

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. Highest Priority – 6 of 7 Region 4 States						
A. (Follow Up) Getting data back from Early Intervention/Part C programs		0	0	1	2	4
B. (Referrals) Getting babies into diagnostic testing		0	0	1	2	4
C. (Border Babies) Don't know about border baby births/NBS		0	0	1	3	3
D. (Diagnosis) Following up with PCP for older children – what is in the scope of the EHDI program		0	1	0	3	3
E. (Education) Educating practitioners about the importance of diagnostic testing		0	1	0	3	3
F. (Education) Educating practitioners about the urgency of repeat testing		0	1	0	4	2
G. (Follow-up) Getting PCP's to support re-screen and/or follow up by encouraging the family		0	1	0	4	2
2. Second Highest Priority – 5 of 7 Region 4 States						
A. (Management) Program evaluation		0	0	2	2	3
B. (Referrals) Timeliness/expedience of re-screening, diagnostic testing		0	0	2	2	3
C. (Referrals) Getting babies who don't pass NB hearing screening re-screened		0	1	1	2	3
D. (Follow-up) Getting data back from audiologist		0	1	1	2	3
E. (Education) Educating parents and PCPs regarding the importance of specialist referrals, Geneticists, ENT, Ophthalmologist, etc.	1	0	1	0	2	3
F. (Referrals) Lack of sources for referring to for an appropriate outpatient screen based on the failed screen		0	0	2	3	2
G. (Border Babies) Information sharing issues due to HIPAA		0	0	2	3	2
H. (Education) Screener competencies		0	0	2	3	2
I. (Later identified/Later onset) Following up with PCP for older children – what is in the scope of the EHDI program		0	1	1	3	2

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Issue	Priority Level					
	N/R	1	2	3	4	5
2. Second Highest Priority – 5 of 7 Region 4 States (Continued from page 1)						
J. (Border Babies) Don't get information back on second screen/diagnostic testing		0	1	1	3	2
K. (Follow-up) Getting confirmation that appropriate testing has been done		1	0	1	3	2
L. (Later identified/Later onset) Missing information on later identified		0	0	2	4	1
M. (Education) 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
N. (Follow-up) 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
3. Third Highest Priority - 4 of 7 Region 4 States						
A. (Education) Educating hospital staff about accurate reporting of NB hearing screen		0	0	3	2	2
B. (Later identified/Later onset) No way to tell if lat on-set was “missed” NBS or not present at NBS		0	1	2	2	2
C. (Data Collection) Not all babies are entered into the system		0	1	2	2	2
D. (Referrals) Preventing multiple re-screens		0	2	1	2	2
E. (Later identified/Later on-set) Entering cases into systems designed for “babies” when the case really isn't a baby		1	1	1	2	2
F. (Border Babies) Information sharing issues due to FERPA		0	0	3	3	1
G. (Management) Funding and sustainability that is not grant dependent		2	0	2	3	1
H. (Data Collection) Late reporting into the electronic system		1	1	1	3	1
I. (Follow-up) Getting confirmation that appropriate referrals have been made for family by follow-up provider		0	0	3	4	0