

## Iowa EHDI Sustainability Plan

From CDC grant -- Sustainability statement: *“The result will be a sustainable system capable of accurately ascertaining the disposition of every occurrent Iowa birth for each step throughout the early hearing detection and intervention process.”*

From HRSA grant – Sustainability statement: *“EHDI procedures and protocols will be integrated into the systems’ and organizations’ practices.”*

Current Practice – During Grant Funding		Vision - Ideal Practice –After Grant Funding Ends	What would it take?	Crosses over to which other infrastructure item(s)?
<p><b>INFRASTRUCTURE TOPIC</b></p> <p><b>DATA</b> – A data system exists that accurately ascertains the disposition of every occurrent Iowa birth for each step throughout the early hearing detection and intervention process.</p>				
All hospitals with more than 50 births per year report newborn hearing screening results electronically.		<p>All hospitals/AEAs enter all data electronically and data are accurate and timely.</p> <p>Data are accessible to child’s service providers.</p> <p>Establish link between EHDI data and vital records</p> <p>Plan for software maintenance and update.</p>	<p>Finances and personnel to maintain electronic data system.</p> <p>Easy and efficient data entry.</p>	
EHDI-supported staff oversees hospital data entry and assure accuracy.		<p>Hospitals assure own accuracy and meet minimum state-set benchmarks. Quality assurance plan for all hospital screeners is used statewide.</p> <p>Funded, full-time state coordinator has authority to enforce minimum standards required of hospitals.</p>	<p>A regulation with teeth to make hospitals conform to all requirements.</p> <p>Funds for state-wide coordinator’s salary after grant ends.</p> <p>TA needed by audiologists to reduce refer rate and improve rescreening results.</p>	Professional Development. Policy/Advocacy
Screener equipment was purchased via EHDI grants and loaners are available as needed via HRSA grant personnel.		<p>Hospital equipment supports current audiologic best practice.</p> <p>Hospitals build equipment needs into their budget.</p> <p>State of the art loaner equipment bank is maintained.</p>	<p>Technical assistance provided by audiologists.</p> <p>On-going budget for loaner screening equipment bank.</p> <p>Hospitals budget annually for supplies and equipment replacement.</p>	
CDC supported staff oversee Hospital screeners and provide ongoing training as needed/requested		Hospitals administrations assure competence of own staff through yearly competency tests (written and demonstration). Best practices are shared by State	<p>Funding for state coordinator’s salary.</p> <p>Funding for technical assistance provided by</p>	Professional Development Policy/Advocacy

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	Coordinator. Site visits scheduled to review policies and procedures and review whether standards are being met at OB hospitals.	audiologists.	
EHDI audiologists input diagnostic data	All practicing pediatric/AEA audiologists enter diagnostic data accurately and expeditiously.	<p>State coordinator communicates periodically with all licensed audiologists.</p> <p>Software is expeditious and updated regularly.</p> <p>Letter sent to al licensed audiologists regarding their responsibility in EHDI system.</p> <p>Database training for all audiologists who see children ages 0-5.</p> <p>Access to database and patient files to all audiologists.</p>	Professional Development
Risk factors are not routinely entered into eSP	Hospital staff members and audiologists enter risk factors as part of required data entry. Information is included in letter from hospital and automatically sent to child’s primary care physician.	<p>Train hospital staff members regarding high risk factors.</p> <p>Software must be revised based on JCIH risk factors.</p> <p>Train NICU discharge coordinators on risk factors.</p> <p>EHDI staff member to provide above listed training.</p>	Professional Development Policy/Advocacy
EHDI data is transferred to Early ACCESS data system (IMS) manually by CDC grant-supported staff.	EHDI data automatically links with IMS data system	<p>HIPAA agreements.</p> <p>Data dump/technical assistance allowing EA and EHDI data systems to talk to each other...</p> <p>Funding (a miracle).</p> <p>EHDI data dump into hearing module of IMS.</p>	Policy/Advocacy
CDC-grant supported staff notifies Early ACCESS of children needing follow-up. HRSA project coordinator sends eSP-generated data to Iowa COMPASS who, in turn, contacts EA liaisons.	<p>eSP automatically notifies one person at each AEA via linkage of data systems.</p> <p>Care coordinators at IDPH child health contract agencies provide pre-service coordination to children needing follow-up.</p>	<p>Funding to continue providing tokens.</p> <p>Investigate whether care coordinators at IDPH child health agencies need eSP access.</p> <p>Training by state coordinator.</p> <p>AEAs develop methods to ensure hearing follow-up for ages 0-5.</p>	Policy/Advocacy
Some, but not all hospitals notify primary care physicians of screening results	<p>All Primary care physicians receive information re: failed, missed screens and/or high-risk conditions that require monitoring.</p> <p>All primary care physicians/medical homes have</p>	<p>Hospital training – notifying PCPs of results is best practice.</p> <p>Public Relations.</p>	Professional Development Policy/Advocacy

Current Practice – During Grant Funding	Vision - Ideal Practice –After Grant Funding Ends	What would it take?	Crosses over to which other infrastructure item(s)?
	access to eSP for follow-up.	Training. Tokens.	
<p>HRSA grant supported staff obtain Releases of Information and refers families to GBYS/Mentors. Family outcomes data from GBYS and Mentors is maintained separately from EA outcomes data. DE partially supports GBYS/Mentor positions</p>	<p>Releases of Information are obtained by hospital at the time of identification</p> <p>GBYS/Mentors and coordinator are paid positions from Early ACCESS and can be dispatched by DPH Service Coordinators, CHSC service coordinators, or other EA service coordinators.</p> <p>Outcomes of GBYS evaluated.</p> <p>Iowa's GBYS/Mentors continue to link with National programs.</p>	<p>GBYS paid through Medicaid Infant and Toddler program and IFSP/IEP trainers and counseling.</p> <p>Funding through state-wide mechanism.</p> <p>GBYS staff receives ongoing best-practice training.</p> <p>GBYS program is publicized.</p>	<p>Professional Development Policy/Advocacy Public Awareness</p>
<p>HRSA-grant supports Hands&amp; Voices coordinator and that coordinator organizes family activities/resources.</p>	<p>Hands &amp; Voices is self-sustaining via dues and/or community grants.</p>	<p>Link with ASK Resources.</p>	
<p>State Coordinator is supported by grants to generate EHDI reports to analyze miss/refer rates.</p>	<p>State Coordinator position is funded and not depending on grants.</p> <p>State coordinator is available to monitor miss/refer rates and to evaluate the sensitivity and specificity of the program.</p> <p>State coordinator monitors work force shortage issues.</p>	<p>Funding for state coordinator.</p> <p>Software upgrades.</p> <p>Reports generated for grant purposes.</p> <p>Quality improvement/assurance monitoring.</p>	
<p>Screening occurs in hospitals.</p>	<p>AAP promotes screening in PCP offices using CPT codes for billing.</p> <p>Change law to require PCPs to report screening results.</p>	<p>Train NHS equipment vendors regarding facilities' responsibilities for screening and reporting.</p> <p>Work with vendors to receive names of practices that have purchased NHS equipment.</p> <p>State follow-up with PCP practices that screen.</p>	

Current Practice – During Grant Funding	Vision/Ideal Practice – After Grant Funding Ends	What would it take?	Crosses over to which other infrastructure item(s)?
<p><b>INFRASTRUCTURE TOPIC:</b></p> <p><b>PROFESSIONAL DEVELOPMENT –</b></p>			
<p>CDC/HRSA grant supported staff provide training and TA to OB hospitals re:</p> <ul style="list-style-type: none"> <li>▪ Screening procedures</li> <li>▪ Entering eSP data</li> <li>▪ Appropriate Parent letters</li> <li>▪ High-Risk information and tracking</li> <li>▪ Follow-up – new brochures</li> <li>▪ Staff awareness</li> </ul>	<p>Standards and protocols exist (emphasizing best practice) and are used by all screeners/diagnostic sources.</p> <p>Web-based or DVD self-study modules exist that can be accessed by new staff or others requiring review.</p> <p>Hospitals are aware of and use mechanisms to fund screeners’ time and equipment costs (insurance/self-insured/uninsured)</p> <p>Tickler file on eSP for children with risk factors – refer on periodic basis for appropriate follow-up.</p> <p>Brochure that includes appointment information.</p> <p>Require hospitals to make appointment for follow-up before family is discharged.</p>	<p>Continued collaboration with all agencies.</p> <p>Revise software.</p> <p>Develop training packages and keep them up-to-date.</p> <p>Funding.</p>	<p>Data system</p> <p>Policy/Advocacy</p>
<p>CDC/HRSA grant supported staff provide training to EA audiologists, EA designated contact re eSP, EA liaisons MCH service coordinators, primary care physicians, parents, EPSDT providers re:</p> <ul style="list-style-type: none"> <li>▪ Importance of early identification for hearing loss</li> <li>▪ EHDI referral procedures</li> <li>▪ GBYS/Mentor Program</li> </ul>	<p>Standards and protocols exist and are used by all screeners/diagnostic sources – including private practice audiologists, primary care physicians, EPSDT care coordinators, Early ACCESS staff, Perinatal Review Team.</p> <p>Web-based or DVD self-study modules exist that can be accessed by new staff or others requiring review.</p> <p>Parents are aware of importance of early identification</p> <p>Guidelines are revised to keep abreast of new research and best practices.</p> <p>Primary care physicians can access up-to-date information re their patients easily and know what to do re: follow-up and monitoring.</p> <p>After two screens, IDPH sends letter to PCP stating that there is a developmental emergency to ensure that diagnostic assessment occurs.</p> <p>eSP would identify kids who fail the birth admission</p>	<p>Funding for audiologists to provide technical assistance.</p> <p>Public relations materials such as PSAs on TV.</p> <p>Revise Early ACCESS developmental wheels to include hearing screening 1-3-6 guidelines.</p> <p>Work with AAP Chapter Champion to adapt PCP education/notification materials for Iowa.</p> <p>Pursue relationship with PEC for GBYS.</p> <p>Investigate whether GBYS could be Medicaid provider.</p>	<p>Professional Development</p> <p>Public Awareness</p>

Current Practice – During Grant Funding	Vision/Ideal Practice – After Grant Funding Ends	What would it take?	Crosses over to which other infrastructure item(s)?
	screen and have no follow-up by six weeks as needing diagnostic assessment.		
GBYS/Mentors received training via HRSA grant funds/DE funds	GBYS/Mentors are part of national Hands & Voices system and DE funding is available as they are considered part of Early ACCESS system.		
EHDl Resources Guides are available via HRSA funds	<p>Community resources are well-known by all EA service coordinators and providers, audiologists and parents. EHDl resource guide is web-based, easily accessible, and up-to-date.</p> <p>Family Resource Guides are available in multiple languages.</p>	<p>Editorial.</p> <p>State coordinator to update resource guide.</p> <p>Funding to maintain web site.</p> <p>In kind submissions/contributions by EHDl Advisory Committee members.</p> <p>Coordinate with Medical Home grant.</p> <p>EHDl Conference.</p>	<p>Public Awareness</p> <p>Professional Development</p>

During Grant Funding – Current Practice		New Vision – Ideal Practice After Grant Funding Ends	What would it take?	Crosses over to which other Infrastructure item(s)?
<b>INFRASTRUCTURE TOPIC:</b>				
<b>PUBLIC AWARENESS</b>				
Iowa Code was written.	Iowa Code continues to be followed.  Legislators are aware of the economic impact of early identification, treatment and follow-up.	Professional development to understand responsibilities and requirements for reporting.  Identify what legislators what to know  Annual issue brief or status statement representing each different group (including challenges, requests, cost savings and early childhood outcomes.)		
HRSA/CDC grant staff surveyed parents re: knowledge and satisfaction of screening information they received at birthing hospital. Translations into several languages were provided.	All families (not just those giving birth) are aware of importance of identification and early intervention.  Consumers are aware of resources to meet their needs (both for screening and for follow-up)  Timely communication occurs with all cultures appropriately.  Consumer input is gathered periodically to assure their needs are being met at all aspects of the EHDI program.  Primary care physicians are aware of importance of early identification and early intervention.	PCPs collaborate with 1 <sup>st</sup> 5 initiative and do developmental screenings at certain timelines.  Early ACCESS Developmental Wheels include importance of hearing screening and follow-up.  Examine and infuse the information in all areas that touch children (i.e. family practices and public health).  Noise induced hearing loss.  Focus on practitioners to educate on importance of early identification. <ul style="list-style-type: none"> <li>• Focus on 2-week well-baby visit</li> <li>• Parents show PCP their NHS paperwork from hospital.</li> <li>• Hospitals send letters to physician in time for 2-week check.</li> </ul> EHDI staff member(s) to work with Iowa Chapters of AAP and AAFP.  Work with Bureau of Refugee Services and Iowa Adoptive and Foster Parent Association to reach families of children not born in Iowa.  EHDI System built with capacity for translation and qualified interpretation beyond Spanish.  GBYS – representative of the population.	Professional Development Policy/Advocacy	
Hands & Voices support is partially supported by HRSA	Hands & Voices is supported by dues and is linked to other parent support and D/HH groups in state and ASK Resource Center.	Increase membership to increase funds.  Pursue Grants/civic support to allow H&V to be all inclusive.		

During Grant Funding – Current Practice	New Vision – Ideal Practice After Grant Funding Ends	What would it take?	Crosses over to which other Infrastructure item(s)?
	Families are aware of their existence and participate.	<p>Develop a mechanism to get the message out to families (public awareness campaign).</p> <p>Staff member at the state level to be a liaison with all support group data being collected.</p> <p>H&amp;V has its own sustainability plan.</p> <p>GBYS disseminates information about H&amp;V.</p> <p>Chat room for H&amp;V.</p> <p>Strategic location of links to H&amp;V web site from other sites (i.e. ISHA, EHDI, DSCI, etc.)</p> <p>H&amp;V has local affiliates.</p>	

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<b>INFRASTRUCTURE TOPIC: POLICY AND ADVOCACY</b>			
Iowa does not have a Deaf Child Bill of	Determine if Deaf Child Bill of Rights is appropriate.  If it is appropriate, Deaf Child Bill of Rights exists in Iowa.	Legislation data and coalition of advocates.  Resource to provide information and connection to the stakeholders.  Buy-in from and coordination among broad stake holders (i.e. IAD, H&V, DSCI, etc.)  Identify and support a champion organization	
HRSA staff and Advisory Committee gathered information re: insurance coverage of hearing aids. One Iowa Legislator is working on the issue.	Hearing aids are adequately covered by insurers in Iowa (public and private)  Review whether the appropriation for hearing aids and audiological services of \$238,500 adequately meets the needs of Iowa families not covered by insurance.	Legislation.  Data.  Coalition of advocates.	
Legislators and general public need to be educated about importance of EHDI activities.	Policy statement will exist regarding EHDI accomplishments and what still needs to be done.  Economic impact of unidentified, non-treated can be articulated.  There is widespread public demand for state funded services and resources.	People able to prepare issue briefs  Data collection (state and national) and keeping up with research.  Public is strongest advocate for newborn hearing screening and follow-up.  Advocacy for federal, state and locally funded services and resources.  Widespread support to maintain effective policy.	Public Awareness  Public Awareness  Public Awareness
HRSA/CDC Staff/EHDI Advisory Committee will investigate other states' mechanisms for reimbursing screening.	State will adopt policies that reimburse for screening and rescreening, if needed. (Comment from work group: Clarify. Insurance coverage?)	Universal healthcare.  Incentives continue to exist for hospitals.	
HRSA-CDC funds support EHDI personnel and EHDI Committee. EHDI council meets once per quarter.	State funding exists for: <ul style="list-style-type: none"> <li>▪ EHDI Advisory Committee maintenance</li> <li>▪ Infrastructure activities</li> <li>▪ Database integrity</li> <li>▪ Project Coordinator(s)</li> <li>▪ Family Support</li> </ul>	State budgetary issue/ask for appropriations. Bill could come from IDPH.  Champion agency or legislator with broad stakeholder support.  Coordinate all related funding issues into one effort "one big package."	

During Grant Funding – Current Practice	New Vision – Ideal Practice After Grant Funding Ends	What Would it Take?	Crosses over to which other infrastructure item(s)?
		Get on governor's budget.	
Not all public agencies know their roles in the EHDI system. Further education is needed to form cohesive system.	All public agencies know their roles re continuity of care for infants and toddlers identified (e.g. DE, DPH, AEAs, CHSC, DHS), including at-risk patients.	(See previous page)	Public Awareness
HRSA/CDC staff drafted standards to assure that children at-risk of developing late onset or progressive hearing loss receive appropriate follow-up services.	Primary care practices, early interventionists, audiologists, families and other appropriate professionals are aware of and abide by standards.	<p>Interagency</p> <p>Data system identifies kids with high risk factors and triggers contact for 0-5 and 5-21. Monitoring risk factors driven by standard of care.</p> <p>State staff keeping up with standards and assessing what parts of the system are keeping up with standards and appropriate levels.</p>	<p>Professional Development</p> <p>Data</p>