

EHDI Follow-up Workgroup – Priority Issues Survey

Green = Four Region 4 states rated as priority level 4 or 5
 Blue = Five Region 4 states rated as priority level 4 or 5
 Yellow = Six Region 4 states rated as priority level 4 or 5

Issue	Priority Level 1 = lowest ~ 5 = highest					
	N/R	1	2	3	4	5
1. Follow-up						
a. Getting data back from Early Intervention/Part C programs		0	0	1	2	4
b. Getting PCP's to support re-screen and/or follow up by encouraging the family		0	1	0	4	2
c. Getting data back from audiologist		0	1	1	2	3
d. Getting confirmation that appropriate testing has been done		1	0	1	3	2
e. Getting specialist appointment confirmation (ENT, Geneticist, etc) from PCP/ PCP gets confirmation so they can confirm with EHDI follow-up		1	1	0	5	0
f. Getting confirmation that appropriate referrals have been made for family by follow-up provider		0	0	3	4	0
2. Education						
a. Educating practitioners about the importance of diagnostic testing		0	1	0	3	3
b. Educating practitioners about the urgency of repeat testing		0	1	0	4	2
c. Educating parents and PCPs regarding the importance of specialist referrals, Geneticists, ENT, Ophthalmologist, etc.	1	0	1	0	2	3
d. Screener competencies		0	0	2	3	2
e. Educating parents of babies who pass NB Hearing Screening (i.e. a positive screen does not mean things are forever going to be ok – screening is a picture in time, there are incremental speech and language milestones to watch for		1	0	1	4	1
f. Educating hospital staff about accurate reporting of NB hearing screen		0	0	3	2	2

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3. Referrals						
a. Getting babies into diagnostic testing		0	0	1	2	4
b. Timeliness/expedience of re-screening, diagnostic testing		0	0	2	2	3
c. Getting babies who don't pass NB hearing screening re-screened		0	1	1	2	3
d. Lack of sources for referring to for an appropriate outpatient screen based on the failed screen		0	0	2	3	2
e. Preventing multiple re-screens		0	2	1	2	2
4. Border Babies						
a. Don't know about border baby births/NBS		0	0	1	3	3
b. Don't get information back on second screen/diagnostic testing		0	1	1	3	2
c. Information sharing issues due to HIPAA		0	0	2	3	2
d. Information sharing issues due to FERPA		0	0	3	3	1
5. Diagnosis						
a. Following up with PCP for older children – what is in the scope of the EHDI program		0	1	0	3	3
b. Low reimbursement rate for diagnosis	1	0	1	2	0	3
c. Low reimbursement rates for screening (when fail initial screen)		0	1	3	2	1
6. Later identified/ Later on-set						
a. Following up with PCP for older children – what is in the scope of the EHDI program		0	1	1	3	2
b. Missing information on later identified		0	0	2	4	1
c. No way to tell if lat on-set was “missed” NBS or not present at NBS		0	1	2	2	2

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d. Entering cases into systems designed for “babies” when the case really isn’t a baby		1	1	1	2	2
7. Management						
a. Program evaluation		0	0	2	2	3
b. Funding and sustainability that is not grant dependent		2	0	2	3	1
c. Legislation		1	0	3	3	0
8. Data Collection						
a. Not all babies are entered into the system		0	1	2	2	2
b. Late reporting into the electronic system		1	1	1	3	1
c. Babies birth names – name changes after entered into system		0	2	2	1	2
d. Electronic data collection method is not accessible by EHDI program for reconciling records		3	0	2	1	1
e. Adopted babies		1	1	3	2	0
f. Receive data in different forms, inconsistency of form		3	1	1	2	0
g. Data reported on hard copy is illegible		2	1	3	1	0
h. Risk Factor Data – informed risk factor is present, but risk factor is not specified		1	3	2	1	0
9. Data Accuracy						
a. Data is inaccurate		1	1	3	0	2
b. Missing data with the Newborn Hearing Screen report		2	1	2	0	2
c. Unnecessary repeat screens		1	1	3	1	1
10. Family Support						

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a. Lack of resources for families to address social-emotional response to EHDI results/concerns		1	0	4	1	1