“Each year 4 million U.S. infants are screened to detect conditions that threaten their life and long-term health...”
DIRECT HEALTH CARE SERVICES

Examples:
Basic Health Services and Health Services for CSHCN

ENABLING SERVICES

Examples:
Transportation, Translation, Outreach, Respite Care, Health Education, Family Support Services, Purchase of Health Insurance, Case Management, Coordination with Medicaid, WIC and Education

POPULATION-BASED SERVICES

Examples:
Newborn Screening, Lead Screening, Immunization, Sudden Infant Death Counseling, Oral Health, Injury Prevention, Nutrition and Outreach/Public Education

INFRASTRUCTURE BUILDING SERVICES

Examples:

CORE PUBLIC HEALTH SERVICES DELIVERED BY MCH AGENCIES
Newborn Screening Program Policy Issues

- Infrastructure Services
  - Policy development
    - Laboratory standards
      - Cut-off values
      - Case definitions
      - Testing strategies
      - Turn around time
      - Nomenclature
      - Report forms

*Items in bold have been discussed or will be at this meeting

JANUARY 2005
Newborn Screening Program Policy Issues

- Infrastructure Services
  - Policy development (Cont)
    - Policies for use and storage of residual blood spots
    - Follow-up protocols
    - Panel of screening conditions
    - Informed decision making/consent/dissent
Newborn Screening
Program Policy Issues

- Infrastructure Services (Cont)
  - Informatics infrastructure
    - Tracking and surveillance
      - Definitions of principles and core functions
      - Defining data dictionary
      - Short and long term tracking capabilities
        - Knowledge base
        - Evaluation
Infrastructure Services (Cont)

Integrated information systems development

Integration of public health and personal health services data
- Provider access to newborn screening results
- Identification of medical home
- Privacy/confidentiality

Linkage of clinically useful data
- Child health profile

Continuous quality improvement
Infrastructure Services (Cont)

- Training on genetics, diseases, treatments and technologies
  - Health care professionals
    - Primary and subspecialty care
  - Public health professionals
  - Laboratories

Health Resources and Services Administration

Newborn Screening Program Policy Issues

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Infrastrucure Services (Cont)

- Research
  - Developing new therapies
  - Developing new testing platforms and strategies

Evaluation

- Cost effectiveness evaluation
- Pilot testing of technology
  - Clinical validity and utility
- Health outcomes evaluation
Newborn Screening Program Policy Issues

- Infrastructure Services (Cont)
  - Quality assurance
    - Policy development for laboratory
      - Data standards
      - Case definitions
      - Cut-off definitions
    - Policy development for programs
Newborn Screening Program Policy Issues

- Infrastructure Services (Cont)
  - Distance communication
    - Reimbursement
    - Legal issues
    - Infrastructure

- Financing of newborn screening system infrastructure
Newborn Screening
Program Policy Issues

- Population based services
  - Education
    - Health care and public health professionals (hospital, obstetric, and pediatric care)
    - General public
    - Parents

JANUARY 2005
Newborn Screening Program Policy Issues

- Enabling services
  - Access to therapies and supplemental therapies and services (OT/PT, early intervention, Title V, CSHCN)
    - Reimbursement
    - Nutrition support

- Family support activities
  - Advocacy
  - Educational workshops
Newborn Screening
Program Policy Issues

- Direct services
  - Genetic counseling
  - Treatment
    - Subspecialty
    - Nutritionist
    - Other necessary treatment and services for comprehensive care
Peter C. van Dyck, M.D., M.P.H.

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