

Problematic Issues with EHDI Follow-up – Highlights from Workgroup Discussion

Table 1. Electronic Reporting

	Challenges	Solutions
IL		
IN		Developing web-based system to provide hearing screening results with info on bloodspot cards and what is provided by hospital; will be able to cross reference. Electronic entry, must be complete, or report is not accepted. Matching algorithm built into program for QA/cross reference.
KY	Web-based system since October of 2006 - KY Child. Working out bugs and changes.	Share info (interface) with vital stats at hospital level, so have same contact info.
MI		
MN		
OH	Doing electronic reporting through the birth certificate, simultaneously receiving paper copies. Often missing data (demographics, Hearing Screening results). OH EDHI does not have access to the birth certificate – they are exploring read only access. If birth certificate is inaccurate or incomplete, info cannot be verified in hi track.	Exploring read-only access to birth certificate
WI		Have a web-based system similar to IN. Data system is populated by NBS blood spot card

Table 2. Incomplete Forms

	Challenges	Solutions
IL		
IN		
KY		
MI		
MN	Receiving data in different forms, missing info, handwritten is undecipherable.	
OH	Doing electronic reporting through the birth certificate, simultaneously receiving paper copies. Paper copies are batched and sorted. Often missing data (demographics, Hearing Screening results). OH is getting incomplete information on forms. If birth certificate is inaccurate or incomplete, info cannot be verified in hi track.	Exploring read-only access to birth certificate to allow reconciling with paper forms
WI	Accuracy of data	

Table 3. Border Babies

	Challenges	Solutions
IL	Border babies - when we know about them, we function well together. Its' the babies we don't know about that are an issue.	
IN	Border Baby issues is a big one. HIPAA, FERPA, sharing of information.	
KY	Border babies are issues	
MI		
MN	Border baby is an issue	
OH	.	OH has a border baby protocol – if we have a baby that is your resident, we will provide screening info to state of residence. If you see an OH born baby for dx follow up, please let us know. WV and PA – lots of communication over the last few years. WV uses OH reporting form for follow up when they recognize a OH born baby
WI	. Challenges – border babies, accuracy of data	
		<ul style="list-style-type: none"> • Protocols for border babies that include: <ul style="list-style-type: none"> ▪ Obtaining hearing screening information ▪ Obtaining diagnostic follow-up information <ul style="list-style-type: none"> • Caveat – audiologists are required by law to send the results to <i>their state of employment</i>
	<ul style="list-style-type: none"> • HIPAA Issues around sharing data across state boundaries 	<ul style="list-style-type: none"> • HIPAA Issues around sharing data across state boundaries <ul style="list-style-type: none"> ▪ What are the issues ▪ How are they addressed

Table 4. Later identified / Later on-set

	Challenges	Solutions
IL	How will we enter babies who aren't really babies? (adopted children, etc.)	
IN		
KY		
MI		
MN	Later onset is an issue	
OH		
WI	Babies who pass NBS but have risk factors for later onset hearing loss. Older kids (later onset) Accuracy of data. Data system is populated by blood card. In WI we get blood cards on children that are not newborns. For example, internationally adopted babies. Progressive, late onset. We are getting confirmation cards on kids late identified, but since we are not collecting risk factors, we can't say if it was missed in NBS or not present. Also, no good way to add these children to the web-based system. WI looking at adding a "case add" function to address entering babies who aren't babies.	Have had to make policy issues about following up with PCPs of these babies...what is the scope of EHDI system in WI.

Table 5. Referrals (is there a place here to focus on the genetic disorder specific issues, e.g. Coordination with Genetic Specialist)

	Challenges	Solutions
IL		
IN		
KY	Some hospitals take the lead on referral to physician and also follow up with EHDI (ideal). Others do not.	
MI		
MN		
OH		
WI		
	<ul style="list-style-type: none"> • Referral Issues <ul style="list-style-type: none"> ▪ Getting babies who don't pass newborn hearing screening re-screened ▪ Getting babies into diagnostic testing ▪ Urgency of re-testing – educating physicians regarding the urgency 	<ul style="list-style-type: none"> ▪ <i>(IL is doing presentations at the Physician Assistant CEU workshop. This is first time have targeted PA's with the information)</i>

Table 6. Follow-up/Diagnostic Testing

	Challenges	Solutions
IL	<p>180,000 births per year, and there are areas of the state without audiologists who can do the testing. Families have to travel far to get Diagnostic. Or – if they can do the testing, they won't accept the public health assignment to do the diagnostic testing because of the comprehensive diagnostic reimbursement rate (approx \$56.)</p> <p>Getting data back from Early Intervention – we make the referral, but we can't close the loop to know how many children are really in intervention</p>	
IN		
KY		
MI		
MN	MN – Part C regs do not allow sharing of child specific data	. Need to create systems for getting info back
OH		
WI	Reimbursement rate for dx ABR, is very low. (Comprehensive is around \$100.)	WI working to see if they can get reimbursement rate for screening and diagnostic increased.
	<ul style="list-style-type: none"> • Issues for EHDI <ul style="list-style-type: none"> ▪ Lack of pediatric audiologists ▪ Low reimbursement rates for screening (when fail initial screen) ▪ Low reimbursement rates for diagnosis 	