Newborn Screening Task Force Report

- Approved by:
  - AAP Board of Directors
  - AAP Committee on Genetics
  - AAP Committee on Fetus and Newborn
  - Medical Home Initiatives for Children with Special Needs- Project Advisory Committee
  - AAP Task Force on Newborn and Infant Hearing
Newborn Screening Task Force

Charge to the Task Force:
- To review issues facing state newborn screening systems
- To make recommendations to strengthen those systems

"Improved coordination and integration of information systems is needed."
Implementation of Task Force Report

- Facilitate the development of public health infrastructure
  - Enhance and expand newborn screening programs
  - Improve linkages between newborn screening programs, the state and community systems of care for CSHCN

HRSA Infrastructure Activities

- Integrated NBS Service Systems (INBSSS) Initiative
  - Builds on State & Territory NBS programs for newborns & children who have, or are at risk of having, heritable disorders
  - To integrate NBS & genetic services into existing State & Territory systems of care, networks of services & supports
INBSSS Initiative

- Title V MCH SPRANS Genetic Services
  - Planning Grants to 22 States
  - Implementation Grants to 11 States
  - FY 2003 Joint Program Initiative Grants to 5 States
- SourceBook on Best Practices
- Self-Assessment Guide

INBSSS Initiative

- Planning Grants
  - Connect newborn screening program and other child health related programs
  - Connect these programs with programs that provide early intervention
  - Smooth the relationships between private and public health entities
  - Enable child’s medical home to provide valuable information and benefit from an electronic child health profile
INBSSS Initiative

- Planning Grants 1
  - Alaska
  - Arizona
  - Colorado
  - Connecticut
  - Hawaii
  - Indiana
  - Iowa
  - Kentucky
  - Massachusetts
  - Michigan
  - Mississippi

INBSSS Initiative

- Planning Grants 2
  - Missouri
  - Minnesota
  - Nebraska
  - North Carolina
  - Oklahoma
  - Oregon
  - Rhode Island
  - Tennessee
  - Texas
  - Utah
  - Wisconsin
INBSSS Initiative

- Implementation Grants
  - Implement State plans for integration of State programs and information systems around NBS programs
  - Improve linkages between public health and personal health systems to enhance service delivery and ensure community-based, comprehensive, and coordinated care

INBSSS Initiative

- Implementation Grants
  - District of Columbia
  - Hawaii
  - Indiana
  - Iowa
  - Massachusetts
  - Michigan
  - Missouri
  - Oklahoma
  - Rhode Island
  - Utah
  - Washington State
FY 2003 Joint Program Initiative
- Collaboration: Genetic Services Branch and Office of Data and Information Management
- Infrastructure building must include information systems
- Data systems must be driven by program and be efficient and cost-effective

Integration of Newborn Screening and Genetic Service Systems with Other Maternal & Child Health Systems: A Sourcebook for Planning and Development
- Identifies and describes best practices leading to integration of metabolic screening programs with other public health programs and their information systems
INBSSS Initiative

- Self-Assessment Guide: A Tool for Program Managers
  - Characterize strategic vision
  - Address organizational readiness
  - Determine where you stand in project life cycle
  - Question data integration needs and strategies

INBSSS Initiative
Lessons Learned – Public Health 1

- NBS and genetics program needs must drive technology development
- States are concerned about security of data (HIPAA Compliance, Family Educational Rights and Privacy Act)
- Development of systems must respond to diverse data needs of public health and community-based medical home and families
- Change is hard and slow
Communication across all stakeholders is critical to the success of the project.

Ongoing struggle to ensure that families have input into the whole process.

Advisory Committee structure must be developed.

Advisory Committees must be part of the infrastructure.

- Must have simple, quick to use forms that do not require significant investment in more hardware/software and integrate with existing office systems.
- Need access to screening results immediately with or without Web access.
- Physicians need additional funding support to provide a Medical Home to CSHCN.
INBSSS Initiative
Lessons Learned – Families

- Wary of having information used to discriminate against them
- Generally support information sharing for their benefit
- Want child’s information in a single place where they control access
- Should not be asked for the same data multiple times

Genetics and Newborn Screening Resource Center of the U.S.

NNSGRC Website: http://genes-r-us.uthscsa.edu
Program Contact

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