

Working Together at the EHDI Program

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Indiana EHDI Program

- 88,000 births
- 106 birthing facilities
- ISDH Staff: Director of Genomics & Newborn Screening, State EHDI Coordinator, UNHS Nurse Consultant, Regional Consultants (8), Parent Consultant, Support Staff (1.5)
- Special Projects with EHDI Partners:
 - Indiana Perinatal Network
 - Indiana Hands and Voices
 - Indiana Outreach for Deaf and Hard of Hearing Children
 - Indiana First Steps
- Tracking for unscreened babies: hospitals and ISDH
- Contact by phone and/or letter to parents, doctors, public health nurses, regional consultants of babies who: 1) have not been screened 2) did not pass 3) passed with risk factors



Utah EHDI Program

- 56,000 births
- 42 birthing facilities
- EHDI Staff
 - CSHCN Medical Director
 - State EHDI Director (.4)
 - State EHDI Audiology Coordinator (.5)
 - Data / Tracking Coordinator (.9)
 - Support Staff (.5)
 - Special Projects (contracts)
- Follow-up
 - Birthing facilities
 - Referral booklet of Ped Audiologists
 - Letters
- Diagnosis
 - Referral to EI / PIP
 - Data sharing agreements (PIP, CHARM, VR, etc.)
 - Parent Notebook



Rhode Island EHDI Program

- 13,200 births
- 7 birthing facilities
- Staff
 - **DOH:** Office of Perinatal and Early Childhood Health, NBS Program Manager is EHDI Coordinator, Additional staff for oversight, grant projects, data management
 - **RIHAP:** Administrator, Audiologists, Data and Support staff (~4 FTE)
- Follow-up
 - Contact by phone and/or letter to parents and pediatric provider for babies who: 1) have not been screened 2) had an incomplete or invalid screen 3) did not pass 4) passed with risk factors



Indiana Legislation

Screening of babies in Indiana for hearing loss is mandated by PL91-1999

16-41-17-10 states that ISDH is responsible for
“A centralized program that provides tracking, follow-up, diagnosis, management, and family counseling and support.”

Individuals with Birth Defects & Problems Registry
Indiana

Code 16-38-4, Rule 410 IAC 21-3-7

January 2004 required physician report
October 2006 required audiologist report



Utah Legislation

- **Newborn Hearing Screening mandated in 1998
(Utah Code Section 26-10-6)**
- **Newborn Hearing Screening Rules (Ut Admin Code R398-2)**
 - **Each facility responsible for program**
 - **Audiologist oversees facility screening program**
 - **Screened prior to discharge**
 - **Includes home births**
 - **Screened by one month**
 - **Reporting**
 - **Parents, PCP, Dept of Health**
 - **“...reasonable efforts within 30 days...”**



Rhode Island Legislation

RI General Law (23-13-13) states:

- **Screening of RI babies for hearing loss is mandated unless parental refusal due to conflict with religious tenets/practices**
- **Physician attending a newborn child is responsible**
- **DOH authorized to establish rules and regulations for fee to cover program costs**
- **Screening shall be a covered benefit reimbursable by health insurers**
- **Creation of advisory committee**

Reporting not required



Indiana LTF/LTD

Loss to follow-up is calculated using the group of referred babies

- Referred babies include:
 - ✓ Babies who do not pass UNHS
 - ✓ Babies who pass with risk factors
- Families are reported to Dept of Health, in addition to Part C and PCP
- Reporting occurs through:
 - ✓ Audiology reporting system (DAE)
 - ✓ Parent report via return letter or phone call
 - ✓ Part C Early Intervention
 - ✓ IBDPR
- If no report received:
 - ✓ Phone calls from Dept of Health
 - ✓ Letter Campaign
 - ✓ Regional Consultants
- Attempts to contact unscreened babies occur 2 years post birth
 - ✓ Phone calls
 - ✓ Letter Campaign



Utah LTF/LTD

- **Tracking by birthing facility / midwives**
 - Babies who do not pass UNHS
 - Births with no reported screening results
 - Includes refused / home births (>750 in '07)

- **Support by State EHDI Loss to follow-up is calculated for all occurrent (live) births**

- **Initial office**
 - Supplement facility tracking by request
 - Transfers, rural births, home births
 - Track documented dx referrals
 - Collaboration with Vital Records

- **If no dx report received**
 - Contact supervising audiologist and referral audiologist
 - Contact to parent and physician (if known)
 - Monitor EI / PIP enrollment



Rhode Island LTF

Loss to follow-up is calculated using the group of infants who failed or had incomplete/invalid screening results and did not complete recommended follow-up

- **Recommended follow-up includes rescreen and/or diagnostic testing**
- **Additional follow-up (not included in LTF rate) is done for infants who:**
 - ✓ **Were not screened**
 - ✓ **Passed but had risk factors**
- **Reporting process:**
 - ✓ **Paper based reporting form for audiologists, web reporting will be available soon**
 - ✓ **If no report received infant remains in the system as needing follow-up**
- **Attempts to contact for follow-up occur up to 30 months**



Indiana Innovations

- EHDI Alert Response System
- Reciprocal Release
- Parent Consultant (follow-up)
- Regional Consultants
- Referral to Family Support Organizations



Utah Innovations

- Loss to Follow-up Projects
 - NCHAM, RTI
- CHARM Data Integration
- PIP screening follow-up collaboration
- Birth Certificate Alert
- Home birth screening project



Rhode Island Innovations

- Alert system reminder letters to parent and physician at 6, 18 and 30 months
- Engage medical home, provider algorithm
- Family guides for follow-up (4 versions)
- Follow-up committee and quarterly checks with EI to ensure connection to services for babies with confirmed hearing loss
- Use of home visiting services
- Diagnostic done prior to discharge for NICU infants if indicated



