Integrating Information Systems Vision and Process

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Outline of presentation

- Who we are
- Brief problem statement
- Current policies/recommendations
- Center for Innovation - HRSA contract 2002-2005
- Developing a vision

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- All Kids Count
- Connections
- Integrating newborn screening programs
- Public Health Informatics Institute

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Center for Innovation Basic premise

Health and health services can be improved by assuring timely provision of accurate information

Currently, information is often not timely and usually fragmented

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All Kids Count (AKC)

AKC I – Experimentation & development of immunization registries

AKC II – Implementation & operation of immunization registries

AKC III – Communication & integration of child health information systems

Immunization registries and NB screening information systems - 1

- Must be established at, or near, birth
- Population-based
- Support clinical decision making at the point of service
- Provide summary public health information
- Provide means of assuring follow-up and completion of recommended action

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Immunization registries and NB screening information systems - 2

Reflect preventive services recommended for, or mandated, for ALL children (societal interest)

Early/prompt delivery of services is needed to assure maximum benefit (delay may be harmful)

Immunization registries and NB screening information systems - 3

Parents/providers may not be accurate in their assessment

Reminder/recall for both parents and providers is essential

Missed opportunities are a real problem

Need to be able to exchange information with other systems to reduce missed opportunities

Immunization registries and NB screening information systems - 4

Face similar issues

- Privacy/confidentiality/security
- Recruiting providers
- Proper functioning/standards
- Sustainable funding

Can benefit from working together (both $ and program success)

Greensboro NC Newborn Hearing Screening, 1998-1999

175 / 5010 (3.5%) of non-ICU newborns had abnormal screens

157 / 175 (89.7%) of abnormal screens had follow-up (18 did not)

9 confirmed hearing loss

Ratio of positives to confirmed hearing loss = 17

Source: Pediatrics 106:e7, 2000

Newborns screened for hyperphenylalaninemia – 1999-1

No. screened	4,024,850
No. NOT NORMAL	3,494
No. NOT NORMAL lost to f-u	154
No. Classical PKU or clinically significant var	302

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Newborns screened for hyperphenylalaninemia – 1999-2

3,494 NOT NORMAL – 154 lost to f-u =

3,340 NOT NORMAL with f-u ->

302 classical PKU or sig. Variant

3,340/302 = 11 f-u/case

154 NOT NORMAL lost to f-u/11 =

14 missed cases??

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Days from birth to initiation of Rx - Classical PKU

Days	No.
0 - 7	38
8 - 14	87
15 – 21	30
>21	14
Unknown	18
NR	12

Source: NNSR - 1999

Barriers to gaining access to newborn screening results – Desposito et al

- Infants born in hospital where physician does not have privileges
- New transfers to the practice
- Infants born in other states
- Personnel time to track results
- Parents notified before Primary Care Pediatrician
- Name change
- Absence of direct communication system linking state newborn screening program to Primary Care Pediatrician

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Average time for notification of initial screen-positive result – Desposito et al

Days	%
1 - 3	12.5
4 - 7	33.1
8 – 10	16.2
11 – 14	14.5
15 – 21	9.4
> 22	4.4
Not	4.5
?	5.4

Average time for notification of screen-negative result – Desposito et al

Days	%
1 - 7	4
8 – 14	19
15 - 21	22
22 – 28	13
>28	16
Not	26

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Conclusions/recommendations Desposito et al - 1

"All initial screening test results, for infants cared for from birth, need to be communicated to the pediatrician:

7 days for screen-positive results and

10-14 days for all results. Newborn screening test results of new patients who enter the practice should be available at the time of the first well-infant visit, ideally by 2 weeks of age."

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Conclusions/recommendations Desposito et al - 2

“Augmented communication systems (including electronic systems) are needed to interface the primary care pediatrician directly with the state newborn screening system to enhance timely retrieval of screen-positive newborns, to gain access to follow-up test results, and to provide documentation for all test results, both positive and negative.”

Healthy people 2010 objectives

16-20 - Ensure appropriate newborn bloodspot screening, follow-up testing, and referral to services

- Ensure that all newborns are screened at birth for conditions mandated
- Ensure that follow-up diagnostic testing for screening positives is performed within an appropriate time period
- Ensure that infants with diagnosed disorders are enrolled in appropriate service interventions within an appropriate time period

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Healthy people 2010 objectives

16-21 - Reduce hospitalization for life-threatening sepsis among children ≤4 with sickling hemoglobinopathies

16-22 - Increase the proportion of children with special health care needs who have access to a medical home

16-23 - Increase the proportion of Territories and States that have service systems for children with special health care needs

Newborn Screening Task Force

- "What is the optimal framework for integrating or coordinating public health systems for newborn assessment and follow-up?
- "What is the role of information systems as part of efforts to improve program coordination?"

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Newborn Screening Task Force

“HRSA’s MCHB should provide grants to states to stimulate development of newborn screening information systems that are connected to the medical home… *and integration with other public health data systems.*”

Integrating genetic services into public health – NNSGRC

“A data collection system capable of identifying community genetic health and health care problems and systems of care is far larger in scope than a categorical registry and may require substantial time and effort to construct. However, efforts could begin by integrating existing surveillance systems (e.g., newborn screening programs, birth defects registries, vital records, CSHCN programs, immunization registries, cancer registries) with genetic service information resulting in a statewide surveillance system for genetics and genetic services.”

ASTHO policy statement on public health genetics

"…the incorporation of up-to-date genetic information in areas such as MCH, occupational health, and prevention and disease focused programs, will improve outcome by providing better prevention information. Data systems capable of monitoring the quality of individual services should include genetic information."

CORN guidelines for clinical genetic services for the public's health

> "There are a number of essential linkages which should occur at every state level for the purpose of monitoring occurrence of specific genetic diseases, outcomes in infants/children with those diseases, and assessment of service utilization and efficiency of service delivery."

CORN guidelines for clinical genetic services for the public's health – essential linkages - 1

- Birth and death certificates <6
- Birth defects and tumor registry data
- Birth defects registry with vital statistics
- In-pt discharge records with birth cert
- Screening database with vital statistics
- Clinical genetics services database and birth/fetal death certificates
- Systems for direct referral from clinical genetics to early intervention services
- Systems for direct referral from clinical genetics to early intervention services

HRSA Guidance on planning grants - 1

“At a minimum, a community-based child health profile should encompass… newborn metabolic and hemoglobinopathy screening data, lead screening, newborn hearing screening, immunization and birth defects surveillance data.…”

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HRSA Guidance on planning grants – 2

"…integrated within the public health departments and accessible to the public health entities… with a goal of decreasing fragmentation and duplication …Systems integration should also allow the ability to evaluate personal health care and achieve a child health profile of an individual child."

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Linkage & Integration

?linkage - modifying existing information systems to exchange information

?integration - comprehensive systems built with, perhaps, individual components

Integration - providing a range of information to the end user in a simple, comprehensive format so he/she can readily take all indicated actions, no matter what the hardware/software looks like

Integration relates to the end user, not to the background machinery

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Center for Innovation - HRSA contract purpose

- Build policy case supporting integration of newborn metabolic screening and genetic services with other early childhood programs and their supporting information systems
- Foundation of policy case is consensus Model of Practice
- Long-term goal - influence health care insurers in supporting the screening infrastructure needed to yield improved health status outcomes

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Model of practice for integrating NMSP and other public health and health care services

- Unclear at present exactly what model will look like
- Model will draw heavily from best practices identified through earlier work with HRSA projects and AKC projects
- May require development of standards
- Work group will be formed to help develop model
- Close linkage with NNSGRC to ensure their work is accurately reflected
- Defining model will require enunciation of a shared vision

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Immunization registry minimum functional standards - 1

- Electronically store data on all NVAC-approved core data elements
- Establish a registry record within 6 weeks of birth for each newborn child born in the catchment area
- Enable access to and retrieval of immunization information in the registry at the time of encounter
- Receive and process immunization information within 1 month of vaccine administration

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Immunization registry minimum functional standards - 2

- Protect the confidentiality of health care information
- Ensure the security of health care information
- Exchange immunization records using HL7 standards
- Automatically determine the routine childhood immunization(s) needed, in compliance with current ACIP recommendations, when an individual presents for a scheduled immunization

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Immunization registry minimum functional standards - 3

- Automatically identify individuals due/late for immunization(s) to enable the production of reminder/recall notifications
- Automatically produce immunization coverage reports by providers, age groups, and geographic areas
- Produce official immunization records
- Promote accuracy and completeness of registry data

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Goal for All Kids Count III

To promote the development of integrated preventive health information systems* that provide public health officials with population-based health data and private health care providers with data about their own patients at the point of service delivery as well as aggregate data

*confidential, computerized information systems that contain information on recommended preventive health services for all children in a community.

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Objectives for AKC III - I

- Develop and endorse a shared vision of integrated public health information systems with key federal, state, regional public health and private sector health care agencies and organizations

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Vision

Where there is no vision, the people perish

Proverbs, 29:18

Oh, the vision thing

GHW Bush, 1987

10-30 year Big, Hairy, Audacious Goal

Collins and Porras, 1996

Vision Statement Activity Plan

- **Conduct initial telephone interviews**
- **Establish Advisory Committee with cross-section of stakeholders**
- **Conduct in-depth interviews with key representatives**
- **Hold regional meetings with a cross-section of stakeholders to develop a vision statement and set of issues to be addressed**
- **Synthesize information obtained, draft a vision statement and circulate it widely for comments**
- **Hold national meeting for consensus**

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Next steps in this meeting

- Discuss process for developing model of practice
- Suggestions for perspectives to be represented on work group

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