

## WORK PLAN

WHAT WE WILL DO	WHO'S RESPONSIBLE	Yr. 1				Yr. 2				Yr.				HOW TO EVALUATE	DATA SOURCE
		Qtrs				Qtrs				Qtrs					
		1	2	3	4	1	2	3	4	1	2	3	4		
<b>Overall Goal/Aim: By March 31, 2017, the Hawaii Baby HEARS Project will use quality improvement methodology to decrease the LFU/D rate of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery from 24.6% (per the 2011 CDC annual survey) to 10%.</b>		X	X	X	X	X	X	X	X	X	X	X	X		CDC Annual Data Report
<b>AIM 1: The Hawaii EHDI Quality Improvement Team (HI- EHDIQI) will be established and will function throughout the grant period.</b>	NHSP Coordinator Project Coordinator	X	X	X	X	X	X	X	X	X	X	X	X		
<b>Strategy 1.1</b> By April 30, 2014, the HI-EHDIQI team will be established.	NHSP Coordinator Project Coordinator	X	X											1. ≥10 volunteers for the team. 2. Team reviews DOH policies & NHSP's statutory authority to collect screening data. 3. Team recommends policies & statutory language.	1.Mtg minutes  2.Mtg minutes; report  3.Report
<b>Strategy 1.2</b> By May 30, 2014, the HI-EHDIQI team will have its first meeting.	NHSP Coordinator Project Coordinator	X	X												

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1.2.1 At the first team meeting, the team will be identified, team members will discuss their roles and commitments, and the meeting schedule and the modes of communication will be determined	NHSP Coordinator Project Coordinator HI-EHDIQI Team	X	X											1. Identify roles & commitments. 2. Mtg schedule through 2017 complete 2 weeks after mtg. 3. Most members attend mtgs. 4. Most of team satisfied with participation.	1.mtg minutes  2.completed schedule  3.sign-in sheets  4.surveys
1.2.2 If needed, training on the Model of Improvement will be arranged for team members	NHSP Coordinator Project Coordinator	X	X											1. # members who need training ID'd. 2. NHSP arranges training by 6/30/14 3. # trained by 7/31/14 vs # who needed training.	1. mtg minutes  2.training schedule  3.training completion notices
<b>Strategy 1.3</b> By August 30, 2014, the HI-EHDIQI team will approve the quality improvement work plan, including strategies that will be implemented using the Model of Improvement.	HI-EHDIQI Team			X	X	X	X	X	X	X	X	X	X		
1.3.1 Team members will review the work plan, prioritize the change strategies, and approve the PDSA test cycles by August 31, 2014. The work plan will be reviewed annually.		X	X											1. Majority review plan & comment by 7/31/14. 2.Change strategies prioritized & approved by 8/15/14. 3. PDSA test cycles approved by	1.written comments  2.approved plan  3.approved PDSA

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														8/31/14.	test cycles
1.3.2 The HI-EHDIQI team will establish work groups that align with the different strategic areas.	HI-EHDIQI Team	X	X											1.Consensus about # work groups & charges. 2.Work group timelines and activities ID'd.	1. mtg minutes  2.mtg minutes; work group mtg. timelines
<b>AIM 2: Decrease the proportion of children who are LFU/D for screening from 1.4% of births (2011 data) to 1.0% of births.</b>	NHSP Coordinator Project Coordinator Hospital NHS Coordinators/Screeners	X	X	X	X	X	X	X	X	X	X	X	X		CDC Annual Data Report
<b>Strategy 2.1</b> Improve the screening rate of home births by at least 10% each year (in 2011, less than 15% of homebirths received newborn hearing screening)	Project Coordinator Hospital NHS Coordinators/Screeners	X	X	X	X	X	X	X	X	X	X	X	X		
2.1.1 The NHSP will develop talking points for midwives to use when discussing newborn hearing screening with parents. <i>PDSA Cycles: -The NHSP will: - test talking point training on two Maui midwives with low rates of infants receiving hearing screening, - modify the talking points based on feedback after six months, - spread training to other midwives on Maui - implement the talking points training statewide</i>	NHSP Coordinator Project Coordinator	X	X	X	X									1. Survey midwives post-training. 2. # of home births screened pre- vs post- training. 3. % midwives receiving training. 4. State level pre- vs post-training screening rates.	1.survey data  2.HI*TRACK 3.training logs 4. HI*TRACK
			X												
				X	X										
						X	X	X	X						
										X	X	X	X		

<p>2.1.2 NHSP staff members will contact parents of children born at home to schedule screening appointments.</p> <p><i>PDSA Cycles:</i>  - NHSP staff will ID home births from one community on the Big Island who have not completed screening.  - contact parents by telephone within 2 months of child's birth to schedule appointments.  - implement in subsequent Big Island communities for at least 12 months  - implement refined intervention state-wide</p>	Project Coordinator Social Services Assistant		X	X	X	X	X	X	X	X	X	X	1. % of parents successfully contacted 2. % home births screened pre-versus post- parent contact intervention. 3. Once expanded, state level pre- vs post-intervention rates.	1. phone log 2. HI*TRACK 3.HI*TRACK
<b>Strategy 2.2</b> Decrease the LFU/D of hospital births at outpatient screening by10% each year	NHS Screener/Project Coordinator	X	X	X	X	X	X	X	X	X	X	X		
2.2.1 The NHSP will develop quality assurance guidelines to support the hospital screening programs and reduce the need for outpatient screening, including: <ul style="list-style-type: none"> <li>◦ Screeners training</li> <li>◦ Screeners' talking points to discuss referrals</li> <li>◦ Screeners' competency checklist</li> <li>◦ Screening report card to the hospitals</li> </ul> <p><i>PDSA Cycles:</i>  -Develop screeners' talking points. Test the talking points on one hospital with high LFU/D rates for outpatient screening. Each screener will test the talking points on three referrals.  - Modify talking points and spread to other hospitals on the same island  -Implement talking points statewide.</p>	NHSP Coordinator Project Coordinator Hospital NHS Coordinators			X	X	X	X	X	X	X	X	X	1. Guidelines approved within timeline. 2. # hospitals with guidelines 3. Rate of screeners completed training within 1 month of assignment. 4. % report cards accessed within 1 week 5. % infants referred for outpatient screening pre- vs post-intervention. 6. Statewide pre- vs post-intervention screening rates.	1.approved, dated guidelines 2.telephone survey data 3. telephone survey data 4. HI*TRACK 5.HI*TRACK 6.HI*TRACK

<p>2.2.2 Improve communication with parents.</p> <p>Two brochures will be revised, printed and distributed to new parents.</p> <p>Brochures will be translated into other languages, as needed.</p> <p>Surveys of hospital coordinators will determine rates of brochure inclusion in new parent packets.</p> <p>The AAP Champion will develop a plan to assess the number of parents receiving brochure 2, via PCP surveys/interviews.</p>		<p>X X X X X X X X X X X X X X</p> <p>X X X</p> <p>X X X</p> <p>X X X</p> <p>X X X</p> <p>X X X X X X</p>	<p>1. Brochures approved, &amp; printed by 4/30/14.</p> <p>2. Need for translations ID'd by 7/31/14.</p> <p>3. # brochures delivered and requested.</p> <p>4. % hospitals putting brochure 1 in parent packet</p> <p>5. % parents who get brochure 2</p>	<p>1. printing order and receipt of brochures</p> <p>2. translation requests log</p> <p>3. request log</p> <p>4. hospital phone survey data</p> <p>5. PCP survey data</p>
<p><b>AIM 3: Decrease the proportion of children who are LFU/D for evaluation from 24.6% (2011 data) to 10%.</b></p>	<p>NHSP staff</p>	<p>X X X X X X X X X X X X X X</p>		<p>CDC Annual Data Report</p>
<p><b>Strategy 3.1</b> Increase the percentage of babies who complete an audiologic evaluation within one month of their referral being received by the NHSP from 50% (2012 data) to 80%.</p>	<p>Social Service Assistant NHSP staff</p>	<p>X X X X X X X X X X X X X X</p>		
<p>3.1.1 Before hospital discharge, screeners will obtain secondary contact information from parents whose children do not pass newborn hearing screening.</p> <p><i>PDSA cycles:</i></p> <ul style="list-style-type: none"> <li>- Two hospitals with low rates of obtaining secondary contact information will be selected to participate in the pilot study.</li> <li>- Use test cycles to find out the most effective way to obtain secondary contact information (e.g., screeners asked to get secondary contact info at time of inpatient referral).</li> <li>- Intervention spread to at least one hospital on each island.</li> <li>- The test will be implemented statewide.</li> </ul>	<p>Project Coordinator Hospital NHS coordinators/Screeners</p>	<p>X X X X X X X X X X X X X X</p> <p>X X</p> <p>X X X X</p> <p>X X X X</p> <p>X X X X X X X X</p>	<p>1. % infants with secondary contact info in HI*TRACK pre- versus post-intervention.</p> <p>2. Statewide pre- vs post-intervention rates.</p> <p>3. ID screeners' assessment of the pilot study.</p>	<p>1. HI*TRACK</p> <p>2. HI*TRACK</p> <p>3. survey data</p>
<p>3.1.2 NHSP staff will contact the PCP of children who are</p>	<p>Social Service Assistant</p>	<p>X X X X X X X X X X X X X X</p>	<p>1. # of calls and</p>	<p>1. call/letter log</p>

LFU/D for audiologic evaluation and for whom the NHSP receives a referral; the NHSP will follow-up on the referral.	NHSP staff							letters to PCPs. 2. # infants with audiologic eval pre- vs post-intervention. 3. # assistance calls and PCP trainings.	2. HI*TRACK  3.tech assistance log; training log	
3.1.3 The NHSP will pilot teleaudiology between Oahu and the neighbor islands. <i>PDSA cycles:</i> - The NHSP will assess the availability of resources at pilot site(s) by surveying neighbor island hospital and/or IT staff. - A neighbor island will be chosen to pilot teleaudiology on 2 infants. Family and audiologist will be surveyed post-appointment to determine satisfaction with the service - Pilot on 2 more infants at same site. - Analyze results prior to strategy revision and expansion of teleaudiology to other sites.	Genomics Section Supervisor NHSP Coordinator Project Coordinator	X	X	X				1. Assess resources at pilot site(s).  2. Pre- vs post-intervention cost assessments. 3. Reliability of teleaudiology ABR 4. plan for expanding teleaudiology to other sites	1. Resource log; needs assessment report; survey data 2. online airfares; survey data.  3. survey data 4. survey data; report; resource log	
<b>Strategy 3.2</b> The NHSP will identify children with permanent hearing loss within two months of the hearing loss being confirmed.	Project Coordinator Audiology Consultant Social Services Assistant	X	X	X	X	X	X	X		
3.2.1 Contracted audiologists will submit diagnostic reports to the NHSP within two weeks of the diagnostic evaluation being performed.	Social Service Assistant NHSP staff	X	X	X	X	X	X	X	1. # missing diagnostic reports 2. # calls to audiologists for missing reports. 3. # reports from audiologists pre- vs post-intervention.	1. HI*TRACK  2. telephone log  3. HI*TRACK
3.2.2 The NHSP staff will identify and request reports for infants who may be lost to documentation but have been followed-up by the audiology department of a birthing hospital. <i>PDSA Cycles:</i>	Project Coordinator	X	X	X	X	X	X	X	1. Mtg between military hospital and CSHNB Administrator. 2. # diagnostic	1. mtg schedule, minutes  2. HI*TRACK

<ul style="list-style-type: none"> <li>- NHSP staff will identify babies born at the military hospital who did not pass screening.</li> <li>- 3 babies' names will be given to hospital personnel.</li> <li>- The hospital will provide copies of the diagnostic reports to the NHSP or enter the results in HI*TRACK.</li> <li>- NHSP staff will send another batch of 3 babies' names to request reports from the same hospital</li> </ul>		<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td> </tr> <tr> <td></td><td></td><td></td><td></td><td>X</td><td>X</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td></td><td></td><td></td><td></td><td>X</td><td>X</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td></td><td></td><td></td><td></td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td> </tr> </table>	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X					X	X															X	X															X	X	X	X	X	X	X	X	X	X	X	X	reports provided pre-vs post-mtg. 3. # military hospital infants identified with hearing loss pre-vs post-mtg.	3. HI*TRACK																																
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<b>AIM 4: Decrease the proportion of children who are LFU/D for intervention services from 11.5% (2011 data) to 9.9%.</b>	NHSP Staff	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td> </tr> </table>	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X		CDC Annual Data Report																																																																																
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<b>Strategy 4.1</b> Develop a Memorandum of Agreement with EI Section (EIS)	Genomics Section Supervisor EI Supervisor	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td><td style="width: 10%;"></td> </tr> </table>					X	X	X	X									1. Signed MOA for NHSP and EIS. 2. Compliance with MOA by 3/31/2017	1. signed MOA 2. HI*TRACK																																																																																
				X	X	X	X																																																																																													
<b>Strategy 4.2</b> The NHSP will collaborate with audiologists and PCPs to ensure children are referred to EI as soon as a permanent hearing loss is identified.  <i>PDSA Cycles:</i> <ul style="list-style-type: none"> <li>-The NHSP will conduct a pilot study with one audiologist and two families.</li> <li>-The test will be spread to five more families with the same audiologist once results are analyzed and the strategy is refined.</li> <li>-The test will be spread to other audiologists.</li> <li>-Similar test will be piloted with one PCP and two families, and then spread to five families.</li> <li>-The test will be spread to two more PCPs and more families.</li> </ul>	NHSP Coordinator Project Coordinator	<table border="1" style="width: 100%; border-collapse: collapse;"> <tr> <td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td><td style="width: 10%;">X</td> </tr> <tr> <td></td><td></td><td></td><td></td><td>X</td><td>X</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td></td><td></td><td></td><td></td><td>X</td><td>X</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td></td><td></td><td></td><td></td><td>X</td><td>X</td><td>X</td><td>X</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td></td><td></td><td></td><td></td><td>X</td><td>X</td><td>X</td><td>X</td><td></td><td></td><td></td><td></td><td></td><td></td><td></td><td></td> </tr> <tr> <td></td><td></td><td></td><td></td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td><td>X</td> </tr> </table>	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X					X	X															X	X															X	X	X	X													X	X	X	X													X	X	X	X	X	X	X	X	X	X	X	X	1. # referral forms from audiologists or PCPs pre- vs post-intervention. 2. Statewide rates of referral forms from audiologists or PCPs pre- vs post-intervention. 3. # infants in EI < 6 months old pre- vs post-intervention. 4. Statewide pre- vs post-intervention rates.	1. referral form log 2. referral form log 3. HI*TRACK 4. HI*TRACK
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<p><b>Strategy 4.3</b> By March 31, 2015, establish written procedures with EIS to share information with the NHSP regarding children with hearing loss who are enrolled in EI.</p>	<p>NHSP Coordinator EIS Supervisor</p>		<p>X X X X</p>	<p>X X X X</p>	<p>1. Development &amp; approval of info-sharing policies between EIS and NHSP. 2. % children with HL ID'd from EI database pre- vs post-policy. 3. % children with HL enrolled in EI programs pre- vs post-policy.</p>	<p>1. approved policies  2. HI*TRACK, EI database  3. HI*TRACK, EI database</p>
<p><b>Strategy 4.4</b> Starting April 2014 and ongoing, improve EI program staff awareness of hearing loss and the NHSP.</p>	<p>NHSP Coordinator Project Coordinator</p>	<p>X X X X</p>	<p>X X X X</p>	<p>X X X X</p>	<p>1. # emails or newsletters sent to EI programs 2. # requests for or feedback on newsletters</p>	<p>1.log of emails/newsletters  2.request/feedback log</p>
<p><b>Strategy 4.5</b> Collaborate with Early Head Start Programs and Home Visiting Programs to identify children who are LFU/D or who may have developed late onset hearing loss.</p>	<p>NHSP Coordinator Project Coordinator</p>	<p>X X X X</p>	<p>X X X X</p>	<p>X X X X</p>	<p>1. # parent consents via EHS 2. # EHS requests screening results 3. # EHS requests for tech assistance  4. # children ID'd with HL via EHS 5. # times equipment loaned to PAT 6. # PAT requests for tech assistance 7. # PAT requests screening results</p>	<p>1.EHS parent consent log 2.EHS results request log 3.EHS tech assistance request log 4.children ID'd via EHS log 5.PAT equipment loan log 6.PAT tech assist. requests log 7.Pat screening result request log</p>



										8. # children ID'd with HL via PAT	8. children ID'd via PAT log	
<b>AIM 5: Increase the knowledge of primary care physicians in meeting the needs of infants with permanent hearing loss.</b>	AAP Champion NHSP Coordinator	X	X	X	X	X	X	X	X	X		
<b>Strategy 5.1</b> Collaborate with the AAP Chapter Champion to conduct a physician survey to identify training needs regarding hearing loss.	NHSP Coordinator AAP Champion			X	X	X	X	X			1. Physician survey approved by HI-EHDIQI team 12/31/2014. 2. # of physicians desiring HL education, knowledge gaps, ongoing education preferences.	1. approved survey  2. physician survey data
<b>Strategy 5.2</b> A training plan will be developed and implemented.	NHSP Coordinator AAP Champion Project Coordinator					X	X	X	X	X	1. Training plan approved 3/31/15 2. # physicians completing training 3. satisfaction 4. knowledge gain.	1. approved plan 2. sign-in sheets; training schedule 3. physician survey 4. physician survey
<b>Strategy 5.3</b> Increase the awareness of, availability of, and access to physician resources.	Advisory Committee Work Groups	X	X	X	X	X	X				1. Practitioner's Manual approved by 12/31/2014 2. # requests for manuals. 3. satisfaction, knowledge gain, and more education	1. approved manual  2. manual request log 3. pre- and post-manual survey data
<b>Strategy 5.4</b> Collaborate with the AAP Chapter Champion to share updated EHDI information with the PCP via newsletter or emails.	AAP Champion Project Coordinator	X	X	X	X	X	X	X	X	X	1. # info shares. 2. # PCP requests for information. 3. # of hits on NHSP website.	1. PCP share log 2. PCP info request log 3. website analytics

## RESOLUTION OF CHALLENGES

Challenges in designing and implementing Work Plan activities	Approach to Address Challenges
Insufficient staffing across the state Department of Health delays the process of obtaining approval to implement activities.	<ul style="list-style-type: none"> <li>▪ Anticipate delays and plan in-advance when submitting paper work that requires approval within the department or within the state system.</li> </ul>
The NHSP is not fully staffed. The state-funded Office Assistant resigned in 10/13; the position is vacant. Approval to hire the Parent Support/Follow-up Coordinator and Project Specialist is pending (submitted to HR in 2013)	<ul style="list-style-type: none"> <li>▪ Increase NHSP staff knowledge of the procurement and personnel process</li> <li>▪ Prepare recruitment and orientation plan while waiting for approval to hire</li> <li>▪ Request an emergency hire to assist with administrative work until the Office Assistant position is filled.</li> </ul>
The military hospital provides screening results but does not report follow-up evaluation, hearing disposition, or intervention information.	<ul style="list-style-type: none"> <li>▪ The DOH Administrator will meet the Hospital Administrator to discuss the barriers and negotiate solutions.</li> <li>▪ The NHSP will develop guidelines for reporting of screening and evaluation results.</li> </ul>
A shortage of pediatric audiologists on neighbor islands continues to be a challenge. Infants must fly to Oahu for diagnostic ABR, which may delay the process of early identification of hearing loss.	<ul style="list-style-type: none"> <li>▪ The NHSP is developing an agreement with an audiologist to evaluate babies on Maui. The audiologist needs training to perform diagnostic ABR.</li> <li>▪ The NHSP will collaborate with the audiology department of the Children’s Hospital on Oahu to pilot teleaudiology.</li> </ul>
Increased time needed to analyze NHSP data due to reporting by one hospital of only summary data.	<ul style="list-style-type: none"> <li>▪ The NHSP Coordinator will establish administrative rules that include the requirement for the reporting of individual data from birthing facilities.</li> </ul>
EI staff shortage. Matching EI and HI*TRACK databases is not done. Matching could help identify children getting EI who are LFU/D or those with late-onset hearing loss.	<ul style="list-style-type: none"> <li>▪ Remind EI data entry staff to enter parent consent to share information and the hearing disposition (ICD-9 code) in the EI database correctly.</li> <li>▪ Develop MOA with the EI Section to specify policy on sharing of family information with the NHSP.</li> </ul>
While the NHSP has established contracts with four community providers to screen home births, greater efforts are necessary to reach out to other home birth populations.	<ul style="list-style-type: none"> <li>▪ Outreach to midwives, provide information about community screening resources.</li> <li>▪ Outreach to pediatricians and PCPs, including discussions about hearing screening referral protocols for home births.</li> </ul>

### Sustainability

The approach to sustainability is based on the incorporation of best practice into policy/procedures, and increased knowledge and improved practices of state and community providers. Currently in place or planned:

- Three NHSP positions (Coordinator, Social Services Assistant, and Office Assistant) are permanent state-funded positions. These positions will continue program activities to assure statewide newborn hearing screening and follow-up, after the federal grant ends.
- Paper work has been submitted to request conversion of the Baby HEARS Project Coordinator from exempt to civil service position. This will result in a greater chance that the position will be supported by the state general fund when federal funding is not available.
- The CSHNB will continue to support the NHSP. The Title V/CSHCN Director fully supports improving newborn screening and will continue to work with the NHSP in efforts toward reducing LFU/D. The CSHNB Research Statistician will continue to support the NHSP in data analysis.
- Hawaii law mandates newborn hearing screening and requires birthing facilities to report screening results to the DOH. Administrative rules with detailed requirements for screening and follow-up are in the process of being established, as are program policies. The NHSP is working with hospitals to develop organizational hearing screening policies that reflect the NHSP policies.
- All birthing facilities are providing newborn hearing screening and have the capability to do two-stage screening.
- A web-based HI\*TRACK data system is in place for sharing of information between hospitals and the NHSP.

## **EVALUATION AND TECHNICAL SUPPORT CAPACITY**

### **Staffing**

Evaluation is a major and important component of all activities so the staffing plan includes a 0.2 FTE dedicated evaluation consultant, Jacquie Stock, MPH. For nine years, Ms. Stock has worked with the Hawaii DOH Genomics Section as the outside evaluator for the HRSA funded Western States Genetic Services Collaborative (WSGSC). The WSGSC works to improve access and education about newborn screening and genetic services in Alaska, California, Guam, Hawaii, Idaho, Oregon, and Washington. Ms. Stock is a Senior Research Associate at Seattle Children's Center for Children with Special Needs. She has seventeen years of experience designing and managing program evaluations and research projects for public health agencies and private health organizations. Between 1999 and 2011, through a Seattle Children's contract with the Washington State DOH Children with Special Health Care Needs (CSHCN) Program, Ms. Stock developed and implemented numerous projects and evaluations to improve systems of care for Washington State CSHCN and families. Example projects include a statewide medical home strategic planning process, measuring outcomes of public health nursing, a CSHCN data portrait, online emergency preparedness guide, and numerous others. Ms. Stock has participated in research projects to evaluate consent processes in whole genome sequencing research and methods for sharing whole genome sequencing results with research participants.

As an outside evaluator, Ms. Stock will provide oversight for evaluation activities to maintain quality collection of data, suggest changes to evaluation activities if needed, and provide unbiased data analysis.

Additional Baby HEARS Project team members who will assist in evaluation and technical support include:

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<b>Staff</b>	<b>Experience, Skills, Knowledge</b>
Po Kwan Wong, MPH Newborn Hearing Screening Program Coordinator	<ul style="list-style-type: none"> <li>▪ NHSP Coordinator since October 2008</li> <li>▪ Experience in planning and program development related to public health, early childhood programs, and social-emotional development of young children</li> <li>▪ Experience working with families in multi-cultural, low-income settings</li> <li>▪ Leader of the Hawaii Team for NICHQ Learning Collaborative B</li> <li>▪ Responsible for the performance measure on newborn hearing screening in the yearly Title V application/annual report. This has been a Title V measure since 2000.</li> </ul>
Jasmine Jones BS Baby HEARS Coordinator	<ul style="list-style-type: none"> <li>▪ Project Coordinator since January 2009</li> <li>▪ Knowledge of Speech Pathology and Audiology (B.S.)</li> <li>▪ Manages the HI*TRACK database system</li> <li>▪ Member of the Hawaii Team for NICHQ Learning Collaborative B</li> </ul>
Sylvia Mann, MS, CGC Genomics Section Supervisor	<ul style="list-style-type: none"> <li>▪ Supervisor, Genomics Section/Hawaii State Genetics Coordinator</li> <li>▪ More than 20 years experience being a Principal Investigator on federal grants</li> <li>▪ More than 20 years experience working with and supervising state genetics, newborn screening, and birth defects programs</li> </ul>
Kirsty McWalter, MS, CGC Project Specialist	<ul style="list-style-type: none"> <li>▪ Project specialist with the Hawaii Genetics Program since 2003.</li> <li>▪ Experience in overseeing research activities including Institutional Review Board issues and evaluation</li> <li>▪ Experience in developing publications for lay audiences and peer reviewed publications.</li> </ul>
Lloyd Miyashiro, BS CSHNB Research Statistician	<ul style="list-style-type: none"> <li>▪ Background in planning, designing, implementing, and managing statistical information systems since 1990</li> <li>▪ Analysis of NHSP data for state/federal reports since 2000</li> <li>▪ Designed/implemented monthly data linkage procedures for use in joint quality assurance activities of the Newborn Hearing and Metabolic Screening Programs</li> <li>▪ Member of the Hawaii Team for NICHQ Learning Collaborative B</li> </ul>
Amelia Enright, MA, CCC-A NHSP Audiologist Consultant	<ul style="list-style-type: none"> <li>▪ Part-time NHSP Audiology Consultant contracted since 2006</li> <li>▪ Hospital newborn hearing screening coordinator since 1994</li> <li>▪ Audiologist serving newborns through adults since 1994</li> <li>▪ Member of the Hawaii Team for the NICHQ Learning Collaborative B and the EHDI Advisory Committee</li> </ul>
Lynn Iwamoto, MD AAP-Hawaii Chapter EHDI Champion	<ul style="list-style-type: none"> <li>▪ EHDI Champion since 2003.</li> <li>▪ Knowledge of the system of health services for newborn hearing screening and follow-up.</li> <li>▪ Experience in providing and arranging continuing medical education sessions for physicians and other health care providers related to newborn hearing screening/follow-up.</li> <li>▪ Medical knowledge regarding hearing loss.</li> </ul>

<b>Staff</b>	<b>Experience, Skills, Knowledge</b>
	<ul style="list-style-type: none"> <li>▪ Member of the Hawaii Team for the NICHQ Learning Collaborative B and the EHDI Advisory Committee.</li> </ul>
Patricia Heu, MD, MPH Chief, CSHNB	<ul style="list-style-type: none"> <li>▪ Experience in planning and developing new processes and programs</li> <li>▪ Experience and general knowledge of the NHSP</li> <li>▪ Member of the Hawaii Team for NICHQ Learning Collaborative B</li> <li>▪ Reports have included the Title V needs assessment and performance measures for children with special health care needs (CSHCN), CSHNB surveys, and CSHCN data reports</li> </ul>
HI-EHDIQI Team	<ul style="list-style-type: none"> <li>▪ Decades of cumulative experience with health care, education, public health, program development, grant advisory committees</li> <li>▪ The NHSP Coordinator is the lead member. Other members include, but are not limited to, AAP Chapter Champion, research statistician, grant PI, EI Supervisor or designated staff, parent representative from the Hands &amp; Voices Hawaii Chapter, state audiologist, audiologist from private practice, and Project Coordinator.</li> </ul>

### Evaluation Methods

Evaluation methods used to assess program outcomes and effectiveness/efficiency of the project in attaining goals and objectives:

- The NHSP Coordinator and Baby HEARS Project Coordinator will document the processes and timelines of accomplishing activities according to the Work Plan. Challenges or reasons for not accomplishing activities or not meeting due dates will be identified and documented.
- The EHDI Advisory Committee will assess program performance by reviewing LFU/D data and 1-3-6 data, trends, program or pilot strategies, and progress in implementing activities.
- The NHSP will obtain information/reports from hospital newborn screening coordinators, midwives, audiologists, Part C care coordinators, etc., on issues related to LFU/D.
- The Project Coordinator and Research Statistician will analyze NHSP data and determine LFU/D rates for screening, audiologic evaluations, and intervention services. Data will be provided annually on screening, audiologic evaluations, or intervention services by timing of services to meet the EHDI 1-3-6 timeline. The NHSP will use this data to track progress. The following measures will be monitored:

<b>Measure</b>	<b>Numerator</b>	<b>Denominator</b>
<b>Screening LFU/D</b>	# of infants not receiving screening (total and by hospital or home births) excludes deceased and parental refusals. <i>Source: HI*TRACK database</i>	# of births <i>Source: HI*TRACK database</i>
<b>Audiologic Evaluation LFU/D</b>	# of infants who did not pass hearing screening and did not receive diagnostic audiologic evaluation, excludes parental refusals or families moved out of state <i>Source: HI*TRACK database</i>	# of infants who did not pass hearing screening <i>Source: HI*TRACK database</i>
<b>Early</b>	# infants with permanent hearing loss who	# infants with permanent hearing

<b>Intervention LFU/D</b>	are not enrolled in EI services, excludes parental refusals or families moved out of state  <i>Source: HI*TRACK database. Data on children receiving EI is from NHSP referrals of children with permanent hearing loss to EI, or from the EI database.</i>	loss  <i>Source: HI*TRACK database (or NHSP files) which has data from audiologist records or EI Care Coordinator reports</i>
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- The NHSP and HI-EHDIQI team will use the National Initiative for Children’s Healthcare Quality (NICHQ) Model for Improvement with PDSA cycles for the following interventions:

<b>Intervention</b>	<b>Quantitative Measure (preliminary)</b>
develop talking points for midwives to use when discussing newborn hearing screening with parents	<ol style="list-style-type: none"> <li>1. Post-training survey/interview data from midwives who participate in talking points training.</li> <li>2. The number of home births who receive newborn hearing screening following midwife talking points training, compared to the number of home births who received newborn hearing screening prior to midwife talking points training (for the midwives in the initial test region).</li> <li>3. Once the intervention is refined and expanded beyond the initial test site, the percentage of midwives who receive talking points training will be determined.</li> <li>4. Once the intervention is refined and expanded beyond the initial test site, pre- and post-intervention screening rates for home births will be compared at the state level.</li> </ol>
contact parents of children born at home to schedule screening appointments	<ol style="list-style-type: none"> <li>1. The percentage of parents of children born at home and needing hearing screening with whom the NHSP are able to successfully make contact.</li> <li>2. The percentage of home births who receive newborn hearing screening following parent-contact intervention, compared to the percentage of home births who received newborn hearing screening prior to parent-contact intervention (in the initial test region).</li> <li>3. Once the intervention is refined and expanded beyond the initial test site, pre- and post-intervention screening rates for home births will be compared at the state level.</li> </ol>
develop quality assurance guidelines, including screeners’ talking points, to support the hospital screening programs and reduce the need for outpatient screening	<ol style="list-style-type: none"> <li>1. Guidelines are developed, revised, and approved within the work group’s identified timeline.</li> <li>2. Proportion of hospitals that have up-to-date hearing screening guidelines that include the four identified items (listed in methodology).</li> <li>3. Proportion of screeners (by hospital and overall) who complete the NCHAM online training curriculum within one month of assignment to screening role.</li> <li>4. Percentage of screening report cards that are accessed by an authorized user within one week of dissemination.</li> <li>5. Percentage of infants completing outpatient screening post-intervention, compared to the percentage of infants completing outpatient screening</li> </ol>

	<p>pre-intervention.</p> <p>6. Once the intervention is refined and expanded beyond the initial test site, pre- and post-intervention outpatient screening rates will be compared at the state level.</p>
obtain second contact information from parents before hospital discharge	<p>1. The percentage of infants with secondary contact information entered into HI*TRACK post-intervention will be compared to the percentage of infants with secondary contact information entered into HI*TRACK pre-intervention at each institution.</p> <p>2. Once the intervention is refined and expanded beyond the initial test site, the rates of secondary contact information entered into HI*TRACK pre- and post-intervention will be compared at the state level.</p> <p>3. Survey data will identify each hospital coordinator's assessment of the pilot study (i.e., ease of collecting secondary contact information, most effective strategies to obtain secondary contact information, amount of time/minutes to collect and enter secondary contact information)</p>
pilot teleaudiology between Oahu and the neighbor islands	<p>1. The available resources at the pilot site(s) will be logged to create a needs assessment report.</p> <p>2. The cost of pre-intervention assessment (travel to Oahu for an ABR) will be compared to the cost of post-intervention assessment (ABR by teleaudiology).</p> <p>3. The reliability of the ABR results obtained by teleaudiology will be compared to reliability of an in-person ABR.</p> <p>4. The feasibility of expanding teleaudiology sites will be determined based upon family and audiologist satisfaction with the pilot study (generated by surveys) and knowledge of the neighbor island resources (generated through needs assessment).</p>
identify and request reports for infants who may be lost to documentation but have been followed-up by the audiology department of a birthing hospital	<p>1. Meeting between the military hospital representative and CSHNB Administrator is scheduled and completed.</p> <p>2. The percentage of diagnostic reports provided to the NHSP (either by copy or entry into HI*TRACK) pre-meeting, as compared to the percentage of diagnostic reports provided to the NHSP post-meeting.</p> <p>3. The percentage of military hospital infants identified with permanent hearing loss pre-meeting, as compared to the percentage of military hospital infants identified with permanent hearing loss post-meeting.</p>
collaborate with audiologists and PCPs to ensure children are referred to EI as soon as a permanent hearing loss is identified	<p>1. The number of referral forms received from audiologists pre-intervention, as compared to the number of referral forms received from audiologists post-intervention (after three PDSA cycles).</p> <p>2. Once the intervention is refined and expanded beyond the initial test site, the rates of referral forms received from audiologists pre- and post-intervention will be compared at the state level.</p> <p>3. The percentage of infants enrolled in EI before age six months pre-intervention, as compared to the number of infants enrolled in EI before age six months post-intervention (at least three PDSA cycles).</p> <p>4. Once the intervention is refined and expanded beyond the initial test site, the rates of infants enrolled in EI before age six months pre- and post-intervention will be compared at the state level.</p>

## ORGANIZATION INFORMATION

### Applicant Agency Experience and Capacity

The DOH organization chart is in Appendix 10. The Baby HEARS-Hawaii Follow-Up Project is within the state NHSP, which is under the CSHNB's Genomics Section.

CSHNB is one branch in the Family Health Services Division (FHSD) of the Hawaii State DOH. The other two branches are the Maternal and Child Health Branch (MCHB) and the Women Infants and Children Services (WIC) Branch. FHSD is the state agency responsible for the state Title V Maternal and Child Health Block Grant. The CSHNB Chief is the Title V CSHCN Director.

The mission of the FHSD is: *“To improve the health of women, infants, children, and adolescents and other vulnerable populations and their families, by: increasing public awareness and professional education about the importance of a life course perspective; advocating for systemic change that addresses health equity and the social determinants of health; and assuring a system of health care that is family/patient centered, community based.”*

FHSD goals include:

- \* All infants, children, and adolescents, including those with special health care needs, will receive appropriate services to optimize health, growth and development; and
- \* Access to quality health care shall be assured through the development of a comprehensive, coordinated community-based, patient/family-centered, culturally competent system of care.

Within the CSHNB, there are three sections, the Children with Special Health Needs Section, the Early Intervention Section, and the new Genomics Section. The NHSP is one of four programs in the Genomics Section. The other three programs are the Newborn Metabolic Screening Program, the Birth Defects Program, and the Genetics Program. The NHSP works towards appropriate and timely screening, diagnostic audiological evaluation, and referral for EI services. It sets standards and guidelines; provides education to health professionals, EI providers and the general public; facilitates ongoing activities of the hearing screening system; provides training and technical assistance; and provides assistance with follow-up for rescreening, evaluation, and/or referral to EI services. The NHSP has three state-funded staff – Program Coordinator, Social Services Assistant, and Office Assistant.

### Personnel Resources

CSHNB programs/staff pertinent to newborn hearing screening:

- **CSHNB Chief:** provides general oversight of the Genomics Section. Assists with grant applications, progress reports, data review, and other areas. The CSHNB works with Family Voices of Hawaii, AAP-Hawaii Chapter, and University of Hawaii/ Department of Pediatrics on efforts toward the six national goals for the CSHCN (family partnerships, screening, medical home, adequate insurance, community-based systems, and transition to adult life).
- **Genomics Section Supervisor:** provides direct oversight of the NHSP, including

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assisting with grant applications and progress reports, managing personnel, providing technical support for various NHSP activities, and assisting with policy and program development.

- **Administrative Services Unit:** provides fiscal support including accounting, reports on grant fiscal status, and oversight to ensure that appropriate fiscal procedures are followed.
- **Research Statistician:** assists in analysis of NHSP data and linking of the NHSP and NBMSPP databases, WIC, and birth records. The Research Statistician works with the NHSP Coordinator to analyze the NHSP database and provide reports as needed.
- **Newborn Metabolic Screening Program (NBMSPP):** assures that infants born in Hawaii are satisfactorily screened for 32 disorders which may have serious consequences, such as intellectual disability or death, if not identified and treated early. The NBMSPP and the NHSP work together on education for midwives on the importance of newborn screening.
- **Early Intervention Section (EIS):** responsible for statewide EI services for children age 0-3 years with developmental delays or biological risk, including hearing loss (assistive technology, audiology, family training, counseling, home visiting, health, medical diagnostic/evaluation, nursing, occupational therapy, physical therapy, psychological, social work, special instruction, speech language pathology, and transportation).
- **Children with Special Health Needs Program (CSHNP):** provides information and referral, outreach, care coordination, social work, and nutrition services for CSHCN age 0-21 years. Financial assistance for medical services is offered to eligible children without other resources. The CSHNP Audiologist works with the NHSP as needed.
- **Genetics Program:** plans, develops, and implements statewide genetics activities; develops activities to promote the prevention, detection, and treatment of genetic disorders; and provides genetics education for the professional and general community. The Genetics Program has actively worked with the NHSP related to genetic services for children with hearing loss.

Newborn hearing screening committees (Attachment 8):

- The EHDI Advisory Committee advises the NHSP regarding policies and other issues related to the EHDI system, and reviews NHSP activities and progress toward the EHDI 1-3-6 goals. It meets at least annually.
- The Hospital Newborn Hearing Screening Coordinators Committee addresses screening policies, procedures, and issues in the hospital setting. It meets annually face-to-face.

## Technology Resources

### 1. Website

The NHSP website, <http://health.hawaii.gov/genetics/programs/nhsp/> is an important resource used to disseminate information to providers and the general public. The website contains general information about the NHSP, educational materials, and data about newborn hearing screening in Hawaii. The webmaster works within the Genomics Section so updates and revisions are easily made to the website.

### 2. Webinars/Teleconferences

Through the use of the web-based program “Go To Webinar,” webinars to share information relevant to project partners and stakeholders can be arranged. Small and large teleconferences may also be utilized to defray the costs of travel for meetings.

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## **PROJECT NARRATIVE**

### **INTRODUCTION**

The purpose of the Baby Hearing Evaluation and Access to Resources and Services (HEARS) - Hawaii Project is to decrease the lost to follow-up/documentation (LFU/D) rate of infants who have not passed newborn hearing screening prior to discharge from the newborn nursery. The project will seek to decrease LFU/D rates for newborn hearing screening, diagnostic audiologic evaluation, and enrollment in early intervention (EI) services.

Hawaii data (2011) show the need to reduce LFU/D: Of 18,922 births in 2011, 1.4% were LFU/D for screening. Of 199 children with failed screens, 24.6% were LFU/D for audiologic evaluation. Of 52 children with permanent hearing loss, 11.5% were LFU/D for EI services.

The project will support Hawaii's efforts toward achieving the Healthy People 2020 Objective for early hearing detection and intervention (EHDI) – that all infants receive newborn hearing screening by age 1 month, audiologic evaluation by age 3 months, and EI services by age 6 months. The Hawaii Newborn Hearing Screening Program (NHSP)'s goal is to have children with hearing loss receive the appropriate services to support their growth and development.

### **NEEDS ASSESSMENT**

#### **Geography**

Hawaii, situated almost in the center of the Pacific Ocean, is composed of seven populated islands located in four major counties. Most of the population lives in the City and County of Honolulu (island of Oahu), concentrated in the Honolulu metropolitan area. The rural “neighbor island” counties are Hawaii, Kauai (islands of Kauai and Niihau) and Maui (islands of Maui, Molokai, and Lanai).

The island geography impacts access to health care. The majority of tertiary health care facilities and specialty/subspecialty services are located on Oahu, in the Honolulu metropolitan area. Thus, neighbor island and rural Oahu residents often must travel to Honolulu for services. Inter-island flights cost approximately \$140-\$360 round-trip, which can be a financial barrier for residents needing services on Oahu. Public transportation is not adequate on the neighbor islands. Residents in rural communities may need an automobile to travel to major population centers for specialty services. Due to the mountainous nature of the islands, road networks are sparse and may include single-lane coastal roads.

#### **Demographics**

In 2012, the state population was 1,360,301. By county, 70.1% live in the City and County of Honolulu, 13.6% in Hawaii County, 11.4% in Maui County, and 4.9% in Kauai County.<sup>1</sup>

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<sup>1</sup>Hawaii State Department of Business, Economic Development & Tourism, <http://hawaii.gov/dbedt/info/census/population-estimate>, 2012.

A comparison of Hawaii with the U.S. (Table 1) shows that:

- Hawaii is ethnically diverse and has no single ethnic majority. The state has higher proportions of people with Asian, Native Hawaiian and Other Pacific Island ethnic backgrounds, and people of two or more ethnic backgrounds, than the general U.S. population.
- Hawaii has a larger proportion of foreign-born individuals than the U.S. general population, with many immigrants from Asia and Pacific.
- Hawaii has a higher proportion of people who speak a language other than English at home, in addition to those who speak English less than “very well”. Asian and Pacific Island languages comprise most of the other languages spoken in the home.

<b>Table 1. Comparison of Demographics for Hawaii and U.S.<sup>2</sup></b>		
	<b>Hawaii</b>	<b>U.S.</b>
<b>Race/ethnicity</b>		
White alone	26.1%	77.9%
Black or African American alone	2.1%	13.1%
American Indian and Alaska Native	0.4%	1.2%
Asian alone	38.3%	5.1%
Native Hawaiian and Other Pacific Islanders alone	10.1%	0.2%
Other race	1.4%	4.6%
Two or more races	23.0%	2.4%
Hispanic (any race)	9.5%	16.9%
<b>Foreign born</b>	17.8%	12.8%
<b>Persons below poverty level</b>	10.2%	14.3%
<b>Speak language other than English at home</b>	25.6%	20.3%

Based on data from the National Survey of CSHCN (2009-2010), 12.3% Hawaii children age 0-17 years (35,022 children) have special health care needs, with a higher proportion among White, Native Hawaiian, and Pacific Island children.<sup>3</sup> The number of live births in Hawaii averaged 18,901 births per year (2010-2012).

### **Data Summary for Newborn Hearing screening, evaluation, intervention, and follow-up**

According to the most recent data available (2011):

#### *Screening and LFU/D*

- Of 18,920 infants:
  - 97.0% (18,330) were screened by age 1 month,
  - 1.4% (272) were screened after age 1 month or age unknown, and
  - 1.3% (255) were LFU/D for screening.

<sup>2</sup>U.S. Census Bureau, 2012 American Community Survey, American FactFinder, quickfacts.census.gov/qfd/states/15000.html.

<sup>3</sup>National Survey of CSHCN 2009-2010 (Data Resource Center for Child and Adolescent Health). Hawaii data retrieved from [www.cshcndata.org](http://www.cshcndata.org).



*Evaluation and LFU/D*

- Of 199 children who did not pass screening:
  - 31.7% (63) received an evaluation by age 3 months,
  - 27.6% (55) received an evaluation after age 3 months,
  - 16.1% (32) died, moved out of state, declined, or had a diagnosis in-progress, and
  - 24.6% (49) were LFU/D.
  
- Of 118 children who received evaluations, 52 were diagnosed with permanent hearing loss: sensorineural (30), mixed (17), permanent conductive (4), and auditory neuropathy (1).
  
- Evaluation rates have held steady over the past several years (Table 3). LFU/D decreased by 9% in 2010 and by 7% in 2011, indicating improvements in loss to documentation.

*Intervention and LFU/D*

- Of 52 children who were diagnosed with permanent hearing loss:
  - 80.8% (42) were referred and received EI services under Part C of IDEA,
  - 7.7% (4) children either moved out of state or the parents declined EI, and
  - 11.5% (6) were LFU/D.
  
- Of the families referred to EI:
  - 64.3% (27) received EI services by age 6 months, and
  - 28.9% (15) received EI services after age 6 months.

The EI rates have slightly improved over the last years (Table 3).

**Table 3: Hawaii success and LFU/D rates for 1-3-6 timeline for screening, evaluation, EI**

	2007	2008	2009	2010	2011
<b>Screening</b>					
% screened by age 1 month	98.1%	97.3%	95.5%	95.9%	97.0%
% screened (total, including age > 1 month)	98.6%	98.5%	96.9%	98.0%	98.4%
% LFU/D for screening	0.8%	1.1%	2.9%	1.9%	1.3%
% births out-of-hospital (home births) LFU/D for screening	43.1%	72.7%	84.7%	87.3%	73.8%
<b>Evaluation</b>					
% evaluated by age 3 months	39.1%	41.3%	38.3%	39.2%	53.4%
% evaluated (total, including age > 3 months)	46.7%	55.5%	51.2%	60.1%	59.3%
% LFU/D for evaluation	44.8%	41.3%	41.6%	32.2%	24.6%
<b>Early Intervention (EI)</b>					
% receiving EI by age 6 months	72.6%	59.0%	75.4%	46.8%	64.3%
% receiving EI (total, including > 6 months)	79.0%	61.0%	83.0%	77.0%	80.8%
% LFU/D for EI	3.2%	1.6%	7.5%	13.1%	11.5%

## **Medical Home**

### Strengths and Resources

- In 2011, 99.2% of hospital-born babies who did not pass newborn hearing screening identified a personal primary care physician (PCP) or nurse before hospital discharge.
- The American Academy of Pediatrics (AAP)-Hawaii Chapter has designated Dr. Lynn Iwamoto as the EHDI Champion. Dr. Iwamoto is an active participant on the Hawaii EHDI Advisory Committee and the Learning Collaborative Team. She meets regularly with NHSP staff and assists in strategic planning, policy development, and annual updates of program goals and objectives. She provides educational sessions for health care providers at grand rounds and conducts workshops for hospital screening staff on Oahu and neighbor islands.

### Gaps and Weaknesses

- Results of the 2012 survey, “Knowledge, Attitudes and Practices of Physician in Hawaii Regarding Newborn Hearing Screening” showed that:
  - 88.3% of respondents reported receiving newborn hearing screening results,
  - 42.4% of respondents believed a child could be definitely diagnosed as having a permanent hearing loss by three months of age, and
  - 11.4% of respondents think their training adequately prepared them to meet the needs of infants with permanent hearing loss.
- Compared to a similar survey from 2005, there was no significant improvement in physicians’ knowledge or attitudes regarding newborn hearing screening. Physician training on their roles in the EHDI process is needed.
- Communication between the NHSP and PCPs needs to improve. 2012 survey results show:
  - 44.3% of physicians have never received information from the NHSP, and
  - 72.9% of physicians have never sent information to NHSP.

## **Screening Services**

### Strengths and Resources

- All 12 birthing facilities in Hawaii do newborn hearing screening. All facilities do screening on home births upon request from the parents.
- Three birthing hospitals (Kapiolani, Tripler and Kaiser) previously implemented the two-stage screening of OAE (otoacoustic emission) and AABR (automated auditory brainstem response). Nine more hospitals implemented the two-stage screening after screeners received on-site training in October 2012.
- All screening hospitals have functional OAE/AABR screening equipment. The NHSP has helped three hospitals, rural and urban, replace older units which were either recalled or malfunctioned. A total of nine hospitals use screening equipment on loan from the NHSP.
- The NHSP has developed agreements with four private providers to perform hearing screening on home birth babies. The providers are on four islands: Oahu, Maui, Hawaii and Kauai. Training and a manual were provided for providers’ staff in November 2012. The screening rate for home births increased from 18% to 31.5% in 2012.

- In 2009, the NHSP participated in the NICHQ Learning Collaborative. One strategy was piloted with a PDSA cycle: giving written documentation of hearing screening results to parents. This procedure was subsequently implemented statewide. Hospitals can write the results on the child's immunization card or on the stork card provided by the NHSP.
- Another newly implemented policy is to provide a roadmap, before hospital discharge, to parents of babies not passing initial screening. The roadmap is a tool to guide the parents through the EHDI process and was another strategy piloted at the Learning Collaborative.
- Informational letters and brochures about newborn hearing screening and newborn metabolic screening are made available to families registering home births through birth registrars.

#### Gaps and Weaknesses

- There is no standard requirement for the training of new screeners; therefore there are inconsistencies in screening techniques performed by the screeners and the approach the screeners use to communicate with parents.
- Hospitals' referral rates vary. Only two have policies monitoring screeners' performance.
- Administrative rules that require birthing facilities to report screening data at the individual child level need to be established.
- The NHSP needs to provide outreach to midwives, such as through the Midwife Association, to inform them about the availability of community screening resources.

### **Diagnostic Audiologic Services**

#### Strengths and Resources

- Two audiologic providers have contracts with the Department of Health (DOH) to provide diagnostic audiologic services to infants born at hospitals without audiology departments.
- Three hospitals have a Rehabilitation Department or Audiology Department that provide follow-up diagnostic audiologic services to infants born at their hospitals.
- Diagnostic OAE and behavioral audiologic testing are available on Oahu. The same tests are available on the island of Hawaii three times per month and one time a month on Kauai.
- Diagnostic ABR testing is available on the island of Oahu.
- The NHSP is contracting with a Maui otolaryngology (ENT) clinic to perform diagnostic ABR and OAE. Prior to this, no audiologist on Maui would see children under two years old.
- In January 2014, the NHSP will initiate a 12-month pilot project with an audiologist to do ABR testing on Hawaii once a month. The NHSP will loan diagnostic equipment and provide airfare for interisland travel.

#### Gaps and Weaknesses

- Diagnostic ABR testing is not available on Kauai. Limited services are available on Maui and Hawaii. Most families must travel to Oahu for ABR diagnostic appointments. Travel and transportation challenges can contribute to delays in evaluation and increased LFU/D.
- A limited number of audiologists see children under two years old. While a statewide issue, the situation is more serious on neighbor islands. Lack of an experienced audiologist results in long waiting periods for appointments or a delay identifying babies with hearing loss.
- The establishment of administrative rules that require audiologists to provide findings of diagnostic audiologic evaluations to the NHSP is needed.

- The military hospital submits child-specific screening results but not diagnostic information. Children who do not pass screening at this hospital are lost to documentation to the NHSP.

## **Early Intervention Services**

### Strengths and Resources

- The DOH EI Section provides EI services for children age 0-3 years with or at biological risk for developmental delays, as required by Part C of IDEA. Services include assistive technology, audiology, family training, counseling, home visiting, health services, medical services (diagnostic/evaluation), nursing, occupational therapy, physical therapy, psychology, social work, special instruction, speech language pathology, transportation, and vision. Services are provided through state and purchase-of-service contracted programs.
- The Deaf/Hard of Hearing (D/HH) Specialist was hired in June 2012. The position had been vacant for four years. NHSP staff work with the D/HH Specialist to support families enrolled in EI programs. The NHSP has sponsored several social and educational events coordinated by the D/HH Specialist, including American Sign Language (ASL) classes, Shared Reading Saturday Program, a music workshop, and an Individual Education Plan workshop.
- The DOH EI Administrative Rules were approved October 2013. Children with hearing loss are considered eligible under the biological risk category, even without developmental delay.
- The NHSP collaborates with EI to have families consent to sharing information with the NHSP. The EI Section has a database field to indicate if families receiving EI have consented. The database can be matched with HI\*TRACK to identify children in common.

### Gaps and Weaknesses

- The EI Section is currently experiencing staff shortages. Several vacant positions, including Supervisor, are not filled. Electronic matching of the EI and HI\*TRACK databases is not available due to the staff shortages. Data matching could help identify children who were LFU/D for newborn hearing screening or children who may have late-onset hearing loss.
- The EI follows the Family Educational Rights and Privacy Act (FERPA) requirement. The EI referral agency, Hawaii Keiki Information Service System (H-KISS), will not release information about the status of a child's referral to the NHSP unless parents sign a consent form. Since NHSP staff contact parents over the phone, it is difficult to get written consent. Without written parental consent, tracking EI enrollment is challenging and some cases become lost to documentation.
- Further streamlining the EI process to share follow-up information with the NHSP is needed. EI staff sometimes do not enter parent consent information in the EI database. An EI Information Technology (IT) staff person does not have time to generate periodic lists of children receiving EI hearing services that the NHSP could use to identify those who are LFU/D for evaluation or have late onset hearing loss. The NHSP may also not be informed by care coordinators when a referred child does not enroll in EI or is discharged.

## **Tracking and Follow-Up**

### Strengths and Resources

- The Baby HEARS Project Coordinator and NHSP Social Services Assistant assist families of children needing follow-up. Responsibilities include working with hospitals to schedule re-

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screens; contacting families, physicians, and audiologists to set evaluation appointments; and making EI referrals if permanent hearing loss is confirmed.

- NHSP staff use the model of change to refine tracking protocols, which includes appropriate entering of data in HI\*TRACK, developing spreadsheets to facilitate tracking, and improving the referral timeline and procedures. As a result, the lost to follow up rate has decreased.

#### Gaps and Weaknesses

- The NHSP is not able to follow-up with births (e.g., home births) known to Vital Records but not known to the NHSP, based on the Deputy Attorney General's interpretation of the Vital Records state law.

### **Family Support**

#### Strengths and Resources

- The Hands & Voices Hawaii Chapter (H&V-HI) inaugurated in March 2013. The NHSP Coordinator and the EI D/HH Specialist are representatives on the Board of Directors.
- In collaboration with the EI D/HH Specialist, the NHSP sponsors parent education workshops. Examples are Individual Family Service Plan development, cochlea implant, and music workshops.
- The NHSP partners with the H&V-HI Chapter and participates in events to increase public awareness of deafness and hard of hearing issues. Since March 2013, the NHSP has cosponsored an information booth at the Mata Expo and the Special Parent Information Network Conferences, Family Fun Day, and Fall Festival.
- In collaboration with the Hawaii School for the Deaf and Blind, the NHSP continues to offer scholarships for families to attend Family Sign Language classes.
- Collaboration with the Hawaii Services on Deafness and the Hawaii School for the Deaf and the Blind has allowed families enrolled in EI to attend classes with families of children who have transitioned from EI to the Department of Education.
- The NHSP sponsors the EHDI Advisory Committee parent representative to attend the annual EHDI Conference. In 2013, two parent representatives attended the conference.
- Hawaii trainings offered by the NHSP or EI Section are open to all parents and professionals.
- ASL interpreters are contracted to interpret at Ohana meetings, EHDI Advisory Committee meetings, and trainings. Foreign language interpreters are available, if needed.

#### Gaps and Weaknesses

- Due to funding restraints, EI no longer supports the Deaf Mentor program. An alternate is to contract H&V-HI Chapter to provide family support with the Guide By Your Side Program.
- The NHSP is waiting for approval from the Human Resource Department to hire a Parent Support/Follow-up Coordinator.
- Ongoing cultural competency training is needed. Multicultural peer workers or families themselves may be good resources for cultural sharing and awareness.

### **Statutes and Regulations**

#### Strengths and Resources of the system

- Newborn hearing screening began in Hawaii in 1990, with passage of a law that mandated

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the DOH to develop methodology to establish, implement, and evaluate a statewide program for early identification of and intervention for hearing loss in infants; and develop guidelines for screening, identification, diagnosis, and monitoring of infants with hearing loss.

- In 2001, the newborn hearing screening law was amended, with efforts initiated by the Children with Special Health Needs Branch (CSHNB) in the DOH. Hawaii Revised Statutes (HRS) §321-361 to 363 require the screening of all infants born in the state, except for babies whose parents/guardians object to screening based on religious beliefs. The law also requires birthing facilities to report screening results to the DOH to ensure a statewide system of screening, diagnostic evaluation, and intervention for all newborn infants with hearing loss.

#### Gaps and Weaknesses

- The establishment of administrative rules is now necessary to implement the law. The NHSP has drafted rules that have been reviewed by the Deputy Attorney General, but further revisions are needed. The lengthy process of establishing administrative rules has 34 steps.
- The HRS does not specify that audiologists are mandated to report diagnostic results to the NHSP. Audiologists who do not have contracts with the DOH can refuse to submit diagnostic reports to the NHSP, resulting in underreporting of children with hearing loss.

### **Information and Education**

#### Strengths and Resources

- The NHSP has provided in-service training for staff, including nurses and screeners, at various hospitals. Training topics included hospital inpatient and outpatient screening protocols, referral procedures, and HI\*TRACK data input and transfer. In-service training was provided onsite, via telephone, and at annual coordinator meetings.
- Dr. Lynn Iwamoto, EHDI Champion for the AAP-Hawaii Chapter, working in partnership with the NHSP and the University of Hawaii School of Medicine pediatric residents, provided hearing screening training to physicians and nursery staff at neighbor island birthing hospitals. The training was to increase awareness of hearing screening and collaboration between hospital screeners, NHSP staff, and the medical home.
- Dr. Iwamoto has presented at the hospital coordinators' meetings on special topics such as the Joint Commission on Infant Hearing (JCIH) position statement, risk factors in hearing loss, congenital cytomegalovirus, and hearing screening.
- NHSP staff presented at the annual Hawaii Early Childhood and Pacific Rim Conferences to provide education about the importance of early identification of and EI for hearing loss.
- The NHSP has cosponsored several statewide conferences. The "Parent Power: Engaging Parents to Improve Outcomes for Children" workshop by Teresa Callaway was offered in 2011 and was well received. Ms. Caraway returned in 2012 to present the same workshop on three neighbor islands and the "Screening Conference" in Honolulu. The "Shining the Light on Young Deaf, Hard-of-Hearing and Deaf-Blind Children" presentation by professors from Gallaudet University was also offered in 2012.
- The NHSP revised the "Can your Baby Hear?" brochure. This brochure is distributed to new parents at the hospital with their baby's screening results. The NHSP is in the process of developing a new "Hawaii Newborn Hearing Screening Program" brochure. This brochure will be provided to parents before screening. Upon request, both brochures will be available at public education events and/or at physician offices.

- The NHSP has a new website at <http://health.hawaii.gov/genetics/programs/nhsp/>. The website will include the new brochures, once finalized. The Hawaii Practitioners Manual for EHDI and a family resource guide will also be posted after revision.

#### Gaps and Weaknesses

- The revised and new brochures need to be translated and printed in different languages.
- Further education is needed for health care providers, community health centers, EI providers, midwives, hospital staff, and families regarding the importance of timely follow-up for hearing concerns and information on effective practices, protocols, and resources.

### **Collaboration with Stakeholders**

#### Strengths and Resources

- The Hawaii EHDI Advisory Committee advises the NHSP regarding policies and issues related to the EHDI system, and reviews NHSP activities and progress toward the EHDI 1-3-6 goals. There are 19 committee members (Attachment 8). The group met twice in 2013. Two work groups were created to revise the Practitioners Manual and family resource guide.
- The Hospital Newborn Hearing Screening Coordinators Committee (Attachment 9) addresses screening policies, procedures, and issues in the hospital setting. This committee meets annually face-to-face with ongoing communication via e-mails or phone calls.
- The NHSP supports the Maui Early Head Start Program and the Parent as Teachers Home Visiting program to conduct hearing screening. The NHSP provides training and technical assistance. The programs will inform the NHSP if they identify children with hearing loss.
- The NHSP Coordinator is an active member of the Hawaii Title V Developmental Screening Committee (Title V State Performance Measure) and the Wellness and Comprehensive Screening Committee of the Early Childhood Learning Initiative.
- The NHSP Coordinator is a member of the Advisory Group with the University of Hawaii Center on Disability Studies Deaf and Blind Project.

#### Gaps and Weaknesses

- NHSP collaboration with the new Home Visitation Program needs to be strengthened and expanded to other home visiting programs.
- NHSP collaboration with the Head Start and Early Head Start programs needs to be expanded. Annual OAE screening is recommended at the Head Start and Early Head Start Programs. This may be an opportunity to identify late onset hearing loss.

### **Financing**

#### Strengths and Resources

- Based on the 2007 National Survey of Children's Health, 96.2% children in Hawaii have insurance coverage.
- Research conducted by the Hawaii Health Information Corporation shows a drop in the annual number of uninsured newborns from 481 (2000) to 230 (2011). This reflects a decrease from 2.8% to 1.3% of hospital births.
- The NHSP uses state general funds to assist uninsured and underinsured families with access to screening and audiologic evaluation.

- The NHSP has three state-funded, permanent staff positions (coordinator, social services assistant, office assistant) that are formally on the NHSP organizational chart.

#### Gaps and Weaknesses

- Financial arrangements with community screening sites are yet to be determined.
- The NHSP has been indirectly impacted by the EI Section's reduction-in-force. Due to vacant EI positions, care coordinators now have higher caseloads, which impact time available to work with the NHSP. Due to a loss of support staff, the EI IT Specialist does not have time to provide the NHSP with a list of children with hearing loss receiving EI services.
- The NHSP is short staffed. The only clerical support resigned in October 2013. The Parent Support/Follow-up Coordinator and Project Specialist positions are awaiting approval from the DOH Human Resources Department.

#### **Technical Assistance**

#### Strengths and Resources

- The NHSP provides technical assistance to hospital screening staff regarding screening and follow-up, training on use of equipment, and updated equipment as needed.
- The NHSP arranged for the company that sells equipment to provide onsite training on the two stage screening at the birthing hospitals and at contracted community providers' clinics.

#### Gaps and Weaknesses

- Screening facilities, including the birthing hospitals and community providers, need to develop quality improvement plans to monitor performance of their screening programs.

#### **Data Management**

#### Strengths and Resources

- HI\*TRACK software is used for EHDI tracking and surveillance. The NHSP provides HI\*TRACK to birthing hospitals to assist them in accurate and timely reporting of screening results. Diagnostic results and EI referral/enrollment information are entered in HI\*TRACK by NHSP staff upon receipt from audiologists, Part C care coordinators, PCPs, and families.
- In 2011, HI\*TRACK became web-based. The DOH IT staff assists with server set up and maintenance. All birthing hospitals submitting monthly screening data to NHSP were converted and now use web-based HI\*TRACK. This allows NHSP staff to have immediate access to data entered by the hospital staff, and vice versa, which facilitates communication and ensures timely referral for follow-ups.
- With the support of the National Center for Hearing Assessment and Management (NCHAM) Help Desk, NHSP staff have learned to use the upgraded version of HI\*TRACK 4.5 more effectively, including data entry techniques, identifying children who need follow-up, and printing management reports such as annual CDC reports and letters to physicians.
- The CSHNB Research Statistician links the NHSP and Newborn Metabolic Screening Program (NBMS) screening databases monthly, and submits them to the DOH Office of Health Status Monitoring quarterly, where the linked NHSP-NBMS database is further linked to birth certificate data. The combined linked database is returned to the Research

Statistician with vital record information for names known to the NHSP and NBMSP. The combined linked database provides a more complete database for NHSP reporting purposes.

#### Gaps and Weaknesses

- In most hospitals, HI\*TRACK is not linked to the electronic medical records system. Hospital staff have to manually enter child's demographic information in HI\*TRACK. It is time consuming. Some hospitals do not enter demographic information that is not required but would be helpful when NHSP staff need to contact families for follow-up.
- The military hospital provides screening data but not diagnostic information. Children who do not pass screening at this hospital become lost to documentation. Children diagnosed with hearing loss at this facility are not entered in the state EHDI system.

#### **Summary of Needs Regarding LFU/D**

##### Needs regarding screening, evaluation, and intervention services for children/families:

- Establish the EHDI Quality Improvement Team to assist with the implementation of the quality improvement plan.
- Develop talking points for midwives and screeners to discuss hearing screening and follow-up with parents.
- Facilitate development of hospital screening program quality assurance plans to monitor screener performance and reduce inpatient and outpatient referral rate.
- Increase referrals for screening for home births.
- Increase diagnostic audiologic evaluation services on neighbor islands. Pilot teleaudiology.
- Improve data tracking system to ensure early identification of children who are LFU/D at each stage of the EHDI process.
- Streamline the EI referral process and improve communication between the NHSP and EI.

##### Needs regarding community collaboration and public education:

- Provide education to PCPs to increase their knowledge of the Hawaii EHDI system.
- Establish Memorandum of Agreements with EI and community providers to strengthen collaboration.
- Establish administrative rules and program policies to require result reporting to the DOH.
- Increase parent supports. Collaborate with the H&V HI Chapter to provide parent education and mentoring support.

#### **METHODOLOGY**

**Overall Goal/Aim: By March 31, 2017, the Hawaii Baby HEARS Project will use quality improvement methodology to decrease the LFU/D rate of infants who have not passed a physiologic newborn hearing screening examination prior to discharge from the newborn nursery from 24.6% (per the 2011 CDC annual survey) to 10%.**

**AIM 1: The Hawaii EHDI Quality Improvement Team (HI-EHDIQI) will be established and will function throughout the grant period.**

Strategy 1.1 By April 30, 2014, a HI-EHDIQI team will be established.

NHSP Advisory Committee members will constitute the core members of the stakeholder quality improvement team. There are 19 volunteer members on the Advisory Committee. There is no formal selection process; invitations are extended to professionals whose work is affiliated with EHDI or parents who are interested in being advocates. Currently, the 19 members are:

- three parents (one is president of the Hands& Voices- Hawaii Chapter);
- three physicians, the AAP Chapter Champion, the Medical Director of the DOH Family Health Services Division, and an otolaryngologist;
- six audiologists (three from the birthing hospitals, the NHSP audiology consultant, the state audiologist, and one in private practice on a neighbor island);
- the Head Start Collaboration Office Director;
- Home Visiting Program representative;
- EI Section representative;
- the Gallaudet University Regional Center Director; and
- three staff from the Children with Special Health Needs Branch who are supervisors or who work in partnership with the NHSP (the Newborn Metabolic Screening Program Coordinator, the Genetics Program Genetic Counselor, and the EI D/HH Specialist).

At a meeting in January 2013, the Advisory Committee decided to meet at least twice a year. Two work groups were established to revise the family resource guide and the “Hawaii Practitioners Manual”. The next meeting will be in February 2014. At that meeting, members will discuss the composition of the QI team and recommend inviting additional stakeholders.

*Measures*

- 1.1.1 A majority of Advisory Committee members attend the February 2014 Advisory Committee meeting.
- 1.1.2 A minimum of ten individuals volunteer to participate on the HI-EHDIQI team.
- 1.1.3 A majority of Advisory Committee members report that they are satisfied or very satisfied with their participation on the Advisory Committee, as determined by post-meeting surveys.
- 1.1.4 The HI-EHDIQI team will review DOH policies and the NHSP’s statutory authority to collect newborn hearing screening data.
- 1.1.5 The HI-EHDIQI team will make recommendations for policies and/or new statutory language, as needed.

Strategy 1.2 By May 30, 2014, the HI-EHDIQI team will have its first meeting.

- 1.2.1 At the first team meeting, the team will be identified, team members will discuss their roles and commitments, and the meeting schedule and the modes of communication will be determined.

*Measures*

- 1.2.1.1 Meeting minutes will identify the roles and commitments of each team member.
- 1.2.1.2 A meeting schedule through 2017 is completed two weeks following the team meeting.
- 1.2.1.3 A majority of HI-EHDIQI team members attend each meeting.
- 1.2.1.4 A majority of HI-EHDIQI team members report that they are satisfied or very satisfied with their participation on the team, as determined by post-meeting surveys.

1.2.2 If needed, training on the Model of Improvement will be arranged for team members.

*Measures*

- 1.2.2.1 The number of team members requiring training is documented in the meeting minutes.
- 1.2.2.2 The NHSP arranges training for team members by June 30, 2014
- 1.2.2.3 All team members who require training will complete training by July 31, 2014.

Strategy 1.3 By August 30, 2014, the HI-EHDIQI team will approve the quality improvement work plan, including strategies that will be implemented using the Model of Improvement.

1.3.1 Team members will review the work plan, prioritize the change strategies, and approve the PDSA test cycles by August 31, 2014.

*Measures*

- 1.3.1.1 A majority of team members have reviewed the work plan and provided feedback by July 31, 2014
- 1.3.1.2 The change strategies have been prioritized and the prioritized plan approved by a majority of the team members by August 15, 2014.
- 1.3.1.3 The PDSA test cycles have been reviewed, timelines set, and both approved by a majority of the team members by August 31, 2014.

1.3.2 The HI-EHDIQI team will establish work groups to align with the different strategic areas.

*Measures*

- 1.3.2.1 Team members will come to consensus regarding the number of work groups and the charge(s) of each work group.
- 1.3.2.2 The team will identify initial meeting timelines and activities for each work group, with subsequent meeting timelines and activities to be developed by the work groups themselves.

**AIM 2: Decrease the proportion of children who are LFU/D for screening from 1.4% of births (2011 data) to 1.0% of births.**

Strategy 2.1 Improve the screening rate of home births by at least 10% each year (in 2011, fewer than 15% of home births received newborn hearing screening)

2.1.1 The NHSP will develop talking points for midwives to use when discussing newborn hearing screening with parents.

Midwives are the frontline professionals delivering babies at home. The NHSP will reach out to midwives by meeting with small groups to provide training on hearing screening, resource materials, and talking points to assist them in discussing newborn hearing screening with parents.

*PDSA Cycles:* The NHSP will test the talking points training on two Maui midwives with low rates of infants receiving hearing screening, modify the talking points based on feedback after six months, and spread training to other Maui midwives before implementing statewide. The effectiveness of the talking points will be assessed by the number of home births screened.

#### *Measures*

2.1.1.1 Post-training survey/interview data from midwives who participate in talking points training.

2.1.1.2 The number of home births who receive newborn hearing screening following midwife talking points training, compared to the number of home births who received newborn hearing screening prior to midwife talking points training (for the midwives in the initial test region).

2.1.1.3 Once the intervention is refined and expanded beyond the initial test site, the percentage of midwives who receive talking points training will be determined.

2.1.1.4 Once the intervention is refined and expanded beyond the initial test site, pre- and post-intervention screening rates for home births will be compared at the state level.

2.1.2 NHSP staff members will contact parents of children born at home to schedule screening appointments.

Using data merged with the Newborn Metabolic Screening Program, the NHSP will identify home births who need screening. NHSP staff will contact parents, explain where hearing screening is available in their community, and offer to assist with appointment scheduling. If the NHSP is not able to contact the parents, staff will request that the baby's PCP make a referral.

*PDSA Cycles:* The NHSP will identify newborns who have not completed newborn hearing screening in one community on the island of Hawaii. NHSP staff will phone parents within two months of their child's birth. NHSP staff will coordinate with the hospital to schedule outpatient hearing screening. This will be implemented in other communities on the island of Hawaii for at least twelve months before state-wide implementation. The effectiveness of the cycles will be assessed by the number of home births who complete hearing screening appointments.

#### *Measures*

2.1.2.1 The percentage of parents of children born at home and needing hearing screening with whom the NHSP are able to successfully make contact.

2.1.2.2 The percentage of home births who receive newborn hearing screening following parent-contact intervention, compared to the percentage of home births who received newborn hearing screening prior to parent-contact intervention (in the initial test region).



2.1.2.3 Once the intervention is refined and expanded beyond the initial test site, pre- and post-intervention screening rates for home births will be compared at the state level.

Strategy 2.2 Decrease the LFU/D of hospital births at outpatient screening by 10% each year (2011 rate for all hospitals was 32%; see Table 2 for 2011 outpatient screening rates by hospital).

2.2.1 The NHSP will develop quality assurance guidelines to support the hospital screening programs and reduce the need for outpatient screening.

Quality screening programs with competent screeners reduce the referrals for outpatient screening and decrease the rate of LFU/D for hospital births. Currently, less than one third of hospitals have written procedures to monitor the performance of their hearing screening programs. The NHSP will provide technical assistance to hospitals to develop or revise guidelines. Proposed guidelines will include:

- require new screeners to complete the NCHAM online training curriculum within one month of assignment to screening role, and to receive ongoing refresher training;
- talking points for screeners to discuss referrals with parents;
- a screeners' competency checklist; and
- require review of the NHSP screening report cards (sent to individual hospitals).

*PDSA Cycles:* Change strategy will be used to develop screeners' talking points. The NHSP will test the talking points on one hospital with a high number of LFU/D for outpatient screening. Each screener will test the talking points on three referrals. The talking points will be modified and spread to other hospitals on the same island before statewide implementation. The effectiveness of the talking points will be assessed by the number of infants who complete outpatient screening post-intervention.

#### *Measures*

2.2.1.1 Guidelines are developed, revised, and approved within the work group's identified timeline.

2.2.1.2 Proportion of hospitals that have up-to-date hearing screening guidelines that include the four items listed, above.

2.2.1.3 Proportion of screeners (by hospital and overall) who complete the NCHAM online training curriculum within one month of assignment to screening role.

2.2.1.4 Percentage of screening report cards that are accessed by an authorized user within one week of dissemination.

2.2.1.5 Percentage of infants completing outpatient screening post-intervention, compared to the percentage of infants completing outpatient screening pre-intervention.

2.2.1.6 Once the intervention is refined and expanded beyond the initial test site, pre- and post-intervention outpatient screening rates will be compared at the state level.

2.2.2 Improve communication with parents

The NHSP will revise the newborn hearing screening brochure. This brochure explains how newborn hearing screening is conducted and is given to parents before newborn hearing

screening (in the packet parents receive when admitted). NHSP staff will conduct a phone survey with the hospitals to determine the number that put this brochure in the parent packet.

The NHSP has a second brochure about ongoing monitoring for hearing concerns. The goal is to provide this to parents when sharing screening results. The AAP champion will develop a plan to have select PCPs ask parents if they received the “Ongoing Monitoring for Hearing Concerns” brochure with their child’s hearing screening results.

Both brochures will be printed and distributed to the screening hospitals. The brochures will be translated into languages for non-English speaking parents, as determined by a needs assessment.

#### *Measures*

2.2.2.1 The “Newborn Hearing Screening” brochure is revised, approved, and printed by April 30, 2014.

2.2.2.2 The “Ongoing Monitoring for Hearing Concerns” brochure is revised, approved, and printed by April 30, 2014.

2.2.2.3 Assessment of need for brochures to be translated into different languages is complete by July 31, 2014 (will include a log of requests for brochures in different languages)

2.2.2.4 A log will be kept regarding the number of brochures delivered to and requested by each hospital.

2.2.2.5 Percentage of institutions placing the “Newborn Hearing Screening” brochure into pre-screening packets for parents.

2.2.2.6 Percentage of parents who report receiving the “Ongoing Monitoring for Hearing Concerns” brochure with their child’s hearing screening results.

**AIM 3: Decrease the proportion of children who are LFU/D for evaluation from 24.6% (2011 data) to 10%.**

Strategy 3.1 Increase the percentage of babies who complete an audiologic evaluation within one month of their referral being received by the NHSP from 50% (2012 data) to 80%.

3.1.1 Before hospital discharge, screeners will obtain secondary contact information from parents whose children do not pass newborn hearing screening.

Hospitals have been inconsistent in adding secondary contact information on referrals sent to the NHSP. The NHSP will engage in a pilot study, requesting that screeners get secondary contact information from parents when a baby does not pass initial inpatient newborn hearing screening. The secondary contact is a person with a different phone number from the primary contact. The secondary contact information (name, phone number, address) will be entered in HI\*TRACK by hospital staff and also on the referral form if a baby is referred for follow-up.

*PDSA cycles:* Two hospitals with low rates of obtaining secondary contact information will be selected to participate in the pilot study. Test cycles will be used to find out the most effective way to obtain secondary contact information. For example, screeners will be asked to obtain

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secondary contact information at the time of inpatient referral. The pilot will be spread to at least one hospital on each island before implemented statewide. The effectiveness will be assessed by the number of referrals with second contact information entered in the database system.

*Measures*

3.1.1.1 The percentage of infants with secondary contact information entered into HI\*TRACK post-intervention will be compared to the percentage of infants with secondary contact information entered into HI\*TRACK pre-intervention at each institution.

3.1.1.2 Once the intervention is refined and expanded beyond the initial test site, the rates of secondary contact information entered into HI\*TRACK pre- and post-intervention will be compared at the state level.

3.1.1.3 Survey data will identify each hospital coordinator's assessment of the pilot study (i.e., ease of collecting secondary contact information, most effective strategies to obtain secondary contact information, amount of time/minutes to collect and enter secondary contact information)

3.1.2 NHSP staff will contact the PCP of children who are LFU/D for audiologic evaluation and for whom the NHSP receives a referral; the NHSP will follow-up on the referral.

Currently, hospitals send screening results and referrals to a child's PCP. NHSP staff only contact a PCP if they have received a copy of the referral and are unable to locate the parents. To improve communication and facilitate referrals for diagnostic evaluation, the NHSP will call or send letters to PCPs to confirm each referral and to coordinate follow-up needs. PCPs with higher LFU/D rates for audiologic evaluation of their infants will be offered technical assistance and/or in-service.

*Measures*

3.1.2.1 The number of calls and letters to PCPs will be logged.

3.1.2.2 The percentage of infants who complete an audiologic evaluation post-intervention will be compared to the percentage of infants who complete an audiologic evaluation pre-intervention, overall and per PCP.

3.1.2.3 The number of technical assistance calls and/or in-service trainings for PCPs will be logged.

3.1.3 The NHSP will pilot teleaudiology between Oahu and the neighbor islands.

Since diagnostic ABR is currently only available on Oahu, neighbor island families currently need to fly to Honolulu for this service. The NHSP will collaborate with the audiology department of the local Children's Hospital to pilot teleaudiology to the neighbor islands.

*PDSA cycles:* The NHSP will assess the availability of resources at potential teleaudiology pilot site(s) by surveying neighbor island hospital and/or IT staff. Based on resource availability, one site will be chosen to pilot teleaudiology. Once the site is determined, the first two infants who need ABR testing and whose parents agree to participate will receive ABR by teleaudiology. In each case, the family and the audiologist will be surveyed to determine their satisfaction with this

service. A further two cases at the same site will be piloted. Results will be analyzed prior to strategy revision and expansion of teleaudiology to other sites.

*Measures*

- 3.1.3.1 The available resources at the pilot site(s) will be logged to create a needs assessment report.
- 3.1.3.2 The cost of pre-intervention assessment (travel to Oahu for an ABR) will be compared to the cost of post-intervention assessment (ABR by teleaudiology).
- 3.1.3.3 The reliability of the ABR results obtained by teleaudiology will be compared to reliability of an in-person ABR.
- 3.1.3.4 The feasibility of expanding teleaudiology sites will be determined based upon family and audiologist satisfaction with the pilot study (generated by surveys) and knowledge of the neighbor island resources (generated through needs assessment).

Strategy 3.2 The NHSP will identify children with permanent hearing loss within two months of the hearing loss being confirmed.

3.2.1 Contracted audiologists will submit diagnostic reports to the NHSP within two weeks of a diagnostic evaluation being performed.

Contracted audiologists are required to submit evaluation reports to the NHSP. NHSP staff will create a HI\*TRACK tracking list, identifying missing diagnostic reports. Two weeks after evaluation appointments, the NHSP will call audiologists or send reminders to request reports.

*Measures*

- 3.2.1.1 Number of missing diagnostic reports two weeks after evaluation.
- 3.2.1.2 Log of calls and/or letters sent to audiologists to request missing diagnostic reports.
- 3.2.1.3 The percentage of diagnostic reports submitted by audiologists within two weeks of evaluation pre-intervention, compared to the percentage of diagnostic reports submitted within two weeks of evaluation by audiologists post-intervention.

3.2.2 NHSP staff will identify and request reports for infants who may be lost to documentation but have been followed-up by the audiology department of a birthing hospital.

Hospitals with their own audiology departments do not send child-specific diagnostic information to the NHSP. Infants who do not pass hearing screening and then receive follow-up services at these hospitals become lost to documentation in HI\*TRACK. The military hospital will be the pilot; this institution does not provide diagnostic result information to the NHSP. The Children with Health Needs Branch Administrator will meet with a military hospital administrator to establish agreements to share diagnostic information.

*PDSA Cycle:* NHSP staff will identify and list babies born at the military hospital in the last three months who did not pass screening and for whom diagnostic information was not received. The three oldest babies on the list will be provided to the responsible hospital personnel. The hospital will provide copies of the diagnostic reports to the NHSP or enter the results in HI\*TRACK.

*Measures*

3.2.2.1 Meeting between the military hospital representative and CSHNB Administrator is scheduled and completed.

3.2.2.2 The percentage of diagnostic reports provided to the NHSP (either by copy or entry into HI\*TRACK) pre-meeting, as compared to the percentage of diagnostic reports provided to the NHSP post-meeting.

3.2.2.3 The percentage of military hospital infants identified with permanent hearing loss pre-meeting, as compared to the percentage of military hospital infants identified with permanent hearing loss post-meeting.

**AIM 4: Decrease the proportion of children who are LFU/D for intervention services from 11.5% (2011 data) to 9.9%.**

Strategy 4.1 Develop a Memorandum of Agreement with EI

Before the reorganization of the DOH Family Health Services Division, the NHSP reported to the EI Section Supervisor. The NHSP now reports to the Genomics Section Supervisor (Attachment 10). It is necessary to establish a Memorandum of Agreement with the EI Section to ensure continued collaboration to serve children with hearing loss. Items in the MOA may include the referral process, consent to share child specific information, and joint staff training.

*Measures*

4.1.1 A signed memorandum of agreement between the NHSP and EI Section is completed by March 31, 2015.

4.1.2 At least 90% compliance with items in the MOA is achieved by March 31, 2017.

Strategy 4.2 The NHSP will collaborate with audiologists and PCPs to ensure children are referred to EI as soon as a permanent hearing loss is identified.

When the NHSP receives a report of a child diagnosed with permanent hearing loss, staff contact parents by phone and obtain verbal consent to refer their child to EI. Without written consent from the parents, however, the EI program will not release information about the status of the referral to the NHSP, making it difficult to track and confirm EI enrollment.

*PDSA Cycle:* The NHSP will conduct a pilot study with one contracted audiologist and the first two families she diagnoses with hearing loss upon start of the PDSA cycle. The NHSP will collaborate with the audiologist at the Kapiolani Medical Center to discuss EI referral with parents when their infant is diagnosed with permanent hearing loss. The audiologist will obtain parental written consent and fax the referral to the NHSP to be forwarded to the EI referral agency. A similar test will be piloted with one PCP and two families not yet referred for EI. The PDSA cycle will be spread to five more families and then to the other contracted audiologist and other PCPs once results are analyzed and the strategy is refined.

### *Measures*

- 4.2.1 The number of referral forms received from audiologists pre-intervention, as compared to the number of referral forms received from audiologists post-intervention (after three PDSA cycles).
- 4.2.2 Once the intervention is refined and expanded beyond the initial test site, the rates of referral forms received from audiologists pre- and post-intervention will be compared at the state level.
- 4.2.3 The percentage of infants enrolled in EI before age six months pre-intervention, as compared to the number of infants enrolled in EI before age six months post-intervention (at least three PDSA cycles).
- 4.2.4 Once the intervention is refined and expanded beyond the initial test site, the rates of infants enrolled in EI before age six months pre- and post-intervention will be compared at the state level.

Strategy 4.3 By March 31, 2015, the NHSP and EI Section will have agreed upon written procedures outlining sharing of information about children with hearing loss who are enrolled in EI. Shared information will include the child's name, birth date, EI enrollment status, history of hearing screening, diagnostic reports, and intervention services.

Upon EI enrollment, parents sign consents to share information with the NHSP. The consent allows EI care coordinators to inform the NHSP of enrolled children with hearing loss, the child's discharge from EI, and screening and diagnostic results. Information sharing helps the NHSP identify children who are LFU/D for screening or audiologic evaluation, plus those with late onset hearing loss. A protocol to share information between EI and the NHSP is currently not included in EI written policies. Therefore, the consent has not been utilized well. The NHSP will work with EI administration to establish written policies regarding information sharing. Policies will be piloted with four EI programs before statewide implementation.

### *Measures*

- 4.3.1 Development and approval of written policies regarding information sharing between the EI Section and the NHSP.
- 4.3.2 The percentage of children with hearing loss identified from the EI database pre-policy implementation versus the percentage of children with hearing loss identified from the EI database post-policy implementation.
- 4.3.3 The percentage of children with hearing loss enrolled in EI programs pre-policy implementation, as compared to the percentage of children with hearing loss enrolled in EI programs post-policy implementation (rates per program and state-wide).

Strategy 4.4 Starting April 2014 and ongoing, improve EI program staff awareness of hearing loss and the NHSP.

To improve EI awareness of the NHSP and hearing loss issues, as well as communication between the EI program staff and NHSP staff, the NHSP will send monthly EHDI updates, by email or newsletter, to the EI programs.

*Measures*

4.4.1 The number of emails and/or newsletters sent to each EI program will be logged.

4.4.2 The number of requests for newsletters, or feedback on newsletters, will be logged.

Strategy 4.5 Collaborate with Early Head Start Programs and Home Visiting Programs to identify children who are LFU/D or who may have developed late onset hearing loss.

NHSP staff provided hearing screening training to all staff at the Early Head Start Program (EHS) on Maui in September 2013. After training, the EHS Program started hearing screening on enrolled children. Collaboration between the NHSP and EHS involves:

- EHS obtains parents' consent to share information with the NHSP,
- EHS requests newborn hearing screening results from the NHSP when there is a hearing concern about a specific child,
- the NHSP provides technical support to the EHS screening program, and
- EHS informs the NHSP when a child is "refer" or is identified with hearing loss.

A formal agreement between the two programs will be established by March 31, 2014. NHSP staff will continue efforts to collaborate with other EHS programs with support from the Head Start Collaboration Office.

The DOH Home Visiting Program contracts several community agencies to provide home visiting services. The NHSP Coordinator has met with the Home Visiting Coordinator and the Parents As Teachers (PAT) staff several times to discuss opportunities for collaboration.

A written agreement will be established between the two programs in early 2014, including:

- the NHSP will loan hearing screening equipment to PAT,
- the NHSP will provide screening training and technical support to the PAT staff,
- PAT staff will request newborn hearing screening results from the NHSP if needed, and
- PAT staff will inform the NHSP when a child is "refer" or is identified with hearing loss.

The training will start after the agreement is signed and will continue throughout 2014.

*Measures*

4.5.1 A formal agreement between the NHSP and EHS is finalized by March 31, 2014.

4.5.2 The number of parent consents received through EHS will be logged

4.5.3 The number of EHS requests for screening results will be logged

4.5.4 The number of EHS requests for technical assistance will be logged

4.5.5 The number of children identified with hearing loss through EHS will be logged

4.5.6 A written agreement between the NHSP and PAT will be finalized by February 28, 2014.

4.5.7 The number of times screening equipment is loaned to PAT will be logged

4.5.8 The number of PAT requests for technical assistance will be logged

4.5.9 The number of PAT requests for screening results will be logged

4.5.10 The number of children identified with hearing loss through PAT will be logged

**AIM 5: Increase the knowledge of primary care physicians in meeting the needs of infants with permanent hearing loss.**

Strategy 5.1 Collaborate with the AAP Chapter Champion to conduct a physician survey to identify training needs regarding hearing loss.

With input from the Advisory Committee, the NHSP and AAP Chapter Champion will design a physician survey. The survey will identify physician training needs regarding hearing loss and will use questions from the 2010 and 2012 physician surveys to compare knowledge gain.

*Measures*

5.1.1 A physician survey will be developed and approved by the HI-EHDIQI team by December 31, 2014.

5.1.2 Survey data will identify the rates of physicians desiring hearing loss education, gaps in hearing loss knowledge, and ongoing education preferences of physicians.

Strategy 5.2 A training plan will be developed and implemented.

The NHSP Advisory Committee and the HI-EHDIQI team will design a training plan based on the needs identified in the physician survey. The training plan will include taking small steps to address specific training topics, and using PDSA cycles to test the effectiveness of each step.

*Measures*

5.2.1 A training plan will be developed and approved by March 31, 2015

5.2.2 Rates of physicians participating in and completing training/education.

5.2.3 Satisfaction of physicians with education, as determined by a post-education survey.

5.2.4 Knowledge gain of physicians, as determined by a comparison of pre-education survey data with post-education survey data.

Strategy 5.3 Increase the awareness of, availability of, and access to physician resources.

A NHSP Advisory Committee work group is revising the Hawaii Practitioners Manual, a resource guide for PCPs. Revisions will continue in 2014; input from PCPs will be solicited to ensure the manual is user friendly and resourceful, including a survey to find out how the NHSP can help PCPs, what types of resources PCPs need, and effective ways for PCPs to access resources. Responses will inform strategies to improve communication between the PCPs, NHSP, and audiologists. The effort to strengthen collaboration and communication between PCPs, the NHSP office, audiologists, and other specialists aligns with the medical home concept and supports the initiatives of the grant funding.

*Measures*

5.3.1 The Practitioner's Manual will be finalized and approved by December 31, 2014.

5.3.2 The number of requests for manuals will be logged.



5.3.3 Pre-manual survey data will be compared to post-manual survey data to determine PCPs' and staff satisfaction with the manual, knowledge gain, and areas for further education/training.

Strategy 5.4 Collaborate with the AAP Chapter Champion to share updated EHDI information with PCPs via newsletter or emails.

In collaboration with the AAP Chapter Champion, the NHSP will distribute or forward periodic newsletters or new resource information to state PCPs. The resource information will be posted on the NHSP website; links to the website will be emailed to PCPs.

*Measures*

5.4.1 The number of information shares will be logged.

5.4.2 The number of requests for information from PCPs will be logged.

5.4.3 The number of hits on the NHSP website will be tallied using website analytics.