



Lessons Learned from an EHDI and DBS Learning Community

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Funding Acknowledgement



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Background



NCHAM and APHL identify common mission



Brainstorm ideas of increasing connectivity between EHDI, DBS, and CCHD



Invited programs to participate, had to meet following criteria



Provided \$30k stipend for participating. Parents had to be paid a minimum of \$25 per hour.

Project Aim

By June 30, 2023, the UNBS-LC will develop a document of promising practices for DBS and EHDl collaboration.

Project Purpose

This LC will serve as a way for peers to both learn and share successful uniting NBS program strategies and spread them throughout the newborn screening system.

Teams

Indiana



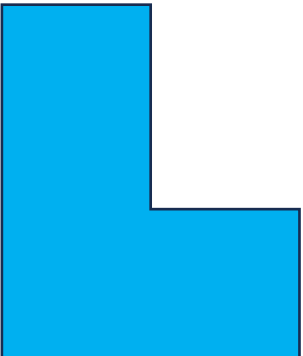
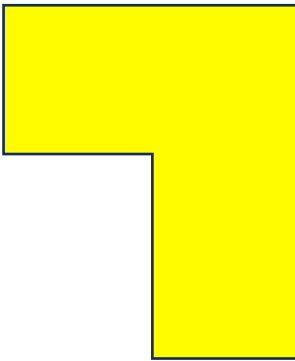
South Dakota



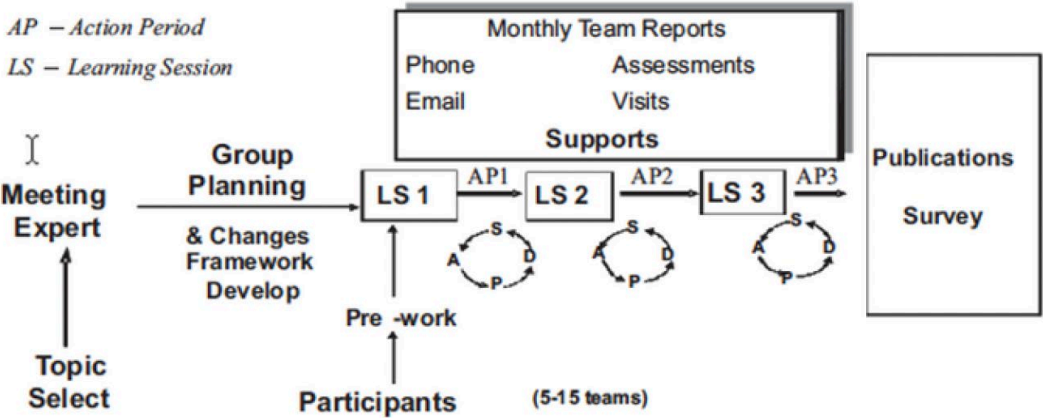
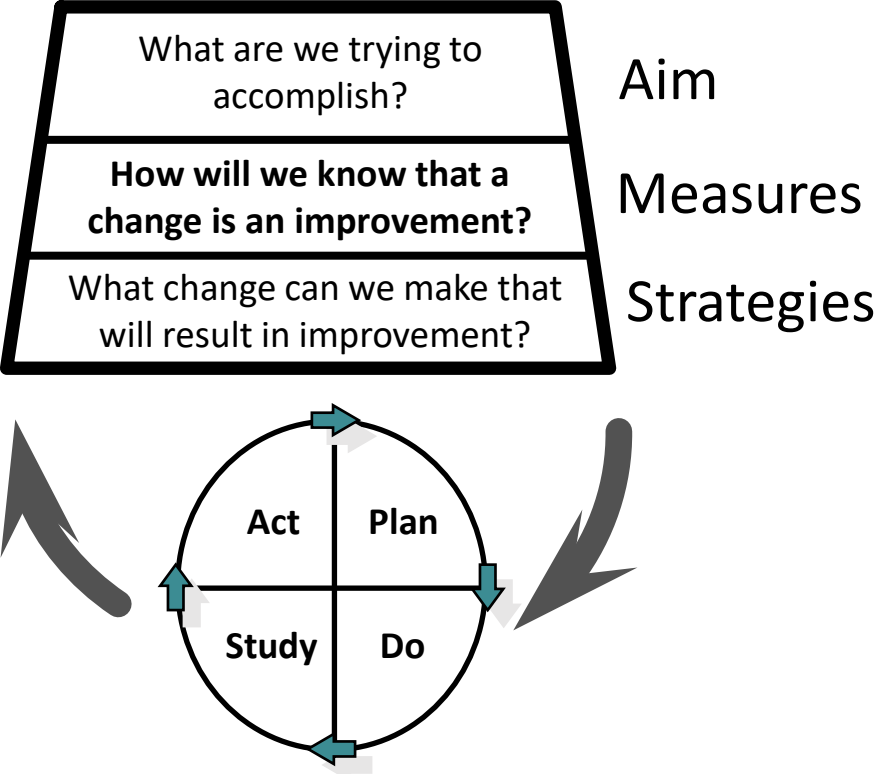
Michigan



Louisiana



The Model for Improvement Breakthrough Series Learning Collaborative



How We Rolled

Over 10-month project period

- 1 in-person, 2-day kickoff meeting
- 5 virtual group meetings
- 4 virtual team meetings
- 1 final webinar
- 1 final report of promising practices



Indiana



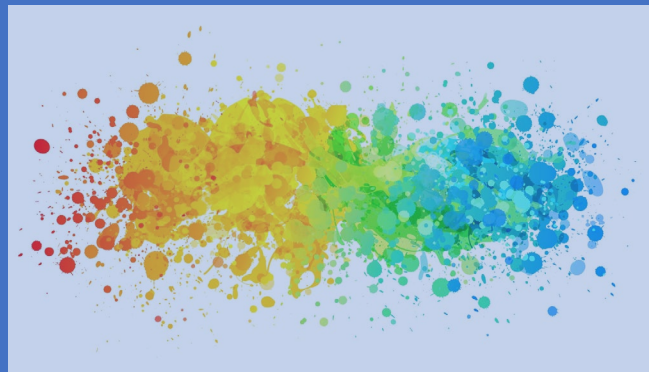
Aim:

By May 2023, we will increase the percentage of providers who report having comprehensive information to give to parents at the time of diagnosis to 80% as determined by a rubric. The team defined comprehensive information to be accessible, high quality, useful, current and include website resources.

Measures:

- Outcome: Percentage of providers whose materials are rated as comprehensive.
- Process: Survey responses by providers about the resources they provided to parents.
- Process: Rubric results from reviewing information provided to parents.

Indiana



Strategies:

- 5 audiologists, 2 metabolic clinics (selected Pompe and PKU)
- Review materials using rubric team developed
- Created a material checklist for providers
- Worked with providers to update materials

Results:

- 100% of participating providers increased to 80% or above the comprehensiveness of materials in:
 - Quality
 - Website
 - Support
 - Accessibility
 - Usefulness

Future Work:

- Customizable, co-branded materials
- One-page resource per condition
- Est a process for updates
- Collab on community events

Challenges:

- Staff Time
- Frequency of updates



Louisiana

AIM:

By May 2024, the LA EHDI and DBS programs will empower LA expectant parents at West Jefferson Medical Center by increasing their knowledge of newborn screening by 50% through birthing classes.

Measures:

- Outcome: Percentage of women who participate in prenatal course that increase their knowledge of NBS.
- Process: Number of eligible individuals to participate in focus groups.
- Process: Number of participants that participated in focus groups.
- Process: Number of completed surveys post focus group.
- Process: Number of prenatal classes where NBS information was presented.

Louisiana

Strategies:

- Focus Groups to develop prenatal materials
- Tested ways to recruit FG participants
- Reviewed existing materials from other orgs
- Tested the materials at one med center with two group of prenatal patients

Results:

- All prenatal class participants scored 80% or higher on post test
- 8 parents participated in focus groups
- 3 participants served in prenatal classes

Challenges:

- Staff Time
- Social media recruitment
- Approval time for med center

Future Work:

- Expand to new medical center
- Board of Medical Examiners distribute materials to providers
- Collaboration during NBS awareness month
- Adding hearing screening to DBS card
- Video of NBS for parents prior to discharge from hospital

Michigan

Aim:

Increase the number of babies born between Jan 6th and May 7th, 2024, to newly trained midwives that receive DBS, CCHD, and NBHS to 50%. With the Sub Aim of increasing the average comfort level, as measured on a 5-point scale of newly trained midwives on performing all three types of screening.

Measures:

- Outcome: Percentage increase of babies born between Jan 6th and May 7th, 2024, to trained midwives who received all three types of screening.
- Process: Increase in comfort level of screening from pre to post training.
- Process: Number of trainings held.
- Process: Number of midwives trained.

Michigan

Strategies:

- Developing and testing curriculum
- Developed video of at home birth identified hearing
- Tested virtual and in-person trainings

Results:

- 2 trainings, 1 virtual, 1 in-person.
- 25 midwives trained
- Increased comfort level from pre to post
- Increased number of babies who received all 3 screenings by midwives

Challenges:

- Time between training and practicing
- Time to report different between DBS and EHDI
- Lack of direct access to hearing screening equipment

Future Work:

- Additional in-person trainings new area in state
- Improve reporting times
- Access to equipment
- Reporting dashboard for community providers

South Dakota

AIM:

By May 2024, 75% of SD NBS partnering organizations will respond that they agree to the statement, “When communicating with the SD Unite team during the LC period of (August 2023 to May 2024), we learned more about the NBS process in SD” to increase the importance of a cohesive NBS process in SD.

Measure:

- Outcome: Survey results to knowledge of the importance of the NBS process
- Process: Number of public-facing materials developed
- Process: Number of partnering organizations engaged



South Dakota

Strategies:

- Developed comprehensive education materials
- Tabled at health and wellness fairs
- Materials to providers and stakeholders
- Presentations to providers and stakeholders

Results:

- 3 new materials developed
- 3 health fairs
- 35 meetings with providers/stakeholders
- 100% engagement with providers
- 94% of providers responded that they understood or somewhat understood the NBS system in SD

Challenges:

- Losing DBS staff member
- Split of programs between two different agencies

Future Work:

- Present work to SD DOH—increase engagement
- Materials for hospitals and birthing centers



Evaluation Pre/Post LC survey

Question	Pre	Post
How do you rate the collaboration between EHDI and DBS?	In place working well: 18% In place, needs improvement: 18% Plan in place to develop: 18% Not in place: 27%N=11	In place working well: 58% In place, needs improvement: 25% Plan in place to develop: 17% Not in place: 0%N=11
What was the inclusion of families in your DBS or EHDI Program?	In place working well: 43% In place, needs improvement: 43% Plan in place to develop: 0% Not in place: 14% I don't know: 0%N=7	In place working well: 31% In place, needs improvement: 31% Plan in place to develop:15% Not in place: 15% I don't know: 8% N=13
Rate your knowledge of quality improvement?	Excellent: 0% Very Good: 36% Good: 27% Fair: 36% Poor: 0% N=11	Excellent: 17% Very Good: 58% Good: 17% Fair: 0% Poor: 8% N=12
I learned new information about other NBS programs as part of my LC participation?		Strongly agree: 77% Agree: 15% Disagree: 8% Strongly Disagree: 0% N=13
Participation in the LC helped me build confidence in working with the other NBS programs in my state?		Strongly agree: 62% Agree: 31% Disagree: 8% Strongly Disagree: 0%N=13
The LC leaders were responsive to our team's needs		Strongly Agree: 85% Agree: 15% Disagree: 0% Strongly Disagree: 0%
Participation in the UNBS-LC was worth my time?		Strongly Agree: 92% Agree: 8% Disagree: 0% Strongly Disagree: 0%N=13
Our DBS and EHDI programs plan to continue working together at the conclusion of the LC?		Strongly agree: 62% Agree: 23% Disagree: 8% Strongly Disagree: 8% N=13
The amount of time for the LC (10 months) was?		Sufficient at 10 months: 31% Should have been shorter (<10 months): 0% Should have been longer (11-12 months): 23% Should have been longer (13-18 months): 31% N=13
The amount of funding provided by the stipend (\$30,000) was?		Sufficient: 80% More than Needed: 0% Not as much as needed: 15% N=13

“I enjoyed learning about DBS but also learning about EHDI. Just last week I ran into an old co-worker that had just visited her 9-year-old niece who was deaf, but unable to receive cochlear implants. I was able to share Louisiana Hands & Voices in hopes that he and his wife would pass the information along. Prior to this learning community, I wouldn't have been able to share such an amazing organization with that family.”

-DBS Parent



“Thank you for selecting Michigan to participate in this learning committee. It was energizing and informative to participate and has set a foundation in our state for future collaboration. I look forward to continued data collection on our project and sharing our experiences at future conferences.”

-MI EHDI Coordinator

CMV

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PUBLIC HEALTH & POLICY
CONFERENCE



MINNESOTA



SAVE THE DATE

SEPTEMBER 7th - 9th

2025



Questions?

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Final Report

