

EHDI Workgroup Meeting
Regional Meeting September 17, 2008

Participating: Gary Hoffman, WI – Workgroup Lead; Gayla Hutsell Guignard (IN); Molly Pope, IN; Kelly Daniel, KY; Joan Ehrhardt, MI; Michelle Garcia, MI; Yaoli Li, MN; Shelley Nottingham, OH; Ravi Shah, WI.

For each of the nine Priority Issues previously identified by the EHDI workgroup, participants:

- 1) reviewed the Priority Issues Action Planning Worksheets
- 2) reviewed resource materials provided by Region 4 states and the Region 4 Coordinator
- 3) completed the EHDI Strategy Assessment Worksheet

A summary of each priority issue follows.

A. (Follow-up) Getting data back from Early Intervention/Part C Programs		
Issues	Existing Strategies	Proposed Strategies
<ul style="list-style-type: none"> • Some children EHDI is required to follow for long term outcomes are residents of a board state – referred to/receive Part C services in their home state but continue to receive medical care in border state. Would like to have complete information on the child. (MN) • There is a general risk of loss to follow up given the possible 45-day waiting period after referral for completion of IFSP, obtaining release to state department of health and actual notification of signed IFSP. (MN) 	<ul style="list-style-type: none"> • Fax-back referral form and justification/description of need for state DH to be on release to Part C staff. Once faxed back, provides contact information on assigned service coordinator so individualized follow-up may be initiated if department of health does not hear back regarding Part C enrollment within given time frame. (MN has tool) • Fax-back form to PCP to confirm referral and/or enrollment in Early Intervention (as verification) (MN has tool) • Verbal agreement with Part C statewide director to follow-up on children referred if unable to contact service coordinator (MN process) 	<ul style="list-style-type: none"> • Pilot PDSA Cycle to offer standardized materials to Service Coordinators (include information on Medical Assistance and other just in time information; include form to collect confirmation of enrollment date, etc., to be faxed back to state department of health (MN)
<ul style="list-style-type: none"> • Difficulty sharing information due to HIPAA rules (KY) • Willingness to work with EHDI (KY) 	<ul style="list-style-type: none"> • Discussions held between Part C and EHDI staff regarding data sharing and availability of appropriate EI providers (KY) • CDC Grant – Years 2 & 3 plans are to have a mechanism for electronic reporting regarding early intervention services 	<ul style="list-style-type: none"> • Dual Point of Entry for Early Intervention services for Deaf/Hard of Hearing (Colorado Co-Hear) (KY)
<ul style="list-style-type: none"> • FERPA/Part C Regulations make it difficult to get data back from Early Intervention/Part C programs (IN) • Irregular use of the First Steps Early Intervention Programs' reciprocal release 	<ul style="list-style-type: none"> • Reciprocal release to share info (IN tool) • Diagnostic Audiologic Evaluation Form required as part of IBDPR regulation (soon to be web-based reporting) (IN tool/process) • Re-referral to Part C by secured email from EHDI (EARS) 	

<p>(which would allow for information to be sent to EHDI)</p> <ul style="list-style-type: none"> • Limited data sharing has occurred between the two lead agencies • Different agencies involved with screening and intervention 	<p>data management system) following initial referral by hospital (IN Process)</p> <ul style="list-style-type: none"> • Phone call from EHDI to Part C or family to document intervention in place (EHDI staff uses follow-up data form within EARS as part of the Child’s Health Information Profile (CHIP) (IN process/tool) • Quarterly meetings with the state Part C Coordinator which includes specific discussion points and possible solutions re: data-sharing (IN process) 	
<ul style="list-style-type: none"> • Part C Privacy Regulations (IL) • Consistency across all regional offices across the state in implementing protocols • Different interpretations of policies • Lack of centralized database 	<ul style="list-style-type: none"> • Illinois uses a release with EI that gives an opt-in or opt-out option. (IL tool) 	
		<p>Fax back form</p> <ul style="list-style-type: none"> • Work with Part C to ensure services that children are receiving services they should be receiving • Getting the details of early intervention services. • Education the families in the services they should be offered through Part C <p>Face to face meetings with Part C for data sharing</p> <ul style="list-style-type: none"> • Reciprocal release • Be part of the process to gain access to information from Part C (use CDC as a resource)

B. (Referrals) Getting babies into diagnostic testing

Issues	Existing Strategies	Proposed Strategies
<ul style="list-style-type: none"> • Lack of audiologists who have the education and equipment to provide infant services; (IL) • Limited or no audiologists in more rural areas of the state • Issues with audiologists accepting specific insurance/Medicaid or serving those without insurance • Knowing who in the state accepts Medicaid so that information may be passed on to parents • “Buy in” from the pediatricians regarding the need for follow-up and follow-up in a timely manner • Transportation for the families to access the appointments and being transported on time • Parents not receiving the message that follow-up is needed in a timely manner/ they should not “wait and see” • Issues regarding the primary language of the family (e.g., sign, Spanish, etc) • Ease of finding interpreters who are qualified (defining “qualified”) • Education for providers re: requirements of the ADA for interpreters • Lack of single point of entry to the state system following a referral on UNHS 	<ul style="list-style-type: none"> • Illinois is working towards interpreter licensure (sign) throughout the Deaf and Hard of Hearing commission http://www.idhhc.state.il.us/ on this site there is an interpreter directory with contact information • IL is searching for funds to provide support for the purchase of screening equipment that can be used in rural areas to re-screen and monitor the 0-3 population • Parents receive 2 letters from the state after not passing UNHS, follow-up phone calls are made; if contact is still not made then the local health departments are asked to make a home visit to locate the family • IL chapter Champion (ICAAP) does some grand rounds in the chicagoland area • ILs Title V assist in paying for UNHS follow-up diagnostics after insurance is maximized • MOU between state agencies for transmittal of information for participating providers 	
<ul style="list-style-type: none"> • Lack of qualified pediatric providers in some areas of the state (KY) • Lack of knowledge of referral sources in area • Loss of contact with families due to incorrect addresses 	<ul style="list-style-type: none"> • Families receive a form letter and a diagnostic resource list within 48 hours after we receive information from the hospital indicating results were a refer or pass/pass with risk indicators (KY) • Hospitals are encouraged to facilitate an appointment with a diagnostic provider prior to discharge • Equipment has been purchased both within our agency and through a Building Community Capacity Grant to increase availability of services in more rural areas • Currently have a MCHB grant addressing loss to follow-up working with nine pilot hospitals to develop direct referral pathways and strategies for 	<ul style="list-style-type: none"> • Working on introducing legislation that would make reporting of results “mandated” but voluntary. Providers would agree to report results in order to be included on diagnostic resource list (KY)

	<p>increasing follow-up. Plan to take successful strategies and implement statewide.</p>	
<ul style="list-style-type: none"> • Limited number of pediatric audiologists with experience and needed equipment (IN) • Decreased number of audiology providers enrolled with Part C • Rural areas of the state where distance and travel is necessary • Mileage reimbursement, while available, is not widely known among parents • Gas Prices 	<ul style="list-style-type: none"> • Hospitals refer directly to Part C after baby does not pass 2 screens or if baby passes but has one of 3 identified risk factors (form) (IN) • Part C SPOE assists family in scheduling follow-up diagnostic testing • Audiologists report findings directly to EHDI using the DAE form (required by IBDPR rule) • EHDI Parent Consultant picks up families who have not followed up diagnostic testing in a timely manner (by phone) • EHDI staff contacts Part C SPOE cluster office on any children who do not appear to be receiving timely follow-up to check status, and offer assistance and/or solutions. 	
		<ul style="list-style-type: none"> • Expand diagnostic testing • Regional Training for Audiologists • Calling physicians (bullet point physician information) • Contact patients

C. (Border Babies) Don't know about border baby births/NBS

Issues	Existing Strategies	Proposed Strategies
<ul style="list-style-type: none"> • Different follow-up procedures in different states by law (IN) • HIPAA issues in sharing names (IN) • Delay in forwarding information to other states (IN) • Different processes for referral to Part C (IN) 	<ul style="list-style-type: none"> • List of border state EHDI contact info (IN) • When notified by the hospital of a baby residing in a different state, IN calls the appropriate contact and verbally shares info (IN) • The IN EHDI program plans to meet and create a Memorandum of Understanding (MOU) with all four border states in the next two years (CDC grant objective) 	<ul style="list-style-type: none"> • Develop MOU for Region 4 to share results across borders (IN) • Consider developing a form that could be used by all in Region 4 to share results (IN)
<ul style="list-style-type: none"> • Lack of consistent reporting across states – states report differently or track infants different ways (KY) • Do not currently have anything in writing (KY) 	<ul style="list-style-type: none"> • Any hospital in KY that births 40 or more babies is required to report results even if state of residence is not KY. (KY) • If we know the source of the infant's follow-up we will attempt to get results, but are not always successful. (KY) • Parents receive form letter and diagnostic resource list of providers in KY within 48 hours after information is received from hospital. (KY) 	<ul style="list-style-type: none"> • Developing Memorandum of Agreement between states (CDC Teleconference – New England MOA PowerPoint) • CDC Teleconference on Data-sharing across states (CDC)
<ul style="list-style-type: none"> • There is a lack of consistency of information obtained for infants who do not pass. Then, lack of consistent information transmitted between states. (IL) • Willingness and ability (allowed by agency) to communicate with other states (IL) • Transmittal of information goes beyond the hospital screening to the diagnostics and intervention. It can be difficult to find out if a child had diagnostics/ intervention on children born in my state but receiving services in other states. (IL) • There is a need for a single phone number per state that families can call to find out where to go for follow-up. (IL) 		
		<ul style="list-style-type: none"> • Adapt Region 4 State-to-State Newborn Screening Follow-up Guidelines

D. (Diagnosis) Following up with the PCP for older children – what is the scope of the EHDI program (after 1 Year of age)		
Issues	Existing Strategies	Proposed Strategies
<ul style="list-style-type: none"> • Family does not return for f/u (MN) • Disconnected household phone (MN) • Transferred to unknown PCP (MN) • Moved out of state (MN) • Some PCPs direct family to audiologist or ENT for f/u (MN) • Much education of PCP about their role in the Medical Home is needed. (MN) 	<ul style="list-style-type: none"> • Phone call to PCP once a CHL report is received (MN) • Just-in-time information package sent to every PCP who has a child diagnosed with PCHL after the phone call. The package includes: <ul style="list-style-type: none"> ○ MN H & V Parent Guide list ○ MN PCP EHDI Guidelines ○ 2007 JCIH Risk Factor List ○ Congenital CMV & HL summary ○ MCSHN Role fact sheet for long-term f/u ○ EHDI Audiologist business card ○ Other materials pertinent, according to HL • Fax back form from PCP to confirm referral a/o enrollment in EI (as verification) 	
<ul style="list-style-type: none"> • Indiana EHDI provides short term follow-up, not long term; Long term follow up is done b Part C; or, for much older children, through the local school. Regardless of age of entrance into EHDI, the IN EHDI program contacts the physician in the same manner as with babies. 	<ul style="list-style-type: none"> • EHDI consults with Early Head Start for assistance in following-up on babies who were lost to follow-up/documentation after screening (IN) • EHDI works with other state agencies that provide services to older children such as the Department of Education (Division of Exceptional Learners) and Outreach Services for Deaf and Hard of Hearing Children. EHDI encourages these agencies to assist in individual families in maintaining their ties to the medical home 	
<ul style="list-style-type: none"> • Lack of primary care and ENT physicians who accept Medicaid insurance. (IL) • Families who have Medicaid often transfer care many times because Medicaid is not always accepted or the wait time is too long. (IL) • All EHDI programs need to follow (or have a mechanism for following) infants past the first year of life. I agree with the states who define EHDI as 0-6 years. (IL) • For families of lower socio-economic status who use community clinics, there is not consistent communication between all providers for the child. (IL) 		
		<ul style="list-style-type: none"> • Sending letters with risk factors • Writing a protocol(s) for follow-up on late onset when risk factors are identified at birth

E. (Education) Educating practitioners about the importance of diagnostic testing

Issues	Existing Strategies	Proposed Strategies
<ul style="list-style-type: none"> • The large number of practitioners in the state (MI) • The number of cases a physician may see over their professional career • Competing with everyone else to get your message across to a busy physician • Getting past the “it’s just fluid” mentality 	<ul style="list-style-type: none"> • Medical home checklist (MI) • Physician packet once a child is diagnosed with hearing loss 	
<ul style="list-style-type: none"> • Hard to get dedicated time to educate practitioners about hearing loss and diagnostic testing (KY) 	<ul style="list-style-type: none"> • Joint speaking engagements with AAP-EHDI Chapter Champion • Grand Rounds with Residents in some larger areas of the state • Exhibitor at KY Perinatal Association Meeting • Continuous Education with Nurses during annual hospital visits • Pediatrician survey on UNHS Knowledge, Attitudes and Practice (KY Tool) 	
<ul style="list-style-type: none"> • Equipment & experience limitations of audiologists (IN) • Funding for conferences/meetings/trainings • Physicians are difficult to reach 	<ul style="list-style-type: none"> • Annual presentations to Part C providers (primarily audiologists) (IN) • Indiana EHDI conference in 2006 (audiologists and physicians) • Letter sent to PCP for babies who were not screened for any reason did not pass or passed but had risk factors (3 identified by Part C) • Physician Toolkit (in development) will be sent to any PCP with a child identified with a hearing loss • Diagnostic Guidelines for Audiologists in Indiana for testing and amplifications (IN tool) • A quarterly one-page newsletter is in the process of development with a different newsletter for each of the following stakeholder groups: audiologists, hospital personnel, parents 	<ul style="list-style-type: none"> • Guidelines for physician follow-up could be developed regionally and a way to disseminate them to PCPs could be determined
<ul style="list-style-type: none"> • Lack of attention to childhood hearing loss due to low incidence • Getting audiologists and physicians to dedicate time away from clinic for training is difficult (IL) 	<ul style="list-style-type: none"> • IL chapter champions provide some grand rounds in the metro areas. Originally the IL EHDI program helped to write the PowerPoint Presentation • IL revised the Guidelines for Pediatric Medical Home Providers from AAP (IL tool) 	
		<ul style="list-style-type: none"> • Expand diagnostic testing <ul style="list-style-type: none"> • Regional Training for Audiologists • Calling physicians (bullet point physician information) • Contact patients

F. (Education) Educating Practitioners about the urgency of repeat testing		
Issues	Existing Strategies	Proposed Strategies
<ul style="list-style-type: none"> • The large number of practitioners in the state (MI) • The number of cases a physician may see over their professional career • Competing with everyone else to get your message across to a busy physician • Getting past the “it’s just fluid” mentality or its not life/death 	<ul style="list-style-type: none"> • 	
<ul style="list-style-type: none"> • Same barriers – lack of education, understanding about newborn hearing screening and process for follow-up (KY) • Lack of awareness about importance of early identification by physicians • 	<ul style="list-style-type: none"> • Joint speaking engagements with AAP-EHDI Chapter Champion • Grand Rounds with Residents in some larger areas of the state • Exhibitor at KY Perinatal Association Meeting • Continuous Education with Nurses during annual hospital visits • Pediatrician survey on UNHS Knowledge, Attitudes and Practice (KY Tool) 	
<ul style="list-style-type: none"> • Hospital screener turnover (IN) • Lack of awareness about importance of early identification by physicians 	<ul style="list-style-type: none"> • Screener guidelines for hospitals (IN tool) • Regional Hospital trainings by ISDH staff • Letters to PCPs for all babies not screened for any reason, did not pass or passed with 3 risk factors • Online training for hospital staff (in development) • Annual visits to hospital EHDI contacts by regional consultants • Recent statewide trainings on the EHDI EARS data management system has allowed EHDI staff to demonstrate the outcomes of early and appropriate management by hospital personnel and the impact their work has on babies and families 	
		<ul style="list-style-type: none"> • Expand diagnostic testing • Regional Training for Audiologists • Calling physicians (bullet point physician information) • Contact patients

G. (Follow up) Getting PCPs to support re-screen and/or follow-up by encouraging the family		
<ul style="list-style-type: none"> • Lack of education, understanding of PCPs on process for newborn hearing screening follow-up (KY) • PCPs may not know the results of the screen-attending PCP in the hospital may not be the PCP that family sees once they are discharged • Families may not have a consistent medical home, but use health departments for immunizations/well child checkups • Lack of diagnostic providers in some areas so PCPs do not refer 	<ul style="list-style-type: none"> • Copy of Hearing Screening Report to the attending PCP-mandated to occur within 24 hours after discharge if there is a refer or a pass/pass with risk indicators (KY tool) • Mandated timeline for reporting – Compliance is checked during annual hospital visits • AAP-EHDI Chapter Champion- lunch/dinner meetings with physicians throughout the state • AAP_EHDI Chapter Champion in conjunction with EHDI staff completed a survey on Pediatricians UNHS Knowledge, Attitudes and Practice (KY tool) • EHDI staff disseminated 1-3-6 materials developed by the CDC to PCPs in local areas. (Materials developed by Provider Relation Branch, CDC) Also disseminated via AAP 	<ul style="list-style-type: none"> • Recording results of newborn hearing screening on immunization records given at the hospital – Parents reportedly keep up with immunization records and share that information with child’s medical provider – Might ensure that medical provider knows of refer/risk so family could be linked to diagnostic services.
	<ul style="list-style-type: none"> • An IL parent group developed a flyer for parents of children who are deaf or hard of hearing to take to the physicians to raise awareness (IL tool) 	
<ul style="list-style-type: none"> • Lack of awareness by PCP of ability to test infant hearing (IN) • Lack of awareness of importance of early identification • Lack of funding for educational conferences/materials to assist the PCPC • Difficulty in “getting the ear” of the PCP • Negative bias towards the validity and reliability of the test tools • An attitude that if a baby passes the newborn screening in one ear, that’s good enough 	<ul style="list-style-type: none"> • Follow-up letters (IN tool) • Regional Consultant campaign to promote PCP involvement (in development) • Phone calls to PCPs by EHDI staff to locate babies lost to follow-up (seems to open doors) • Presentations at medical schools, grand rounds and other hospital-based venues 	
		<ul style="list-style-type: none"> • Expand diagnostic testing <ul style="list-style-type: none"> • Regional Training for Audiologists • Calling physicians (bullet point physician information) • Contact patients

H. (Follow-up) Providing information to primary care providers at the time of identification – positive screen or reports

Issues	Existing Strategies	Proposed Strategies
<ul style="list-style-type: none"> Family may not have stable medical care (KY) Family may be unwilling to sign release of information – Agency policy does not allow us to send results to PCP unless they were the referring provider (KY) 		
<ul style="list-style-type: none"> Creating “just the right tools” so that physicians will read it/use it (IN) 	<ul style="list-style-type: none"> Hospital alerts PCP of screen result through a report or discharge summary EHDI sends letters to PCP for all babies not screened for any reason, passed with risk factors or who did not pass 2 screens Audiologists send DAE & or report to EHDI and PCP Part C requires PCP signature for referral for diagnostic testing 	<ul style="list-style-type: none"> Develop a form for all hospitals to use to report findings to PCP
<ul style="list-style-type: none"> Physicians actually reading the letters sent from the state or hospital re: the screening results. At times these reports are only filed. (IL) Identification of the primary care physician who will provide on-going care past the first month. Often physicians listed on the hospital discharge summary will only care for the child at the first post-birth visit. 	<ul style="list-style-type: none"> 	<ul style="list-style-type: none"> Using the strategy of “if you won the lottery tomorrow who could we call to reach you?” (IL)
		<ul style="list-style-type: none"> Expand diagnostic testing <ul style="list-style-type: none"> Regional Training for Audiologists Calling physicians (bullet point physician information) Contact patients

<ul style="list-style-type: none"> I. Follow-up Providing information to family at the time of identification~ positive screen or report 		
<ul style="list-style-type: none"> Lack of resources in some areas (KY) Lack of appropriate early intervention services in some areas Family “not ready” to hear information Inconsistent practices throughout the state 	<ul style="list-style-type: none"> Developed “Opening Doors” materials to give to families at time of diagnosis. EHDI Regional Coordinators have attempted to disseminate information to diagnostic audiology providers throughout the state. We also feel this is a way for us to indirectly “track: infants who have hearing loss. (KY tool/process) 	
<ul style="list-style-type: none"> Hospitals tell families of results in different ways (screener vs physician) (IN) Lack of pediatric audiologists with experience and equipment to provide prompt follow-up testing 	<ul style="list-style-type: none"> Screening certificate (IN tool) Brochure “What if your baby needs more hearing tests?” (IN tool) Periodic audiology survey to develop list of level 1 providers for diagnostic testing EHDI Parent Consultant makes phone call to families once a baby is reported as having a diagnosed hearing loss, provides information about available resources in IN EHDI Parent Consultant sends family the Parent Toolkit Hands & Voices Annual Family Conference for newly identified children and those identified earlier H & V teleconferences for families (in development) H & V GBYS (coming soon to IN) 	
<ul style="list-style-type: none"> Cultural competency (IL) Multiple communication modalities/ languages 	<ul style="list-style-type: none"> IL has a family website www.illinoissoundbeginnings.org 	
		<ul style="list-style-type: none"> Incorporating genetics information into follow-up information for parents Audiologists handle genetic information