PROJECT ABSTRACT

Project Title: Reducing Loss to Follow-up/Documentation at All Stages of the EHDI System.
Applicant Name: Minnesota Department of Health (MDH)

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PROBLEM*:* While Minnesota's loss to follow-up rate is lower in most stages of the EHDI process compared to the national average, a recent review of data shows that approximately 3.5% of children born were not reported as receiving an initial screen. Almost 11% of children who did not pass their initial screen at birth were not documented to have received a follow-up rescreen (8.3%) or confirmed diagnosis (2.6%). Once confirmed, the EDHI program is only able to assure that 55% of children were actually enrolled into an early intervention program. The primary purpose of this initiative is to reduce the number of infants who are lost to follow-up/documentation at each stage of the EHDI process.

GOALS AND OBJECTIVES: Goal 1) The MDH will assure that families of infants identified with hearing loss will have appropriate linkage to medical, audiologic, family-to-family support, intervention services and community resources. Objectives include 1) Develop and mobilize partners to promote changes and advance adoption of best practices in systems for care of children who are deaf or hard of hearing 2) Enhance current systems to connect families to existing resources 3) Eliminate disparities for early intervention and connection to resources among children with hearing loss because of linguistic, cultural or financial barriers. 5) Develop and utilize EHDI Follow-up Self Assessment Tools. Goal 2) The MDH, along with state and local partners, will reduce loss to follow-up and delays to EHDI services/supports through the enhancement of existing state systems. The Minnesota EHDI Program will decrease loss to follow-up/documentation (LTFU/D) at each stage of the EHDI process as follows: 1) decrease from 3.5% to 1.0 % the number of children LTFU/D that did not receive an initial newborn hearing screen; 2) decrease from 8.3% to 3% the number of children LTFU/D between the initial hospital screen and rescreening; 3) decrease from 2.6% to 1% the number of children lost LTFU/D between rescreening and audiologic diagnosis; 4) decrease from 45% to 15% the number of children LTFU/D between initial diagnosis of hearing loss and entry into a program of early intervention.

METHODOLOGY: Goal one of the project will utilize the Breakthrough Series Collaborative framework and the "Model for Improvement" to enhance existing systems and assure children with a hearing loss are offered enrollment into early intervention (Part C) and are connected to early supports and services. Goal 2 of the project aims to employ a proven follow-up model successfully implemented by the MDH Perinatal Hepatitis B Prevention program. Follow-up services and documentation in the EHDI Surveillance system will be assured by utilizing local public health nurses to facilitate and report rescreening, diagnosis, and connection to early intervention services.

COORDINATION: Local Public Health; Families/ MN Hands and Voices; Early Intervention – Part C; MN Departments of Education & Human Services, 16 Regional EHDI teams; Medical Home Providers; and the Newborn Hearing Screening Advisory Committee

EVALUATION: MDH will have ongoing process and outcome evaluations to determine the reduction in the rates of loss to follow-up and to determine which activities are completed on time, their degree of completeness, & quality. Evaluation will include bi-monthly data analysis to determine loss to follow-up rates at each stage of the EHDI process MDH will use performance measures, data reports, parent surveys & health indicators to monitor the effectiveness of the linkage system to ensure that families of infants identified with hearing loss will have appropriate referral to early intervention and services.

OVERALL PROJECT ACCOMPLISHMENTS (REDUCING LOSS TO FOLLOW-UP)

The purpose of this project is to enhance existing systems to reduce the number of infants who are lost to follow-up/documentation at each stage of the EHDI process and to assure children with a hearing loss are connected to early supports /services. The EHDI Community Collaborative project (Goal 1) has been working to establish a foundation for improvement of the Early Hearing Detection and Intervention System through the Institute of Health Improvement Breakthrough Series™ Model for Improvement since April 1, 2008. The addition of supplemental funds in September 2009 (Goal 2) has provided opportunity to enhance local public health engagement in the EHDI Collaborative and spread successful strategies throughout Minnesota that were identified as a result of the Model for Improvement within the EHDI Collaborative. This tested strategy employs an existing system and proven model in which MDH will contract with local public health nurses to facilitate and document rescreening, diagnosis, and connection with early intervention programs for families whose infants are lost to follow-up. By reimbursing for facilitation of services and documentation of milestones achieved in the EHDI service delivery system, the MN EHDI surveillance system will more accurately discern true loss to follow-up and best identify actual gaps in the system in need of further intervention/improvement.

Steering Committee has continued provide guidance on the EHDI Community Collaborative project including the development of a Collaborative Aim and Measures. During year two of the Collaborative, measures were narrowed to focus specifically on identified loss to follow up elements that will best be targeted for improvement. This approach in addition to the initiation of public health follow up of identified loss to follow up cases provides a very strong foundation for steady improvement to Minnesota's EHDI loss to follow up rate, especially in the 6 areas of the state that have active community collaborative teams.

PROGRESS ON GOALS AND OBJECTIVES

Goal #1:

The Minnesota Department of Health along with state and local partners will assure that families of infants identified with hearing loss will have appropriate referral and connections to medical, audiologic, and intervention services (including family-to-family support) and community resources by six months of age.

MDH is using the following key elements of the Breakthrough Series to accomplish our grant goal (Figure 1):

1) Faculty recruitment
2) Development of Framework and Changes
3) Enrollment of Participating Organizations and Teams
4) Learning Sessions
5) Action Periods (Model for Improvement)
6) Summative Congresses and Publications
7) Measurement and Evaluation

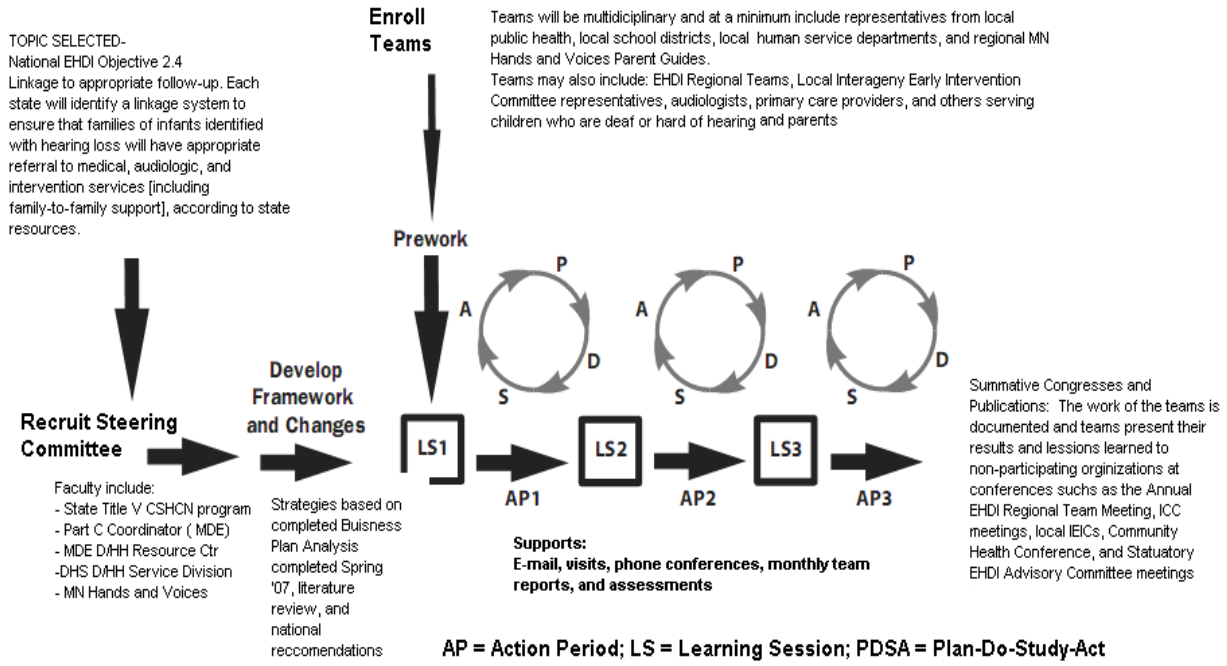

Figure 1: EHDI Follow-up Collaborative Model for Improvement

<u>Objective 1:</u> By March 2011, develop and mobilize policy and practice partnerships among state and local level government program leaders, community experts and families of children with a hearing to effectively promote changes and advance adoption of best practices in systems for care of children who are deaf or hard of hearing.

Activities:

<u>1.1) Identify, recruit, and train Steering committee (all three years of the grant).</u>
Minnesota has many state and local leaders and community experts in the area of hearing loss (including regional EHDI team members) able to mobilize and promote change within their communities. A key element of the Breakthrough Series is to recruit faculty to provide leadership to the project. The MDH EHDI Follow-up Coordinator, in consultation with the state EHDI team, and statutory Newborn Hearing Screening Advisory Committee have identified and recruited 16 experts including subject matter experts, application experts, and others who are familiar with the Breakthrough Series Model to make up the EHDI Community Collaborative Steering Committee. These experts represent the following agencies and positions:

Minnesota Department of Health (MDH)

- MDH Newborn and Child Follow-up Supervisor
- Public Health Lab EHDI Coordinator
- MDH Part C Planner
- Minnesota Children with Special Health Needs (MCSHN) District Nurse Consultant

Minnesota Department of Education (MDE)

- EHDI Education Coordinator, D/HH Resource Center

- EHDI Part C Coordinator

Minnesota Department of Human Services

- Supervisor - Deaf and Hard of Hearing Division
- Part C Representative

Minnesota Hands and Voices

- Coordinator/Parent

Other Community Partners

- Deaf Community Health Worker Project /Representative of an organization representing culturally deaf persons
- Clinical Audiologist – Minnesota Children's Hospital and Clinics
- Program Manager, Children, Youth and Families
  Hennepin County Human Services and Public Health
- Representative for the American Academy of Pediatrics Minnesota Chapter

Ad Hoc Members –

- MDH Section Manager, MCSHN /Title V
- MDH Medical Home Coordinator
- DHS Medicaid Representative

Collaborative Staff -

- EHDI Epidemiologist
- MDH EHDI Follow-up Coordinator
- MDH EHDI Coordinator

The Steering Committee meets bimonthly-quarterly and is responsible for establishing the vision of the Collaborative, providing leadership, and teaching and coaching for participating EHDI Community Collaborative teams. In addition, they are assisting to develop the framework and the specific curricula for the EHDI Community Collaborative Learning Sessions including appropriate aims, measurement strategies, and a list of evidence-based changes.

A few Steering Committee members have previous knowledge or have experience using the Model for Improvement as participants in other learning collaborative sessions (e.g. Medical Home, NICHQ National EHDI). However, others have had limited information about the Model. All members were given an orientation to the Model for Improvement and the Breakthrough Series at the initial Steering Committee Meeting (7/08). In addition, Steering Committee members joined the collaborative teams during the first three Learning Sessions (9/08, 1/09, 5/09,) as MDH's Quality Improvement Advisor, Jane Taylor, trained teams on the Model for Improvement and the Breakthrough Series. In November, 2009 MDH contracted with Richard Scoville, PhD to provide consultation to MDH staff as an improvement Advisor and support the development of the Early Hearing Detection and Intervention (EHDI) Community Collaborative Project. Dr. Scoville has expertise in the Institute for Healthcare Improvement Breakthrough SeriesTM Model for Improvement, including a history of work with the National Initiative for Children's Healthcare Quality (NICHQ) and the Institute for Healthcare Improvement (IHI). He participated in the August 2009 Steering Committee meeting providing consultation as the Committee developed a driver diagram for the project. Steering Committee members were also invited to participate in Learning Session Four (10/09) .

1.2) Identify, recruit and train local EHDI Community Collaborative teams

Another key element in the Breakthrough Series is to identify and enroll participants into the EHDI Community Collaborative. In the first year, four EHDI Community Collaborative Teams were formed and include representatives of local organizations that are essential in connecting families of children with hearing loss to resources and support services. In the second year, two more EHDI Community Collaborative teams were recruited. Team membership includes local public health agencies, local school districts, and local departments of human services. Teams include parents of children with hearing loss and Minnesota Hands and Voices Regional Parent Guides. Most teams include a clinical audiologist as a critical member of the established team. Collaborative teams represent rural, suburban, and urban areas of Minnesota. Teams were also recruited to represent culturally and linguistically diverse communities.

MDH staff in collaboration with the Steering Committee developed a Charter for the Collaborative to clarify the Collaborative processes, roles, and expectations of organization leaders and team members.

1.3) Enhance capacity and infrastructure for MCSHN staff to use quality improvement methods. (year one)

An Improvement Advisor is devoted to helping identify, plan, and execute improvement projects throughout the Collaborative, deliver successful results, and spread changes throughout the entire system. within year one of the grant, an Improvement Advisor consultant working with the ongoing Minnesota Medical Home Collaborative was instrumental in introducing the Breakthrough Series Model for Improvement to MCSHN EHDI staff, the EHDI Steering Committee and the EHDI Collaborative teams. In year two an Improvement Advisor was hired as a consultant to work with the EHDI Community Collaborative project coordinator to shape EHDI Community Collaborative activities, assessment and evaluation. The Improvement Advisor also was the primary presenter of the Model for Improvement and coaching of EHDI Community Collaborative teams. He will continue to be involved throughout years two and three of the grant.

1.4) Participation in National EHDI Learning Collaborative **(COMPLETED):**

Minnesota participated in the National EHDI Learning Collaborative: Improving the System of Care For Children and Youth with Special Healthcare Needs. This Collaborative was developed & facilitated by the National Initiative for Children's Healthcare Quality (NICHQ).

The Minnesota team attended each of the three Learning Sessions held, collected and submitted monthly data via the extranet, participated in monthly calls, and held monthly-quarterly team meetings. As a result of the Collaborative, significant progress was made reducing lost to follow-up at three months of age; communication with primary care providers, specialists, and the state EHDI program; and connection to family support. The Team also was successful in the development and testing of a Roadmap for Minnesota Families (from diagnosis through one year). Improvements made as a result of the Collaborative were shared at the 2009 EHDI National Conference (poster presentation).

Measures (years one and two):

1. By June 08, the Steering Committee will be appointed and represent various disciplines and expertise including parent-to-parent support, health, human services, and education (achieved)
2. By Aug 08, Steering Committee will meet regularly (monthly during year one and at least quarterly in years two and three). (achieved)
3. By Aug 08, three-four teams will be enrolled into the Collaborative. (achieved)
4. By September 08, teams will attend the first Collaborative Learning Session. (achieved)
5. By September 09, two additional teams will be added to the Collaborative. (achieved)

Objective 2: By March 2011, a system will be in place within each EHDI Community Collaborative team community to effectively connect families to existing resources for children with hearing loss.

Activities:

2.1) Steering Committee creates the framework and Change Package for the Collaborative –

In August 2009, the project Steering Committee and MDH Follow-up Staff in conjunction with the Improvement Advisor developed an EHDI Driver Diagram. This tool is used to conceptualize an issue and its system components that help to demonstrate a pathway to achieve the desired outcome. The diagram defined a list of EHDI processes designed to target specific loss to follow up activities. EHDI Surveillance data was reviewed and priority processes were chosen for areas that have the highest loss to follow-up rates (i.e. Diagnosis to Early Intervention). Data indicators were re-defined to measure changes in local and state loss to follow up related to the priority processes including entry into timely services. (Table 1):

EFFECTIVE AUDIOLOGY PROCESSES AFTER DIAGNOSIS OF HEARING LOSS	Data Measure
1) Audiologist(s) routinely confirms hearing status within one month of referral (including children with middle ear concerns)	HAF
2) Audiologist(s) routinely refers families to Hands & Voices immediately after diagnosis	
3) Audiologist(s) routinely refers families to Help Me Grow immediately after diagnosis	D2HV
4) Audiologist(s) routinely completes hearing aid fitting within one month of diagnosis (all parents who want child to listen/speak)	HAF, HAFLO*
5) Audiologist(s) inform family of ALL resources/services available (i.e., financial, Help Me Grow, therapy, hearing aid loan bank)	EPC
6) Audiologist(s) provide family with unbiased, culturally/linguistically appropriate materials (including the Parent Road Map)	
7) Audiologist(s) emphasize families learning about all communication options before making a choice.	

II. EFFECTIVE, INTEGRATED PROCESSES AFTER REFERRAL TO EARLY INTERVENTION	
1) Coordination of contacts to families (i.e., Coordinate the order and timing of contacts with family)	D2HV
2) Families receive needed resources for financial, social, medical linkage issues (related to completing audiology and amplification)	HAF, HAFLO*
3) Families receive contact from Hands & Voices promptly after diagnosis (initial referral from community)	D2HV
4) Help Me Grow promptly involves a teacher of the deaf and hard of hearing (DHHT) or other specially trained provider (initial contacts, assessment, IFSP development) (only for Help Me Grow)	EPC
5) Community supports broad, interagency, active IFSP team memberships as appropriate to each child and family including public health as appropriate and private therapists, Deaf role models, etcetera based on family choice to receive these services.	
6) Hands & Voices, Help Me Grow, Public Health all inform family of all resources/services available (i.e., financial, therapy, expertise in different communication choices, hearing aid loan bank, etc) via widely available community-specific information	
7) Provide family with unbiased, culturally/linguistically appropriate materials (including the Parent Road Map)	
III. EFFECTIVE PROCESSES AFTER INITIATION OF EARLY INTERVENTION SERVICES	
1) Provide the family with unbiased information on communication choices (including a means to know that this occurs)	
2) Provide ongoing services to family from a DHHT or other specially trained provider with expertise in the family's chosen communication method(s) (Help Me Grow, Public School, Deaf Role Model, Private Therapist or other specialized DHH program)	
3) Link the family to providers with expertise in the family's chosen communication method(s)	
4) Link the family to other families with experience in using the family's chosen communication method(s) (including means to know this occurs)	
5) Assess communication development at a minimum of 6 month intervals using MDE recommended protocol (electronic reporting - pending)	CDM
6) Share the trajectory of language development with families so that data-driven decision making can occur (including a means to know that this occurs)	
IV. INTEGRATED CHILD FIND ACTIVITIES SPECIFIC TO CHILDREN AT-RISK FOR HEARING LOSS	
1) Integrating/coordinating EHDI child find activities into the current interagency early intervention child-find system (local, regional, state)	LTFU, HAF, HAFLO*
2) Providing ongoing public awareness of the importance of EHDI through a variety of media	

and specific to various cultures and community groups (families of DHH children, families of young children, expectant parents, professionals, general public, service organizations, philanthropic organizations, etc)	LTFU, D2IFSP
3) Preventing loss to follow up of all children by actively supporting the referral of those with congenital hearing loss to early intervention services and supports by 3 months of age (community members are aware of urgency for prompt intervention)	LTFU, EPC, D2IFSP
4)Actively supporting the identification and entry into services for children with late-onset hearing loss throughout childhood	LTFU, HAFLO*

These MDH data elements are the measures anticipated to improve as EHDI Collaborative Teams develop and implement effective processes.

Key	**Data measures for children up to age 3 with a permanent hearing loss (PHL)**	**Numerator**	**Denominator as reported to MDH (MN residents)**
LTFU	Percent of infants with known permanent hearing loss who are lost to follow-up	Children missing a hearing aid fit date and not enrolled in Part C by 3 months post-diagnosis	All children with a PHL, 3 years or under, excluding those who declined amplification or Part C
HAF	Time from diagnosis to date of hearing aid fitting *(reported as mean, median and mode # of days, range of days, and % within 1 month)*	Children for whom a hearing aid fit date is on file with MDH	All children with a PHL, 3 years or under, excluding those who declined amplification
HAFLO *	Percent of children with late onset hearing loss receiving services/amplification in one month	Late onset children for whom a hearing aid fit date is on file with MDH, and date of fit is within 30 days of diagnosed hearing loss	All children with a PHL, 3 years or under, who passed their newborn screen, excluding those who declined amplification
D2HV	Time from diagnosis to date of contact with Hands & Voices *(reported as mean, median and mode # of days, and range of days)*	Families reported as having been personally contacted by MN Hands & Voices	All families with a child with a PHL, 3 years or under, referred to MN Hands & Voices by MDH
EPC	Percent enrolled in Part C	Children with an IFSP date on file with MDH	All children with a PHL, 3 years or under
EOEI*	Percent enrolled/participating in other early intervention services	Children for whom participation in other EI services is reported (e.g., Follow Along, clinical therapy)	All children with a PHL, 3 years or under
D2IFSP	Time from diagnosis to date of IFSP *(reported as mean, median and mode # of days))*	Children with an IFSP date on file with MDH	All children with a PHL, 3 years or under
CDM	Number of children that received communication	Children for whom communication development assessment was	PHL caseload, 3 years or under, due for

	monitoring per MDE protocol	completed (monthly/cumulative)	communication assessment during reporting period

*HAFLO and EOEI will begin to be collected in 2010.

Table 1. Crosswalk between process change measures and state data collection measures anticipated to improve as EHDI Collaborative Teams develop and implement effective processes.

2.2) Plan and implement Collaborative Learning Sessions (2 in year one, 3 in year two, 3 in year three)

In year one, two face to face meetings (Learning Sessions) were conducted (September 08 and January 09), bringing together the multidisciplinary teams (40 participants) from each community and the expert faculty to exchange ideas. In year two there have been two face-to-face Learning Sessions conducted (May 09 and October 09). A Web Ex Learning Session is planned for February 10. In year three of the project a face-to-face Learning Session will be held at the end of April 2010, another in October 2010 and the final Learning Session will be held in February 2011.

An important part of each Learning Sessions is training in the Model for Improvement by the Improvement Advisor. This Model will enable teams to test these powerful change ideas locally, and then reflect, learn, and refine these tests. During the October 09 Learning Session each EHDI Community Collaborative Team performed a self assessment of the processes in Table 1, prioritized their needs, developed an aim statement and planned for Plan-Do-Study-Act small tests of change to occur during the intervening three month period until the Learning Session to be held in February 10, 2010. Specific change package ideas were introduced from the NICHQ change package that has been made available nationally in order to assist the teams in their planning of possible activities for small tests of change.

Evaluations of the Learning Session conducted in October 2009 showed the difference in knowledge base between the experienced teams from year one and the newly recruited year two teams. Although the year one teams appreciated some repetition of the Model for Improvement and conducting small tests of change, they would have appreciated more team planning time whereas the new year two teams required the lengthy introduction and explanation of the Model for Improvement.

2.3) Assist and assure teams utilize the Plan-Do-Study-Act cycles (See PDSA and AP cycles in Figure 1)

Using the results of their self assessment and identified areas of focus, teams have implemented the "Plan-Do-Study-Act" (PDSA) cycles of learning. Through this cycle, teams plan to test the change, taking into account their various communities and organizational characteristics. Teams have planned needed changes to their procedures and will track progress using quantitative measures specified by MCSHN EHDI. The teams have studied the results of implementation and have gained insight on how to improve and determine whether to make the successful changes permanent or to adjust the changes that need more work. This process continues and refinement is added with each cycle. During the Action Periods (AP), teams will continue to be

supported by EHDI follow-up staff through scheduled conference calls, site visits, and e-mail consultation. The focus of conference calls and WebEx meetings that involve all of the collaborative team members is to share information with each other. This process has built collaboration and offers support to the organizations as they try new ideas and test changes.

2.4) Collect data monthly from teams

In year one, collaborative teams have been required to regularly collect and submit data on all key measures. A change in year two includes additional focus of the teams to evaluate their own priorities and only report on 3-6 key measures. Outcomes of the Collaborative will be measured by improvement in loss to follow up data items identified in Table 1. The reports have been sent to the MDH monthly. The MDH EHDI Epidemiologist regularly assesses the data and reports to the Collaborative Steering Committee monthly. The Committee reviews reports to assess the overall progress of the Collaborative and offers strategies for improvement. Teams have been given a small financial payment ($150/month) to submit data on a monthly basis through a contract with Minnesota Hands and Voices. The money is be used to assist the teams as a resource for further PDSA cycles and must be related to their Collaborative Aim.

MDH Follow-up Staff in consultation with the Steering Committee distributed a survey (May. 2009) to families of children (birth-3) with hearing loss in the Collaborative Regions. There was a 50% response rate on the survey which determined: 1) parents' perceptions of needs related to their child; 2) child's insurance coverage and use of other reimbursements; 3) language or cultural barriers encountered in parents' past experiences with accessing care for their child; 4) parents' perceptions of successes and barriers in accessing care and early intervention services for their child. Results of the survey have been used to evaluate progress and improvements related to the Collaborative goals and shaped the selection of specific processes of focus for collaborative team work. Survey results indicate:

- 100% of respondents spoke English.
- Approximately 30% (5/18) of the respondents had medical assistance as their primary or secondary insurance.
- 11% of families (2/18) indicated that during the past 12 months, there was a time when their child with a hearing loss was not covered by any health insurance.
- 94% of families indicated that they were very satisfied or satisfied with their health professional's knowledge/experience in working with infants and young children with hearing loss.
- 85% of families (12/14) indicated that they were very satisfied or satisfied with the care and services their child received from professionals in their child' Early intervention Program and on their child's IFSP team.

2.5) Review and report data to local, state, and national audiences (i.e. teams, Newborn Hearing Screening Advisory Committee, Part C

Aggregate data have been reported to teams during Learning Sessions in order to spread strategies that are effective. It is anticipated that reports will again be presented to the Newborn Hearing Screening Advisory Committee in 2010 to remain transparent with our stakeholders. The expansion toward outcomes beyond the standard '1-3-6' reporting for EHDI has been due to participation in the national and local learning collaboratives, and has greatly influenced the way in which the MN EHDI program views and presents its data. Specialized data have also been furnished to stakeholders, such as to the family support organization under contract to the MDH, and in ongoing communication with the MN Dept of Education (MDE), as to drive continued quality improvement efforts. Finally data has been shared with the steering committee as to best inform their capacity to create the framework for the collaborative and on an ongoing basis as to facilitate advice on further directions for the collaborative.

Monthly reports of region-specific data are provided alongside statewide rates for measures so that teams can see how their region compares to the MN average. See Table 1 for the data elements reported. Additional outcomes will be included in future reports as additional activities are rolled out in early 2010 that will cover hearing aid fit dates for children with late onset hearing loss and percent enrollment in early intervention services.

With the identification of specific data to be collected to measure collaborative success the data shown on Table 2 will be used as a baseline to measure change starting in 2010.

Key	**Statewide**	**Counties in Collaborative**	**Counties not in Collaborative**
LTFU Percent of infants with known permanent hearing loss who are lost to follow-up	Of the 107 families, one declined amplification, an additional 7 declined EI, leaving 99 families. Of those 99, EI closed one case and determined one not to be eligible for services, leaving 97. Of the 97, there were an additional 4 who asked not to be referred to EI, leaving 93. Of the 93, 61 were missing a HA fit, and of those 41 had no IFSP on file. Therefore, 41/93 = 44% were considered 'lost to follow-up'	Of the 93 active/eligible cases, 30 families lived in counties participating in the collaborative. Of the 61 that had no fit date on record, there were 19 that lived in counties participating in the collaborative. Of these 19, 10 were also without an IFSP date. Therefore, 10/30 (33%) were considered 'lost to follow-up'	93 active/eligible cases, 63 families lived in counties participating in the collaborative. Of the 61 that had no fit date on record, there were 42 that lived in counties participating in the collaborative. Of these 42, 31 were also without an IFSP date. Therefore, 31/63 (49%) were considered 'lost to follow- up'
HAF Time from diagnosis to date of hearing aid fitting	Of the 107 families, one declined, resulting in 33 of 106 (31%) whom were fit with hearing aids. Mean 54 days Median 36 days Mode 36 days Range 13 to 227 days	Of the 33 families, 12 (36%) were fit with hearing aids. Mean 62.5 days Median 36.5 days Mode #N/A Range 13 to 227 days	Of the 74 children, one family declined, resulting in 21 of 73 (29%) whom were fit with hearing aids Mean 49 days Median 36 days Mode 35 days Range 16 to 164 days

D2HV Time from diagnosis to date of contact with Hands & Voices	Of the 101 children referred, 78% were contacted. Mean 59 days Median 41 days Mode 62 days Range 3 to 347 days	Of the 31 children referred, 87% were contacted. Mean 65 days Median 32 days Mode 56 days Range 3 to 341 days	Of the 70 children referred, 74% were contacted. Mean 56 days Median 45 days Mode 41 days Range 6 to 347 days
EPC Percent of children enrolled in Part C	Of the 102 active cases, 6 declined services, 1 was determined to be 'not eligible' per EI, and one case EI closed, leaving 94 cases, of which 34 have an IFSP date on file (36%).	Of the 32 children, 1 was determined to be 'not eligible' per EI, and one case EI closed, leaving 30 cases, of which 15 have an IFSP date on file (50%).	Of the 70 children, 19 have an IFSP date on file (27%).
D2IFSP Time from diagnosis to date of IFSP	Of the 34 dates on file, 7 were prior to a dx of a hearing loss, leaving 27 dates on which to run data: Mean 89 days Median 54 days Mode 46 days Range 7 to 373 days	Of the 15 dates on file, 3 were prior to a dx of a hearing loss, leaving 12 dates on which to run data: Mean 96 days Median 67.5 days Mode #N/A Range 39 to 262 days	Of the 19 dates on file, 4 were prior to a dx of a hearing loss, leaving 15 dates on which to run data: Mean 83 days Median 54 days Mode 46 days Range 7 to 373 days
HAFLO *	Percent of children with late onset hearing loss receiving services/amplification in one month	Not yet available	Not yet available
EOEI*	Percent of children enrolled/participating in other early intervention services	Not yet available	Not yet available

*HAFLO and EOEI will begin to be collected in 2010.
Table 2. Baseline measures to track change and monitor progress among the EHDI collaborative

The most notable progress to date on the statewide level since the start of the EHDI Community Collaborative project has been seen with data on those children "lost", representing those who have failed a hospital hearing screen and have not been reevaluated, as well as in the documentation of parent-to-parent support. State-added measures regarding parent-to-parent support and specialist visits have led to protocol changes as a direct result of PDSA cycles under the collaborative model for improvement. Furthermore, with the addition of referral to public health for identification/tracking of lost to follow-up cases it is anticipated that rapid improvement may occur in statewide loss to follow-up rates.

Objective 3: By March 2011, expand the Medical Home concept to include co-management of a medical home between primary care practitioners and specialists for children with hearing loss in Minnesota.

Activities:

3.1) The Minnesota Medical Home Collaborative project ended in June 2009 after 5 years of activity. As such, it is no longer possible to partner to conduct Learning Sessions in concert with the existing Medical Home Teams.

3.2) Enhance the coordination of services between audiologists, specialists, and primary care providers for children with hearing loss.

While service coordination through the Early Intervention system is essential for families of children with hearing loss, the Early Intervention (Part C) system can not work single-handedly. Providers such as audiologists and primary care providers are also responsible for ongoing care and coordination, particularly for connections to medical (genetic, ophthalmology) and audiolgic services. The EHDI Collaborative includes clinical/diagnosing audiologists on both the Steering Committee and within the local EHDI Community Collaborative teams. The Committee will continue to be asked to develop recommendations specifically to address improvements in coordination of care.

The MCSHN EHDI follow-up staff implemented new procedures including a fax-back communication form to primary care providers that has improved communications between MDH and primary care regarding specialists, early intervention, and audiology.

Measures (year one):

By October 2008, Learning Session evaluations will reflect satisfaction with holding the sessions in concert with the Medical Home Collaborative. (achieved)

Objective 4: By March 2011, eliminate disparities related to enrollment into early intervention and connection to resources among children with hearing loss because of linguistic, cultural or financial barriers.

Activities:

4.1) Identify and recruit community teams serving families with linguistic, cultural or financial differences.

Each of the 6 community teams serves families with linguistic, cultural or financial differences and have applied the Model for Improvement to specifically address disparities.

4.2) Identify and include strategies within the Change Package and measurement strategies that address improvements to reduce and eliminate disparities due to linguistic, cultural, or financial barriers.

Through the NICHQ National EHDI Learning Collaborative, a MN Parent Roadmap for Children with Hearing Loss (from diagnosis through the first year) has been developed and translated into Spanish.

MDH Follow-up Staff in consultation with the Steering Committee developed a parent survey that was distributed (May 2009) to families of children (birth-3) with hearing loss in the Collaborative Regions. Unfortunately, none of the identified Spanish speaking families in the collaborative areas responded to the survey.

Another initiative has begun to improve child find and follow through by families of children with hearing concerns from diverse cultures. A television program is under development titled "Childhood Hearing Loss and Deafness" that will be targeted to families that are Somali, Hmong, Spanish speaking or low-literacy English-speaking families. It is anticipated that these television programs will be aired in April and May 2010 on cable and public television stations throughout Minnesota and then be available via the internet.

Measures: no data at this time

Objective 5: By March 2011, develop and utilize EHDI Community Self Assessment/Measurement Tools including The EHDI Community Index and The EHDI Community Family Index (based on the Medical Home Index and The Medical Home Family Index).

As staff learn more about coordinating the EHDI Learning Collaborative , the need for an EHDI Community Self Assessment/Measurement tool becomes even more apparent. This tool can translate broad indicators of an effective referral and coordination system offered through Part C into observable, tangible behaviors, and processes of care and coordination. It is understood that creating communities that seamlessly coordinate and connect families to services is a process. Like the Medical Home Index, this tool will measure a community's progress in this process.

Beginning development of a self assessment tool has begun by MDH staff. Best practices based on staff expert knowledge are reflected thus far in the tools development. Further analysis and review of evidence based practices utilized by Minnesota and other states still need to be accomplished. Additionally, further collaborative input from stakeholders is needed.

During Learning Session #4 (10/09), teams were asked to use excerpts from the draft assessment tool to identify and rate their processes in the following areas:

- Effective audiology processes after diagnosis of hearing loss
- Effective, integrated processes after referral to early intervention
- Effective processes after initiation of early intervention services
- Integrated child find activities specific to children at risk for hearing loss

A standard guide was used for each of the teams to rank their effectiveness in the above processes. Teams ranked themselves from 0 (process is not defined/ unknown) to 5 (routine

measures of the process are integrated into services and may be reported. Process outcomes predictable. The process consistently meets the needs of children and expectations of all families and/or providers). The majority of teams were surprised that in each of the above areas, processes in their communities were NOT well defined and ranked themselves as 0-2.

The debriefing during this session provided an opportunity for teams to discuss the need for standard process and they reached the conclusion that unless they worked on standardizing their process, the chances of failure were high. Teams prioritized the processes that they wanted to work on first. Teams will report monthly on improvements in the process areas they chose to focus on.

Goal#2:

The Minnesota Department of Health, along with its local partners will reduce loss to follow-up and delays to EHDI services/supports through the improvements in existing state systems.

Objective 1: By March 2011, decrease the number of infants lost to follow-up/documentation that did not receive an initial newborn hearing screen in the hospital from 3.5 percent to no more than 1.0 percent.

Activities:

1.1) Hospital training including documentation requirements & current best practice guidelines

All hospitals have been provided with Minnesota's current best practice screening guidelines via a mailing in September, 2009. Specific education and training at six on-site hospital visits focused on reporting the final in-patient hearing screening result to the MDH Newborn Screening Program, documenting the correct primary care provider, providing results to the parents and scheduling an appointment for follow-up before hospital discharge.

1.2) Development and implementation of follow-up protocol for MDH staff which includes timely notification to hospitals of all children without documented screening at 15 days of age.

Having a consistent follow-up protocol has proven successful in the timely follow-up of infants who did not pass an initial hearing screening. Using a similar approach, a consistent protocol for all infants without a documented hearing screening is being drafted by the MDH Public Health Lab Newborn Screening Program. The protocol will be refined and enhanced through small tests of change and implemented through collaboration with local public health.

The MDH Public Health Lab will develop and implement a new follow-up protocol for program staff to identify infants not screened at birth. By law, it is the responsibility of the hospital to assure that all newborns born in that hospital have been screened. The newly developed protocol will include notification to individual hospitals of those children without a documented screen at

15 days of age. Technical assistance will be provided to hospitals on how to improve reporting, screening, and follow-up screening.

Objective 2: By March 2011, decrease the number of infants lost to follow-up/documentation between the initial hospital screens and rescreening from 8.3 percent to 3 percent.

Activities

2.1) Develop and implement a follow-up strategy for local public health agencies to facilitate rescreening of children lost to follow-up

Connections to local public health agencies will be vital in the implementation and outcome evaluations for this project. In the original UNHSI grant, Minnesota Maternal and Child Health (MCH) coordinators identified local public health agencies role and shared responsibility for follow-up as defined under Minnesota's Local Public Health Essential Activities. Performance measures already established through these essential activities include improved outcomes based on the elimination of health barriers and disparities as well as cultural competence with diverse populations public health nurses support on a routine basis.

There are 54 Community Health Boards in Minnesota covering all of its 87 counties. There are also eleven Tribal Agencies. All boards and agencies have been given an opportunity to participate in the project. Contracts outlining the expectations for participation in this granting opportunity have been developed and distributed to boards and agencies.

MDH regional and district staff have be used to gain robust multi-level local public health support for the project. Regional MDH Public Health Nursing Consultants have presented information at the county administrative/director level to engender global buy-in and commitment to the project. A key strategy was to present a comprehensive fee-for-service and outcomes-based plan to directors at regional meetings in September and October 2009. Meeting objectives included education, project rationale, and reimbursement strategies to engender support and a commitment for local public health's participation in the follow-up plan. The EHDI team exhibited information and resources at the director level through the Community Health Conference in October of 2009. County specific data identifying the current status of loss to follow-up was distributed to directors on an individual county basis. MDH staff was available to answer specific questions and to promote participation in the grant. MCSHN District Staff and the EHDI staff met with local MCH Coordinators and other local public health nurses at regional meetings in order to promote a more grass-roots approach. Those agencies that agree to participate in the project will execute an amendment to existing MDH contracts with Community Health Boards.

Current county and tribal agency interest in the project has been strong, with over 75 percent indicating they will contract with MDH to close the gap on loss to follow-up. Those willing to participate in the follow-up strategy will identify one public health nurse in each county or tribal agency as the EHDI liaison and content expert. Training has been developed targeting a

systematic community-based approach to locating each child identified as deaf or hard of hearing or in need of follow-up testing. Training will focus on the role of the public health nurse as coordinator from the initial failed screening in the hospital, to the facilitation of the re-screen and confirmed diagnosis, and the public health nurse's role in ensuring children are given the opportunity to enroll in Early Intervention. The vision is to drill down the training to an operational level, with the public health nurses as case coordinators ensuring children are not lost to follow-up. These nurses are uniquely suited to this role as they work in concert with education, human services, health care, community organizations, families, and children on a routine basis in their local communities. They also have established connections to federal, state, and local partners and participate actively in identifying best practices through research and data reporting. Ultimately, the nurse is a partner in referral and case management in the current Part C Early Intervention system. As noted in Goal 1, public health nurses fill an important roll in the collaborative teams and have been identified as key participants on a dual approach involving their participation in the teams and as key liaisons to the medical community. and families. Nurses will be trained in the remaining months of 2009 and as contracts are received in 2010. Webex online training will be available and reinforcement through written materials and support will continue on a case-by-case basis as children are identified and contracts are returned. It is the expectation that the key content expert from each county will complete the training before invoices submitted to MDH are honored.

Local public health will facilitate screening/rescreening and report to MDH. The Public Health Lab Newborn Screening Program will notify local public health if a child was not screened at birth or needs a rescreening and has been determined to be lost to follow-up. LPH will facilitate initial screening or rescreening. Some LPH Agencies will also be provided with OAE equipment and training to rescreen children if necessary and will be required to report data to MDH. (This equipment has already been purchased by the Minnesota Children with Special Needs section of MDH through funding outside the scope of this grant and will be used to ensure the success of the supplemental grant. Information regarding the opportunity to obtain OAE equipment has been given to each county agency. Directors and county supervisors have indicated a high level of interest in the utilization of these tools in home visiting and through other county programs. Now that interest has been established, an equitable method for determining distribution and use of the equipment will be identified using current demographic and loss to follow-up data. Logistics, protocol and methods for using the equipment to reduce loss to follow-up will be determined by location and demographics)

Data elements needed in reports to MDH have been defined. These elements are: the confirmation of demographic information, confirmation that MDH has received screening results from the audiologist or health care facility,, rescreening date, facility, future appointments and verification of the primary care provider and their name and address. All defined data elements will be required for local public health to receive reimbursement for case coordination.

2.2) <u>Decrease refer rates by identifying hospitals with high refer rates and providing enhanced technical assistance and training.</u>

A quality assurance report will be run monthly to identify hospitals with refer rates greater than four percent. The 10 hospitals with the highest refer rates (weighted by birth numbers & refer

rate) will be contacted via letter as well as email and/or phone regarding measures for program improvement. Typically, assistance will include: a review of the hospital's hearing program policy and procedure for alignment with current Minnesota best practice guidelines, educational materials for parents, community, and screeners; refresher training for screeners regarding early hearing detection and intervention, and hands-on hearing screening training.

Objective 3: By March 2011, decrease the number of infants lost to follow-up/documentation between rescreening and audiologic diagnosis from 2.6 percent to 1 percent.

3.1) Develop and implement a follow-up strategy for local public health agencies to facilitate diagnosis of children lost to follow-up.

Information for this activity involving local public health agencies is contained in the sections above and includes the reporting actions related to the facilitation of diagnosis and reporting. Data elements have been defined and include the date of evaluation and next appointment, the diagnosing facility, audiologist and verification of the primary care provider and their contact information.

3.2) Provide the National Center for Hearing Assessment and Management (NCHAM) comprehensive diagnostic and management training, for selected audiologists based on need to enhance the use of best practice guidelines and reporting.

MDH staff has begun to identify audiologists interested in attending the National Center for Health Assessment and Management (NCHAM) Diagnostics and Amplification for Infants & Toddlers Workshop and the criteria that will be used to select the audiologists that will attend. An e-mail notification about this opportunity has been sent to all audiologists who have provided diagnostic reports to the MDH within the last few years. In year 1 of this grant, Minnesota plans to send nine audiologists who currently assess, diagnose, and provide ongoing amplification for infants and toddlers to this training.

Audiologists who agree to attend will be asked to test the reporting of screening, diagnostic, and follow-up results through the new MDH Minnesota Electronic Disease Surveillance System (MEDSS).

Objective 4: By March 2011, decrease the number of infants lost to follow-up/documentation between initial diagnosis of hearing loss and entry into a program of early intervention from 45 percent to 15 percent and assure that families of children diagnosed with hearing loss have been connected to supports and services within 6 months of diagnosis.

4.1) Develop and implement a follow-up strategy for local public health agencies to facilitate connection to services and support of all children diagnosed with a permanent hearing loss.

Information for this activity is contained in the sections above but also includes the reporting actions related to the facilitation of connections to initial services. Reporting data include: Individual Family Service Plan (IFSP) and its initial date, name and contact information for the service coordinator, ear nose and throat (ENT) evaluation date, current audiologist/facility and contact information, date of hearing aid fit, loaner hearing aid status, insurance status, known risk factors, verification of primary provider and connections to family-to-family support. Data elements listed as required for this activity must be reported completely for reimbursement for this set of interventions for loss to follow-up.

Additionally, local public health agencies will provide six month post diagnosis connections to supports and reporting. Reporting data has been identified and include the verification of the current primary care provider, a genetics evaluation date, ophthalmology evaluation date, the insurance status and information on required assistance with individual funding for hearing aids. Data elements listed as required for this activity must be reported completely for reimbursement for this set of interventions.

An integral tool to ensure the success of this project is the use and development of a direct link to the Minnesota Department of Health through the Minnesota Electronic Disease Surveillance System (MEDSS). MEDSS has been developed for use with other MDH health priorities, and since the initial grant application, work has been done to tailor the system to EHDI needs. The system allows direct communication from MDH to LPH as a vehicle for notification of those children lost to follow-up in each area, and the subsequent actions and data confirmation from LPH to MDH. Training for system use with EHDI is planned in concert with the training outlined above.

Staffing (current and staffing plan)

Newborn screening funds have been appropriated to the MCSHN Section to fund EHDI Follow-up staff. To utilize these and other existing resources, MDH have used existing EHDI program staff to implement many of the activities during the first two years of the grant.

In May 2009, MDH hired a program planner at 1 FTE to oversee the work of the Collaborative project for years two and three. Unfortunately, the planner will be leaving the position in mid-November. MDH plans to rehire a planner for the work of the Collaborative.

MDH planned to hire a grants manager to track follow-up and reimbursement for local public health agencies (goal 2). MDH has not yet been able to hire this position and no longer plans to use grant dollars for the grants manager position. Instead, the EHDI Collaborative planner position will take on some grant position responsibilities to better integrate the work of local public health agencies with the EHDI Community collaborative. Additional grants manager responsibilities such as tracking invoices and data entry will be completed by EHDI Program staff through newborn screening fee dollars.

In December 2007 the EHDI epidemiologist was hired and began working in January 2008. While funded through newborn screening funds instead of the grant, the EHDI Epidemiologist is

responsible to assist in EHDI related quality improvement activities and therefore will continue analyze team data, assist in the development of assessment tools, evaluate the project, and offer technical assistance to the grant activities.

Technical Assistance Needed

Continued training and technical assistance to staff on quality improvement strategies, specifically the Model for Improvement and the Breakthrough Series will assist staff in providing technical assistance and guidance to EHDI Community Collaborative teams. Continued opportunities where state staff and national experts can share best practices and learn essential information/updates regarding diagnostic and early intervention (such as the National EHDI Conference) are important to support young children with hearing loss and their families.

Collaboration/Coordination (linkages with other programs) –

A priority of the EHDI Community Learning Collaborative has been to improve collaboration and coordination between systems that families of children with hearing loss encounter. MDH has very intentionally created a Steering Committee made up of representatives of many systems and perspectives (see Steering Committee membership under activity 1.1). In addition, MDH has required EHDI community teams to broaden the former EHDI Regional teams (consisting of only representatives from local school districts) to at least include parents, public health, and clinical audiologists. Increased coordination with local public health agencies and primary care providers will be a focus for year three of the grant.