



Report of Promising Practices

Prepared by Project Leads

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Background and Introduction

Children and Youth with Special Healthcare Needs (CYSHCN), including children who are identified with conditions through newborn screening (NBS), have historically and continue to be a priority population for the federal Maternal and Child Health Bureau of the Health Resources and Services Administration (MCHB; HRSA; Warren et al., 2022). NBS benefits babies by detecting life threatening or life altering conditions before symptoms negatively impact the infant. Screening for conditions at birth allows for early treatment to improve outcomes and may reduce the cost of treating the conditions throughout the infant's lifetime. There are three parts of newborn screening: the dried bloodspot screening (DBS), a panel of tests for certain metabolic and genetic conditions and two point-of-care screenings; the hearing screening, done with either an otoacoustic omission or an automated brainstem response test for potential hearing loss; and the pulse oximetry screening for Critical Congenital Heart Disease (CCHD). All states have NBS programs and systems in place, typically managed through their state departments of public health.

The DBS programs and the Early Hearing Detection and Intervention (EHDI) programs, the programs that oversee newborn hearing screening (NBHS), are frequently led by different divisions, presenting an opportunity to support collaboration and a more cohesive approach to advance these services in state NBS programs—note that most states do not have a dedicated CCHD program. As such, the National Center for Hearing Assessment and Management (NCHAM) and the Association of Public Health Laboratory (APHL) serving EHDI and DBS respectively, came together with funding through HRSA (#UG8MC31893) to lead a learning community (LC) between DBS and EHDI to unify NBS programs. Specifically, the purpose of this LC was to bring together up to five state DBS and EHDI programs to develop promising practices for collaboration within the newborn screening system. Each state team was comprised of four people, one of which served as the team lead. Teams could also include a CCHD representative if available but was not required. The learning community was to test and produce a promising practices that will serve as a resource to other states/territories who would like to improve their DBS and EHDI collaboration.

The Unite Newborn Screening Learning Community (UNBS-LC) complemented national priorities regarding CYSHCN. This LC was in alignment with MCHB's recently released Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs (McClellan et al., 2022). Moreover, this LC followed the MCHB recommendation that families are involved in all aspects of the newborn screening (NBS) system. This recommendation has been highlighted in the recent MCHB funding of the Family Leadership and Language (HRSA-20-051) and Newborn Screening Family Education program (HRSA-18-111) and components of NBS technical assistance centers such as the EHDI National Technical Resource Center (NTRC; HRSA-20-048) and Center for NBS System Excellence (Excel; HRSA-23-077).

Goal, Aim, and Objectives

The *goal* of the LC was to serve as a way for DBS and EHDI peers to both learn and share successful uniting of NBS program strategies and spread them throughout the newborn screening system. The project *aim* was to “By June 2024, the UNBS-LC will develop a document of promising practices for DBS and EHDI collaboration.” This promising practices document will fulfill the aim for this project. Promising practices are defined by the Association of Maternal and Child Programs (AMCHP; n.d.) as practices that 1) present evaluation data that shows the impact of the practice on your target population; 2) describes how biases in the way the practice is implemented or evaluated may impact outcomes; 3) describes both positive and negative unexpected outcomes and any changes made because of them; and 4) describes the practice’s continuous quality improvement efforts.

The project goal and aim were met through the following objectives:

Obj 1: By July 31, 2023, review and select applications from no more than five DBS and EHDI teams to participate in the UNBS-LC.

Obj 2: By September 15, 2023, plan and implement a UNBS-LC kickoff meeting with participating teams.

Obj 3: By April 30, 2024, hold at least four virtual learning sessions.

Obj 4: By May 31, 2024, meet with individual teams for technical assistance at least four times.

Obj 5: By June 30, 2024, highlight UNBS-LC projects nationally through a webinar.

Obj 6: By June 30, LC participants will agree or strongly agree that participating in the UNBS-LC was a valuable use of their time.

Methods

Participating teams were solicited through NCHAM and APHL’s listservs of EHDI and DBS programs. The following criteria had to be met in order for teams to apply and be selected. Participating teams were offered a \$30,000 stipend for time and management of the project, of which they were required to pay parents a minimum of \$25 per hour.

1. Have a committed team for the entire project period from August 2023 to June 2024 that consists of at least one DBS staff, one EHDI staff, one DBS parent representative, one EHDI parent representative, and one CCHD representative if available.
2. Attend and participate in the LC’s kick-off meeting and four virtual meetings throughout the project period (August 2023-May 2024). See LC schedule in table 1.
3. Provide facilitators with a monthly summary, of no more than two pages, consisting of strategies tested, time allocated, and budget spent. A template for these summaries was provided.
4. Complete and submit a pre and post Learning Community survey.
5. Participate at the end-of-Learning Community webinar.
6. Participate in opportunities to share your LC experiences at the 2024 National EHDI Conference and the 2024 APHL Newborn Screening Symposium.

Table 1: UNBS Learning Community Timeline

Meeting	Date/time	Details
Introductory call	August 3, 11:00 am MT/1:00 pm ET—60 minutes	Virtual
Kick-off meeting	September 6-8, 2023. Please plan to arrive by 4:00 pm MT September 6 and depart no earlier than 3:00 pm MT on September 8.	In person meeting, Salt Lake City, Utah
Learning Session 1	October 4, 11:00 am MT/1:00 pm ET – 90 minutes	Virtual
Individual check ins	November, TBD	Virtual
Learning Session 2	December 6, 11:00 am MT/1:00 pm ET – 90 minutes	Virtual
Individual check ins	January, TBD	Virtual
Learning Session 3	February 7, 11:00 am MT/1:00 pm ET – 90 minutes	Virtual
Individual check ins	March, TBD	Virtual
Learning Session 4	April 3, 11:00 am MT/1:00 pm ET – 90 minutes	Virtual
Individual check ins	May, TBD	Virtual
Webinar to share lessons learned	TBD– 60 minutes	Virtual

The project leads had several inquiries about participating with many teams encountering challenges with getting administrative approval and getting a full team in place. By the deadline, NCHAM received five applications to participate. One team had to later withdraw due to administrative issues. The selected teams were from Indiana, Louisiana, Michigan, and South Dakota.

This LC utilized the Model for Improvement (MFI; see Figure 1) Quality Improvement (QI) methodology to test promising practices through a modified Breakthrough Series (BTS). The MFI asks teams to identify an Aim (What are we trying to accomplish?). The aim needed to include for what, by whom, how much, and by when. The team then needed to identify measures of evaluation (How will we know that a change is an improvement?). This required teams to identify an outcome measure (included in the Aim) as well as process and potentially balance measures. Later the teams identified strategies or activities (What changes can we make that will result in improvement) that could help them meet their aim. Those strategies were then tested through rapid plan-do-study-act cycles. The BTS model compliments the MFI by applying the methodology to a group of teams working toward accomplishing their aim through meeting regularly with all teams with action periods in between (see figure 2).

Figure 1: Model for Improvement

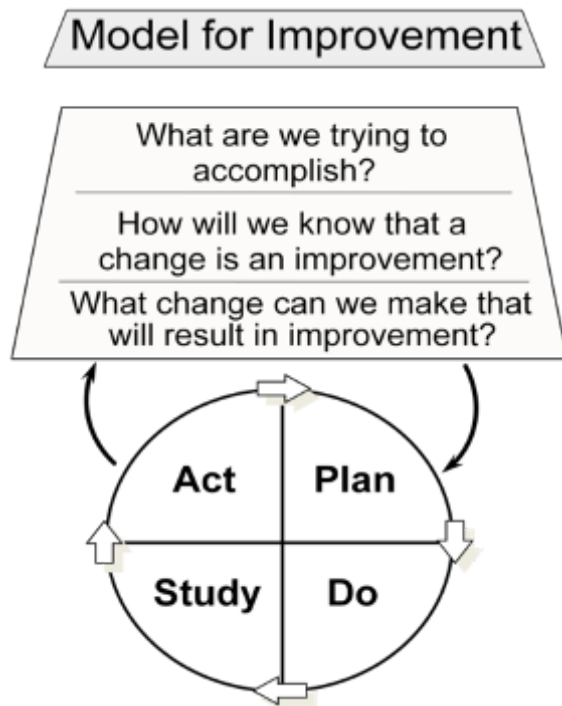
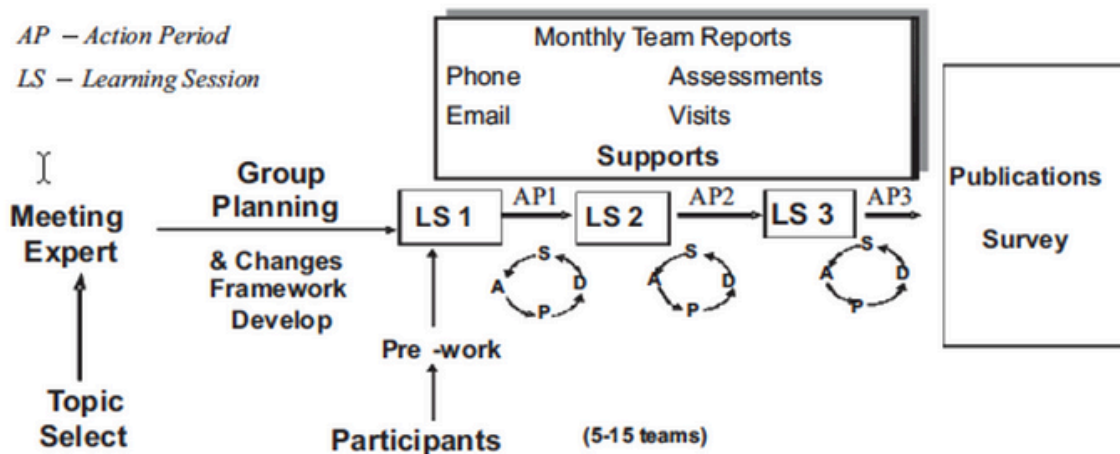


Figure 2: Breakthrough Series Learning Collaboratives



UNBS Learning Community Activities

Introductory Meeting

This meeting was held August 3, 2023. The agenda was to provide an overview of the LC, what to expect and the role of the facilitators. We also did group introductions.

Kick-Off Meeting

The LC kick-off meeting was held in Salt Lake City, Utah September 6-8, 2023. During the kickoff meeting (See Appendix B for the kick-off meeting agenda), teams learned more about both NCHAM and APHL and got an overview of each EHDI/DBS team. Each team member was provided a kick-off packet that included all the documents and activities that were going to be used throughout the meeting. The teams participated in system mapping activities to identify areas of potential collaboration. Once the teams selected an area, the LC facilitators led the teams through creating aim statements, measures, and brainstormed strategies. One leading principal of the facilitators was to meet teams where they were, as each team had unique circumstances.

Learning Sessions (LS)

The LC was comprised of four, 90-minute virtual LS. Each session was comprised of a topical presentation then followed by each team presenting their work to date using a provided template. There was opportunity for discussion and for teams to provide insight and ideas to one another.

Individual Check-Ins

The facilitators divided up the states with Mandy Jay being the primary point of contact for South Dakota and Louisiana and Alyson Ward as the primary contact for Indiana and Michigan. This enabled each team to build a trusted relationship with their facilitator and spread the workload between facilitators. The facilitators met with each team individually in November 2023, January 2024, March 2024, and May 2024.

Webinar

On June 5, 2024, all teams participated in webinar where they presented the work they had done during the LC. The webinar was advertised through listservs of NCHAM and APHL. Those listservs received an email that stated:

In August 2023, the National Center for Hearing Assessment and Management (NCHAM), with funding from the Association of Public Health Laboratories, began facilitating the Unite Newborn Screening Learning Community (LC) designed to increase collaboration between newborn screening programs. EHDI and Dried Bloodspot (DBS) screening programs were invited to jointly apply.

Teams from Indiana, Louisiana, Michigan, and South Dakota were selected to participate. Each team consisted of two staff (one from EHDI and one from DBS) and two parents (one from EHDI and one from DBS). Through system mapping, each state team looked at potential areas of improvement that they could collaboratively address. Using Quality Improvement (QI) methodology, teams were able to develop aims, measures, and strategies that were then tested in an effort to identify promising practices for current and future collaborative work.

On June 5th, representation from each of the four teams will share their promising practices with the greater EHDI and DBS communities during an NCHAM hosted webinar. The presentation will highlight the process of building an improvement team, determining a specific project (aim) to work on together, identify measures to assess progress, steps for how to test and implement strategies, and challenges and successes encountered.

UNBS Team QI Projects

The following pages contain information about each individual team projects including their aim, measures, and strategies tested followed by successes, challenges, and future work identified by each team.

Indiana

The Indiana team selected their improvement project based on discussions around the current resources provided to parents before, during, and after a diagnosis. The team recognized the time constraints of providers to keep resources updated, the lack of consistency of information given by providers, and inconsistent connection with family support services. Based on these discussions the team selected a project to ensure accurate, comprehensive information provided to families.

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.

Strategies

The team began by targeting five audiologists and two metabolic clinics, all of whom the programs had established, positive relationships. The team surveyed the providers and collected information provided by parents regarding pediatric hearing loss and of two DBS conditions, Phenylketonuria (PKU) and Pompe. The team then created a rubric that they used to evaluate the materials collected. The actions from the rubric were to keep material as is, update the material, or replace the material. To represent a parent with little or no knowledge of the subject, the audiology materials were reviewed by parents of children with a DBS-identified condition and the Pompe and PKU resources were reviewed by parents of children who are deaf or hard of hearing. The results from the rubric were then reviewed with the providers with the offer of the Indiana UNBS-LC team to help them revise or replace their materials. As part of this offer, the UNBS-LC team created a checklist for providers to use when creating or disseminating NBS information to parents. The rubric used to evaluate the materials and the checklist are located in Appendix D.

Successes

The Indiana team welcomed the opportunity to deepen their relationship with the medical teams they worked with. They also enjoyed collaborating with each other for work shared by the programs, specifically including parent perspective.

Percentage of providers initially with “Comprehensive” resources for parents.

- Quality 65%
- Website 30%
- Support 0%
- Accessibility 16%
- Usefulness 45%

Challenges

Challenges have included a lack of staff time to collect resources for specific conditions such as deaf and hard of hearing and metabolic disorders. We have utilized audiology graduate students to begin the process of collecting resources and information. We will continue to collaborate with the providers who responded initially as part of the process. The other challenge has been to determine how often to update the materials and who will be responsible for those tasks.

Future Work

The team plans to make revised or replaced materials in clinic settings and allow them to be customizable. They also plan to make one-page resources per condition that includes an FAQ for families as well as state and national resources. They also plan to make the checklist for resources available to providers and to establish a process for resources to be reviewed and updated on a regular basis. Over time, they plan to add resources for additional conditions. The Indiana team also plans to collaborate on community events, projects, and provider education.

“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



Louisiana

The Louisiana team identified their selected area of improvement by reviewing similar stages presented in their system maps and where they saw opportunities for collaboration. Both DBS and EHDl programs found gaps in their system around NBS awareness prior to birth. Therefore, the LA team decided to focus on prenatal education for their improvement project.

Aim

By May 2024, the LA EHDl 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.

Strategies

The LA team wanted to conduct focus groups to aid in the creation of their prenatal education materials and tested multiple strategies to recruit focus group participants including posting on several social media outlets (i.e., Facebook, Instagram, Tiktok), through existing health department databases, and via identified through the newborn screening process for both bloodspot and hearing. They also reviewed existing prenatal NBS materials—particularly those developed by Baby’s First Test. After identifying materials, they held multiple focus groups to get feedback about the experiences of families who gave birth within the past three years so the materials needed to be modified for LA parents. Once the materials were revised, they presented the materials to women enrolled in prenatal classes at West Jefferson Medical Center. See materials developed by the LA team in Appendix E.

Successes

The LA team was successful at reaching families to participate in the focus groups. Figure X shows how the team engaged families for focus groups and how they were eventually able to reach out to eligible families to participate in the focus groups. Initial engagement plans for focus group participation were broad with limited targeted outreach to prospective participants, so the next PDSA cycle included more targeted outreach in order to connect with families known within the EHDl/NBS system (see Figure 3). The first cycle used social media to elicit parent participation, while the second utilized information from the LA EHDl and Newborn screening databases. Figure X details the number of parents who engaged in each step of the process, with a significant learning curve taking place relative to identifying participants who represented our target population truly. Due to time constraints, the team was able to gauge impact of education on just two prenatal classes. A posttest was administered to participants around their knowledge about newborn screening.

Figure 4 shows the post test results that indicated better than the goal of 50%, with all expectant parents achieving 80% or better with regard to their acquired NBS knowledge (see Appendix E for the posttest). Other successes of the LA team during the LC were that DBS can now utilize the strong EHDl parent and community network. DBS can also access EHDl can access each other’s databases to get information that was missing in their databases.

Challenges

As with other LC teams, the LA team found finding time to work on this project and connecting with one another to be a challenge. Additionally, the recruitment of focus group participants through social media did not work well. Because the post offered a monetary compensation, they recruited fake participants and had to start the focus group recruitment process over. Additionally, merging the DBS and EHDl records to find focus group participants was time consuming. Lastly, due to the time it took to get approval to present new material at a prenatal class, the team only had time to post-test in two prenatal classes during the LC time period.

Future Work

Based on a deepened relationship built through the LC, the team plans to distribute the new NBS prenatal education materials to other prenatal classes and pregnancy providers. The team also fostered a new relationship with the director for the Louisiana Board of Medical Examiners who is proactively sharing the flyer through email to all pregnancy providers and pediatricians. The LA team also plans to Newborn Screening work together on messages sent out during NBS Awareness month in September and will collectively develop social media messages geared toward pregnancy providers. In collaboration with the state lab, they have also explored adding hearing screening results to the DBS card for earlier reporting and to solidify a process for families/providers to request the DBS card. Lastly, the team wants to develop a video about NBS that parents are required to watch prior to discharge from hospitals.

Figure 3: Participant Engagement by Method of Contact

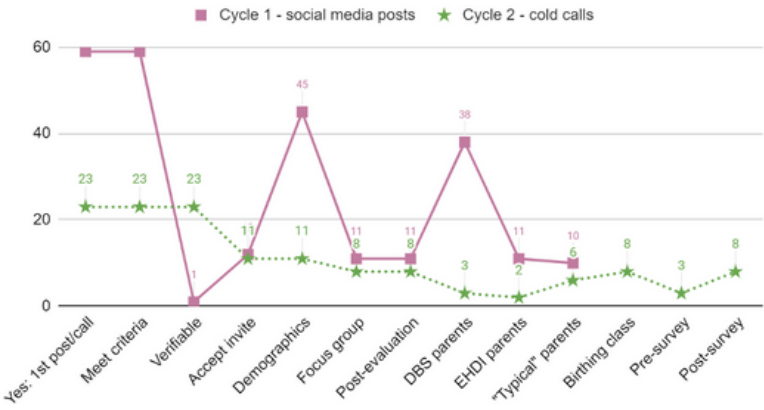
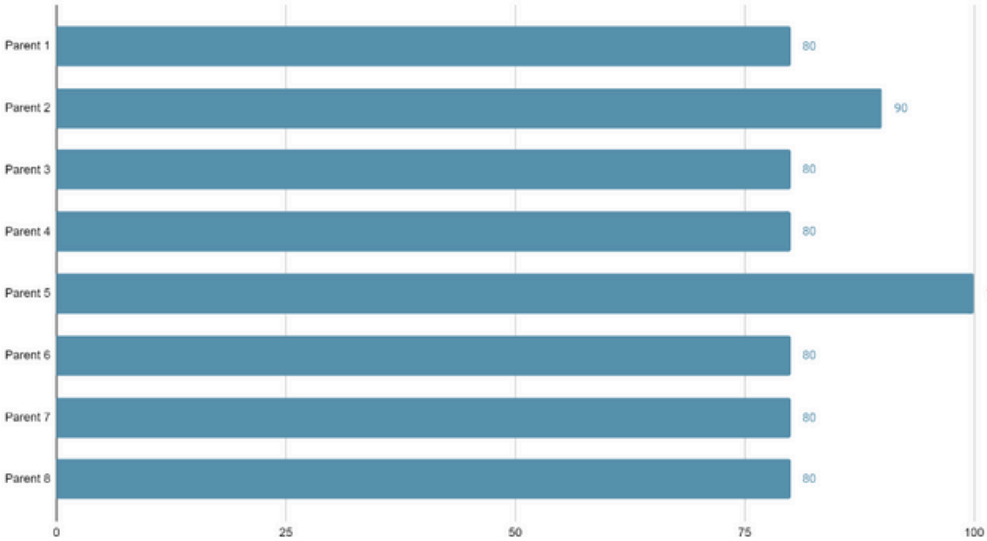


Figure 4: Birthing Class Post Test Scores



Michigan

During the kick-off meeting, the Michigan team quickly identified that they wanted to collaborate on provider training. After much discussion and recognizing the short timeline of the LC, the team decided to select education and training for midwives to increase rates of screening for all three screening programs—dried blood spot (DBS), critical congenital heart disease (CCHD), and newborn hearing screening (NBHS).

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.

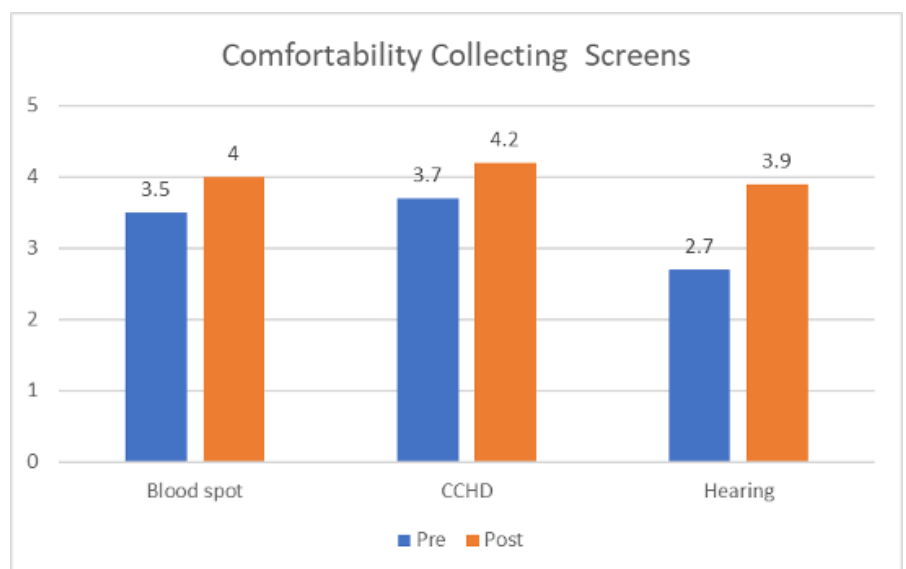
Strategies

The team tested multiple strategies and engaged in many tasks during the project period, including the development of a comprehensive training consisting of lecture and skills practice for all three types of screening. To engage midwives in newborn screening, the team tested education by developing a short video of a mom who delivered at home and whose baby was identified with a hearing difference. The team also tested if in-person or virtual trainings worked better and why. The MI team found that this project highlighted the value of parent participation in an improvement project. See Appendix F for MI materials.

Successes

The team completed two trainings, one in-person and the other virtual. There were 25 total midwives trained, 16 in person and 9 virtual. The team found that collaborative trainings increased the average comfort level of attendees, as measured on a self-reported 5-point scale (see Figure 5).

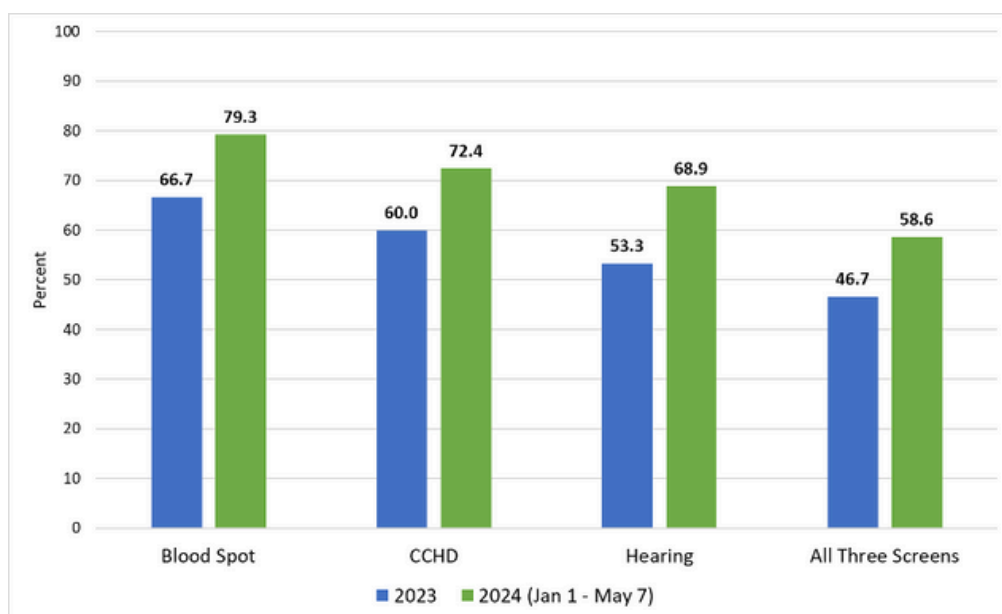
Figure 5: Comfort Level of Midwives Pre and Post Training



Due to the project timeline, the outcome measure of increased screening rates compared all of 2023 to a subset of 2024 (January-May). Following training, the team found increases in each of the three types of newborn screening. In addition, the number of babies born to newly trained midwives that received all three types of screening increased to over 50% (see Figure 6).

These initial findings suggest that training programs for midwives could increase their comfort level in performing newborn screening and increase the numbers of babies receiving all types of newborn screening. The team will continue to collect data to evaluate these findings long-term.

Figure 6: Comparisons of screenings for infants delivered to trained midwives



Challenges

All improvement projects come with challenges. The challenges the MI team cited were that the target audience of the training were new and student midwives. As such, these new providers need time between training and establishing their practice to have a large sample of births to evaluate. Additionally, time to report is different between screening types. DBS is typically the first to report given the time-sensitive nature of the specimen followed by CCHD (online reporting) and hearing screening (manual reporting). Furthermore, not all attendees had direct access to screening equipment during the project reporting period, with some still in application status to obtain equipment.

Future Work

The MI team plans to continue work on the midwife training project and have another in-person training scheduled for October 4, 2024, in another area of the state. They will also continue tracking the screening data to determine if the trainings are continuing to help increase NBS for the community birth population. The MI team plans to expand this project by improving reporting times, increasing access to screening equipment, and exploring the possibility of a reporting dashboard for community screening providers.



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South Dakota

South Dakota (SD) newborn screening has a unique structure, with the DBS program being located at the SD Department of Health and the EHDI program being run by the University of South Dakota. The SD team experienced personnel challenges during the LC and had to pivot from their original aim, improving communication at notification. They then focused their work on increasing stakeholder knowledge about NBS in SD.

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.

Measures

- 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

Strategies

The SD team tested several strategies to engage stakeholder understanding of the importance of NBS. They attended and tabled at several health and wellness fairs and participated in the DBS and EHDI luncheon at the EHDI Conference in Denver. They developed and tested talking points for providers when receiving a presumptive positive. They also tested calling parents who have a presumptive positive baby. They ramped up their connection via public facing materials such as website and educational brochures to have both DBS and EHDI materials in one place and cross referenced in others (e.g., website, brochures). In May 2024, SD also officially added newborn hearing screening to their NBS panel of tests. See Appendix G for SD materials.

Successes

The SD team found success that superseded reaching their aim. All providers they reached out to agreed to review the materials presented to them. After engaging with the providers, the team asked the providers to respond to a 10-question survey in which 100% of the providers responded that they agreed that through their communication with the SD NBS team they increased their understanding of the NBS process in SD. Furthermore, the survey asked, “Select your level of understanding of each agencies’ role in NBS.”

Select your level of understanding of each entity's role in the newborn screening process in South Dakota. - South Dakota Department of Health (SD DOH), Sanford Children’s Specialty Clinic, State Hygienic Laboratory at the University of Iowa, University of South Dakota (USD), Birthing Hospitals, Physicians/Healthcare Providers, Parents/Caregivers/Families of Newborns- I understand this entity’s role, I somewhat understand this entity’s role, I do not understand his entity’s role, this entity does not have a role (see Table 2). The team was also able to hold 35 meetings with NBS stakeholders to explicitly discuss the connection between DBS and EHDl during the project period and were able to develop three public-facing materials that included information about DBS and EHDl.

Table 2: *Partner Understanding of the role of organizations in the NBS System*

Agency	Understand	Somewhat Understand	Do Not Understand	Does Not Have A Role
SD DOH	4	2	0	0
Sanford	4	1	1	0
Iowa	4	1	1	0
USD	4	2	0	0
Hospitals	5	1	0	0
Providers	3	3	0	0
Parents	5	1	0	0

Challenges

The biggest challenge for the SD team was needing to pivot on their project after losing a team member. There were, and continue to be, challenges with the set up between two different agencies running NBS efforts.

Future Work

The SD UNBS team plans to present their work to the SD Department of Health (DOH) as they were unable to participate after the loss of the participating staff member. Their hopes are that sharing this work with the DOH will help them better understand all the partners involved in maintaining a cohesive NBS program. The team also seeks to develop comprehensive educational materials for hospitals and birthing centers that present both DBS and EHDl information.

Evaluation

To accomplish the project aim: “By June 2024, the UNBS-LC will develop a document of promising practices for DBS and EHDI collaboration” facilitators documented the work of the teams throughout the LC cycle. Based on this documented work, the facilitators drafted these promising practices, and each team reviewed their respective work and were given opportunity to add and edit to best reflect their work in a succinct manner. This document was fully drafted by June 30, 2024, and submitted to APHL by July 31, 2024—the end of the project period. The document will be shared through NCHAM and APHL’s networks and posted on their respective websites.

Obj 1: By July 31, 2023, review and select application from no more than five DBS and EHDI teams to participate in the UNBS-LC. To achieve this objective, facilitators released the calls for applications on May 8, 2023, with a due date of July 13, 2023. The call was released through both NCHAM and APHL listservs. Though 10 states expressed interest in applying, only five full applications were received. After assessing applications through a pre-determined rubric, all five met the criteria to participate. An email was sent out to the team point of contact on July 27, 2023, notifying their acceptance and gave details of next steps including details of getting a contract in place to provide the \$30,000 stipend. After the introductory call, however, due to lack of full administrative approval, one team had to pull out of the learning community, leaving four states fully committed to the LC.

Obj 2: By September 15, 2023, plan and implement a UNBS-LC kickoff meeting with participating teams. The LC kick-off meeting was held in Salt Lake City, Utah September 6-8, 2023, at the Little American Hotel. To achieve this objective, the facilitators went to great lengths to plan a productive 1.5-day kick-off meeting. Facilitators planned a full agenda (see Appendix B), provided a workshop packet for all attendees, and added networking time throughout (see Image 1). The kick-off meeting was attended by all four representatives for each of the four teams. Areas of collaboration and coinciding aims were as follows. Specific team information was presented earlier in this document.

- Indiana: 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.
- Louisiana: By May 2024, the LA EHDI and DBS programs will empower LA expectant parents at West Jefferson Medical Center by increasing the newborn screening education they receive prenatally by 50%.
- Michigan: 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%.
- South Dakota: 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), learned about the NBS process in SD” to increase the importance of a cohesive NBS process in SD.

Image 1: Pictures from Kickoff Meeting



Obj 3: By April 30, 2024, hold at least four virtual learning sessions. Four learning sessions (LS) were held.

- LS 1: Held October 4, 2023. Presentation by Mariana Raia from Expecting Health on parent support resources for the DBS system. Followed by team presentations and discussion.
- LS 2: Held December 6, 2023. Presentation by Lisa Kovacs from Hands & Voices on parent support resources for the EHDI system. Followed by team presentations and discussion.
- LS 3: Held February 7, 2024. Presentation by LC facilitators Alyson Ward and Mandy Jay on marketing health messages. Followed by team presentations and discussion.
- LS 4: Held April 3, 2024. Presentation by Jodi Tervo Roberts on reaching underserved populations. Followed by team presentations and discussion.

Obj 4: By May 31, 2024, meet with individual teams for technical assistance at least four times (see Table 3). The individual team meeting schedules are highlighted in the table below. Prior to the meeting, each team submitted a 1–2-page report of their work using a provided template. During these meetings, teams reviewed the report with their facilitator and added additional information. They also had an opportunity to seek guidance on any challenges they were experiencing.

Table 3: Individual Check-in Schedule

Indiana (AW facilitator)	Louisiana (MJ facilitator)	Michigan (AW facilitator)	South Dakota (MJ facilitator)
November 8, 2023	November 8, 2024	November 15, 2023	November 30, 2023
January 29, 2024	January 22, 2024	January 24, 2024	January 26, 2024
March 18, 2024	March 18, 2024	March 18, 2024	March 18, 2024
May 3, 2024	May 24, 2024	May 29, 2024	May 23, 2024

Obj 5: By June 30, 2024, highlight UNBS-LC projects nationally through a webinar. On June 5, 2024, all teams participated in webinar where they presented the work they had done during the LC. Each team was provided 12 minutes to present and there were 15 minutes reserved for questions at the end of the webinar. The webinar was well attended with 184 unique participants including multiple Center for Disease Control and Prevention and Health Services Administration staff. The webinar recording can be accessed at <https://www.infantheating.org/webinars/2024/6-5-24-unite-newborn-screening.html>

Obj 6: By June 30, LC participants will agree or strongly agree that participating in the UNBS-LC was a valuable use of their time. To measure the work of the LC, each team member completed a pre and post LC survey. Select results of these surveys are outlined below.

Table 4: Pre and Post Learning Community Surveys

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

Outcomes and Discussion

Most newborn screening is done through laboratory analyses of dried bloodspot specimens collected from newborns. With the acceptance of newborn hearing screening in 2006 and critical congenital heart disease screening in 2011 to the Recommended Uniform Screening Panel (RUSP) as point-of-care tests, this was a paradigm shift for newborn screening, which required states to develop new programs and protocols. This paradigm shift left the DBS, EHDI, and CCHD to grow into programs of their own, which are often siloed at the public health level. From a survey conducted with EHDI Programs in 2023 (unpublished), nearly half of the funded 59 programs stated that they collaborated with DBS only somewhat or not at all. This was particularly surprising because public health has had nearly 20 years to integrate the DBS with hearing screening and 13 years to integrate CCHD with DBS.

Though the DBS, EHDI, and CCHD programs are often siloed at the health department level, they interface with the public—hospitals, healthcare providers, and families simply as newborn screening. Therefore, it is essential that public health DBS, EHDI, and CCHD programs find a unified approach to deliver a cohesive message to hospitals, healthcare providers, and families to help ensure timely screening, diagnosis, and connection to additional resources and providers. The Unite Newborn Screening Learning Community was an approach to do just that, to bring DBS, EHDI, and CCHD (where available) together to identify areas of collaboration and to identify promising practices. It is the hope of NCHAM, APHL, and the LC teams that the practices in this document may influence other public health agencies to improve the collaboration between all their newborn screening programs and to recognize the importance of including families affected by newborn screening identified conditions in this process.

“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

References

Association of Maternal and Child Health Programs (n.d.). *Practice Continuum Checklist*.
<https://amchp.org/innovation-hub-ih-practices/>

McLellan, S., Mann, M., Scott, J., & Brown, T. (2022). *A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth with Special Health Care Needs and Their Families*. *Pediatrics*, 149(s7). DOI: <https://doi.org/10.1542/peds.2021-056150C>

Warren, M., McLellan, S., Mann, M., Scott, J., & Brown, T. (2022). *Progress, Persistence, and Hope: Building a System of Services for CYSHCN and Their Families*. *Pediatrics*, 149 (s7). <https://doi.org/10.1542/peds.2021-056150E>

Appendices

Appendix A: Kick-Off Meeting Agenda

Day 1, September 6		
Location: Uintah/East Terrace (weather permitting) Food: Dinner and drinks will be provided		
Time	Details	Responsible
6:30 pm	Kickoff: welcome and intros	Alyson and Mandy
Day 2, September 7		
Location: Snowbasin Food: Breakfast, lunch, and breaks will be provided (dinner on your own)		
8:00-9:00 am	Breakfast	
9:00-9:05 (5)	Welcome and LC overview	Mandy
9:05-9:15 (10min)	Overview of EHDI and DBS and TA centers	Mandy and Ashley
9:15-9:30(15)	Introduction of QI and systems	Alyson
9:30-10:30 (60, 15min presentation and 5min Q&A per team)	Program overviews· Where are you housed, division etc.· Collaboration with parents · Education and outreach (e.g., target populations, materials)· What they are hoping to achieve through this LC	Team Leads
10:30-10:45 (15)	Break: coffee provided	
10:45-11:15 (30)	Teamwork, communication, and collaboration	Mandy
11:15-12:30(75)	System mapping· Presentation· Team Time	Alyson lead/Teams participate
12:30-1:15(45)	Lunch—mix and mingle Sit with other programs/parents not from your state (EHDI with other EHDI, DBS with other DBS, Parents with other parents, etc.)	
1:15-1:30(15)	System mapping· Report out	Mandy/Teams
1:30-3:00(90)	Creating Aim Statements· Presentation· Team Time· Report out	Alyson lead/Teams participate
3:00 pm – 3:15 (15)	Refreshment Break	
3:15-5:00(105)	Developing measures· Presentation· Team Time· Report out	Alyson lead/Teams participate
5:00-5:15	Wrap-up, Questions, Plans for tonight/tomorrow	Mandy
Day 3		
Location: Snowbasin Food: Breakfast and coffee break provided		
8:00 am – 9:00	Breakfast	
9:00-9:15 (15)	Recap of Day 2, plans for Day 3, questions	Mandy
9:15-9:45(30)	Submitted proposed and implemented strategies and share of current resources	Sophie
9:45 – 10:00 (15)	Break – Coffee Provided	
10:00-12:00(120)	Brainstorming strategies, developing PDSA cycles· Presentation· Team Time· Report out	Alyson
12:00-12:30(30)	Hot Topics in Newborn Screening	Ashley and Alyson
12:30-1:00(30)	Questions, Review of Monthly reporting, Wrap-Up, Next steps	Alyson and Mandy



Unite Newborn Screening Learning Community Workbook

This project is 100% supported by the Health Resources and Services Administration (HRSA) under grant #UG8MC31893 as part of an award totaling \$3.3 million dollars. This information or content and conclusions are those of the authors and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS or the US Government.



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.

Aim

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



Agenda Day 1

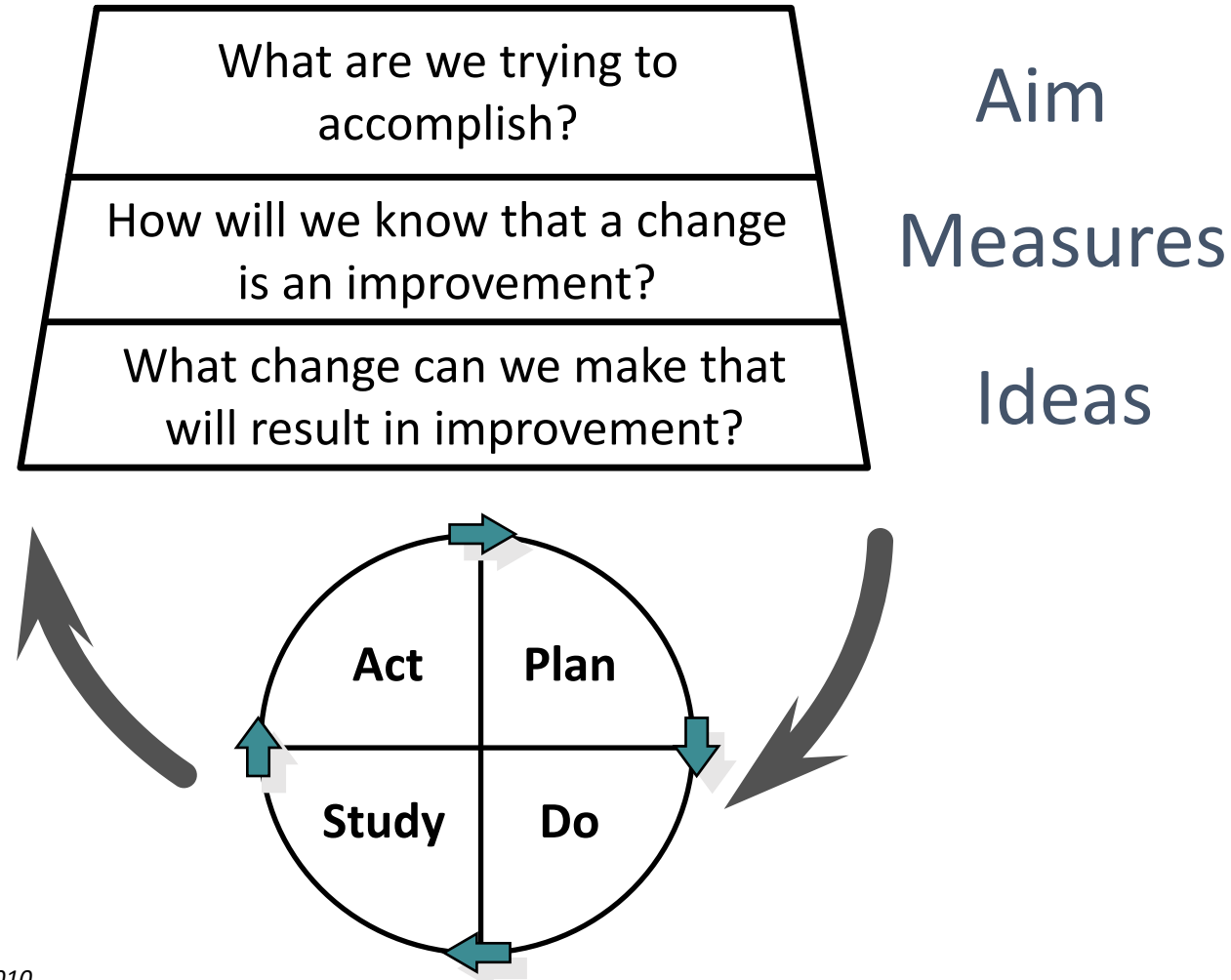
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3:15-5:00 (105)	Developing measures	Alyson lead/Teams participate
5:00-5:15	Wrap-up, Questions, Plans for tonight/tomorrow	Mandy

Program Overview Notes

System mapping

System mapping

The Model for Improvement



Considerations for Improvement Projects



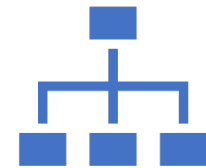
Opportunities



Barriers

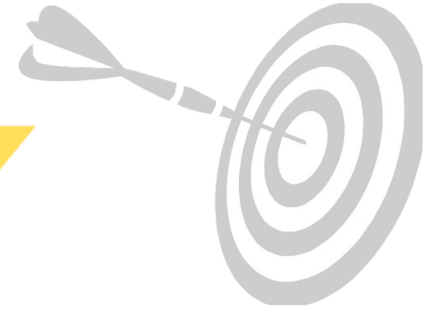


Balance measures



Org culture

AIM Statements – What are we trying to accomplish?



AIM STATEMENT

SMART GOAL



What will be done



Who will do it



How much will you improve



Who will benefit



By when will it be done

Specific

Timely

Measurable

Realistic

Actionable

Creating Your AIM

S	Specific	<ul style="list-style-type: none"> • Who is going to do what (e.g., hospital, program, stakeholders, parents) • To whom (who will benefit, often implied) 	
M	Measurable	<ul style="list-style-type: none"> • How much change will you see (e.g., percentage, number) • How many will you work with (e.g., hospitals, screeners) • How much time/money? • Where will data come from? 	
A	Achievable	<ul style="list-style-type: none"> • Can you do this in the time you have? • What resources do you have to start? • What resources do you need and how will you get them? 	
R	Relevant	<ul style="list-style-type: none"> • How does this move you closer to your program goal/s? 	
T	Time-bound	<ul style="list-style-type: none"> • When will you start/end? • Does anything need to happen before you start? 	

Change Selected

List AIM of project:

List change Idea 4: (Describe a change idea related to the aim)

Describe tools and/or resources that will be used to help with the change or maybe created as a result of the change:

Finalize AIM Statement

Write Team Aim Here:

Example: By August 2024, the increase by 10% from baseline, the number of homebirth babies who receive newborn screening by one month of age.

Types of Measures

Outcome Measures Measures the impact or change; used to measure program effectiveness; reflected in your AIM statement	Process Measures Measures how the system works and whether the system is performing as planned; is system moving toward accomplishing outcome measure	Balanced Measures Measures unintended change in consequences; tracks changes that were unexpected
Examples <ul style="list-style-type: none"> • 98% of newborns will receive a hearing screening by one month of age. • 98% of DBS samples will be received by the laboratory within 24 hours of collection due to HL7 messaging. 	Examples <ul style="list-style-type: none"> • Number of babies who receive hearing screening within 24 hours after birth. • Number of homebirth babies who receive a hearing screening by one month. • Number of lab reports released to providers within 48 hours. • Percent of medical centers with follow-up protocols (pre and post). • Percent of hospitals sending and receiving orders with HL7 messaging. 	Examples <ul style="list-style-type: none"> • Significant increase in false positives or false negatives. • Burden on staff time • Increase in declination of screening • Significant increase in additional samples or out-of-range results. • Change when hospital staff educate parents at night prior to newborn screen (moved from 9am to midnight).

Measurement -
How will we know a change is an improvement?

Measurement Considerations

What information is important to collect?

Does it help you see movement toward your aim?

Why is it important?

Who will collect the data?

How frequently will you review the data?

How will you analyze the data?

Where and when will data be collected?

How will you share the data?

How will you display the data?

What is the numerator and the denominator?

Measurement Planning: Example

Measure/goal	Percentage of homebirth babies who receive NBS by one month of age to 20%
Type	<input checked="" type="checkbox"/> Outcome <input type="checkbox"/> Process <input type="checkbox"/> Balance
Rational (why important)	Homebirth babies are at risk of not receiving NBS. Some populations that choose homebirths are also at increased risk for certain genetic conditions. Homebirth babies also feed in the total number of live births and are reflected in the over missed screening numbers.
Data source	Vital records, DBS records, NBHS records
Operational definition	Numerator: Number of homebirths who receive DBS and NBHS Denominator: Number of homebirths
Baseline data	8% as of August 2023
Other details -Who will collect? -How frequently will it be collected and reviewed? -How will you display your data? -How will you share your data?	-DBS staff and EHDI staff -Monthly collection and review -Run chart -Share at monthly check-ins between DBS and EHDI, bi-annual advisory committee meetings

Measurement Planning

Measure/goal	
Type	<input type="checkbox"/> Outcome <input type="checkbox"/> Process <input type="checkbox"/> Balance
Rational (why important)	
Data source	
Operational definition	Numerator: Denominator:
Baseline data	
Other details -Who will collect? -How frequently will it be collected and reviewed? -How will you display your data? -How will you share your data?	

Measurement Planning

Measure/goal	
Type	<input type="checkbox"/> Outcome <input type="checkbox"/> Process <input type="checkbox"/> Balance
Rational (why important)	
Data source	
Operational definition	Numerator: Denominator:
Baseline data	
Other details -Who will collect? -How frequently will it be collected and reviewed? -How will you display your data? -How will you share your data?	

Measurement Planning

Measure/goal	
Type	<input type="checkbox"/> Outcome <input type="checkbox"/> Process <input type="checkbox"/> Balance
Rational (why important)	
Data source	
Operational definition	Numerator: Denominator:
Baseline data	
Other details -Who will collect? -How frequently will it be collected and reviewed? -How will you display your data? -How will you share your data?	

Measurement Planning

Measure/goal	
Type	<input type="checkbox"/> Outcome <input type="checkbox"/> Process <input type="checkbox"/> Balance
Rational (why important)	
Data source	
Operational definition	Numerator: Denominator:
Baseline data	
Other details -Who will collect? -How frequently will it be collected and reviewed? -How will you display your data? -How will you share your data?	

Agenda Day 2

8:00 am – 9:00	Breakfast	
9:00-9:15 (15)	Recap of Day 2, plans for Day 3, questions	Mandy
9:15-9:45 (30)	Submitted proposed and implemented strategies and share of current resources	Sophie
9:45 – 10:00 (15)	Break – Coffee Provided	
10:00-12:00 (120)	Brainstorming strategies, developing PDSA cycles <ul style="list-style-type: none"> • Presentation • Team Time • Report out 	Alyson
12:00-12:30 (30)	Teamwork, communication, and collaboration activity or Hot Topic in Newborn Screening: CMV	Mandy
12:30-1:00 (30)	Questions, Review of Monthly reporting, Wrap-Up, Next steps	Alyson and Mandy

Strategies
(What changes
can we make
that result in
improvement?)

Tips on selecting changes

- **Chose ideas wisely**
 - What do you think will have the biggest impact on your aim
 - What is going to be the easiest change to test (low hanging fruit)
- **Consider if your ideas are:**
 - Outside of your control
 - Dependent strongly on IT needs
 - Are expensive
 - You cannot try right away
- **If it feels too complex it is**
 - 80/20 rule
- **Remember, 25%-50% of our ideas do not result in improvement**

Change Concepts

CHANGE CONCEPT – is a general notion or approach to change that has been found to be useful in developing specific ideas for change that do lead to improvement. After generating change concepts, we run PDSA cycles to test a change or group of changes on a small scale to see if there is improvement.

1. Eliminate Waste
- 2. Improve Work Flow**
3. Optimize Inventory
4. Change the Work Environment
- 5. Enhance the Producer/Customer Relationship**
- 6. Manage Time**
7. Manage Variation
8. Design Systems to Avoid Mistakes
9. Focus on a Product/Service

Examples

2. Improve Workflow

- Minimize Hand offs
- Are there bottlenecks?
- **Adjust Time of Day**

5. Enhance the Producer/Customer Relationship

- Listen to the families
- Focus on Outcome to families

6. Manage Time

- Reduce Setup/Startup Time
- Reduce Wait Time

Change Selected

List AIM of project:

List change Idea 1: (Describe a change idea related to the aim)

Describe tools and/or resources that will be used to help with the change or maybe created as a result of the change:

Change Selected

List AIM of project:

List change Idea 2: (Describe a change idea related to the aim)

Describe tools and/or resources that will be used to help with the change or maybe created as a result of the change:

Change Selected

List AIM of project:

List change Idea 3: (Describe a change idea related to the aim)

Describe tools and/or resources that will be used to help with the change or maybe created as a result of the change:

Plan, Do, Study, Act (PDSA) Cycles

Why we PDSA

Fast – We have a short attention span

Low risk – no harm option

Try everything

Create confidence

Learn how to adapt

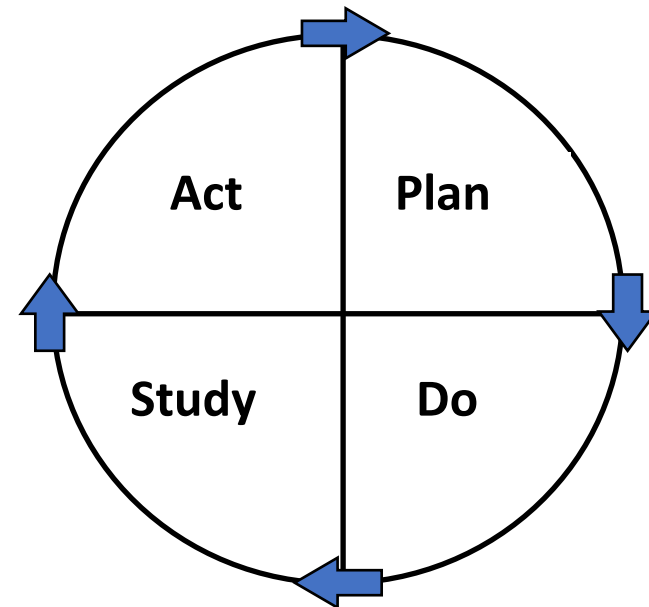
Evaluate side-effects

Build momentum

Decrease resistance

Make REAL improvement

PDSA Cycles Accelerate Learning!



PDSA Planning Worksheet

What is the objective of the PDSA?



Step 1, Plan: Plan the test, including a plan for collecting data

Questions and predictions:

Who, What, Where, When:

Plan for collecting data:



Step 2, Do: Run the test on a small scale

Describe what happened:

What data did you collect:

What observation did you make:



Step 3, Study: Analyze the results and compare them to your predictions

Summarize and reflect on what you learned:



Step 4, Act: Based on what you learned from the test, make a plan for your next step

Determine what modifications you should make—adapt, adopt, or abandon

PDSA Planning Worksheet

What is the objective of the PDSA?



Step 1, Plan: Plan the test, including a plan for collecting data

Questions and predictions:

Who, What, Where, When:



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Step 1, Plan: Plan the test, including a plan for collecting data

Questions and predictions:

Who, What, Where, When:

Plan for collecting data:



Step 2, Do: Run the test on a small scale

Describe what happened:

What data did you collect:

What observation did you make:



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Summarize and reflect on what you learned:



Step 4, Act: Based on what you learned from the test, make a plan for your next step

Determine what modifications you should make—adapt, adopt, or abandon

PDSA Cycles where to start and END

CURRENT COMMITMENT WITHIN ORGANIZATION

		No COMMITMENT	SOME COMMITMENT	STRONG COMMITMENT
Low degree of belief that change idea will lead to Improvement	Cost of failure large	<i>Very small-scale test</i>	<i>Very small-scale test</i>	<i>Very small-scale test</i>
	Cost of failure small	<i>Very small-scale test</i>	<i>Very small-scale test</i>	<i>Small-scale test</i>
High degree of belief that change idea will lead to Improvement	Cost of failure large	<i>Very small-scale test</i>	<i>Small-scale test</i>	<i>Large-scale test</i>
	Cost of failure small	<i>Small-scale test</i>	<i>Large-scale test</i>	<i>Implement</i>

Unite Newborn Screening Learning Community Monthly Report

State / Team Members:

AIM Statement:

What have you accomplished this month? Be as specific as possible 😊

What challenges have you faced this month?

What has worked well for your team?

What is your budget looking like?

Please provide any accompanying data in the space below:

Any additional comments? Anything we can support you with?

Newborn Screening

1

Newborn screening: Blood screen

Three simple screens



A baby may look healthy but be born with a serious health condition.



All babies in the United States receive newborn screening. Each state decides which conditions to screen for.

Helps identify inherited, endocrine and metabolic conditions.



If found early, many can be treated.

Blood screen process



Heel stick

Before a baby leaves the hospital, a health care provider pricks the baby's heel to get a few drops of blood. The blood drops are placed and dried on a special paper.

This should happen within 48 hours of a baby's birth.



Shipping and testing

Within 24 hours of the heel stick, the paper with blood drops should be sent to a newborn screening lab for testing.



Lab results

Within 5 days of birth, results for time-critical conditions should be shared with the baby's provider.

Within 7 days of birth, results for all other conditions should be shared with the baby's provider.



Follow-up

All newborn screening results should be reported to the baby's provider within 7 days of birth.

Positive screen results require further testing and immediate follow-up.

Negative screen:

- ✓ Provider is notified.
- ✓ Provider should follow up with baby's family.
- ✓ If parents don't hear about results, call and ask the provider.

Positive screen:

- ✓ Provider is notified.
- ✓ Provider follows up with baby's family for further testing.
- ✓ Diagnostic tests must be done immediately to confirm results.
- ✓ Intervention should begin as soon as possible.



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2

Newborn screening: Hearing screen

Three simple screens



A baby may look healthy but be born with a hearing problem.



All babies in the United States receive newborn screening. Each state decides which conditions to screen for.

Helps identify babies at risk for hearing loss. If found early, babies can be referred for additional testing.



If found early, many can be treated.

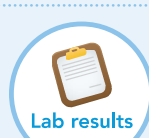
Hearing screen process



Hearing screen

Before a baby leaves the hospital, a health care provider places a soft earphone in the baby's ear that plays sounds.

This checks how the baby's ear and brain respond to sound.



Lab results

If there are signs of hearing loss in one or both ears, the baby needs more tests.

The baby needs to be tested at least 2 more times in the first month after birth.



Follow-up

All hearing screening results should be reported to the baby's provider.

Positive screen:

- ✓ Provider should follow up with the baby's family.
- ✓ Provider refers the baby to a pediatric audiologist to evaluate the baby for permanent hearing loss before the baby is 3 months old.
- ✓ If the baby has hearing loss, provider refers the baby to an early intervention program before the baby is 6 months old.

Negative screen:

- ✓ Baby is released from the hospital and no additional testing is needed.



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3

Newborn screening: Heart screen

Three simple screens



A baby may look healthy but be born with a serious heart condition.



All babies in the United States receive newborn screening. Each state decides which conditions to screen for.

Helps identify conditions called critical congenital heart disease (CCHD).



If found early, many can be treated.

Heart screen process



Pulse oximetry

Within 48 hours of a baby's birth, a health care provider places a sensor on the baby's hand and foot for a few minutes.

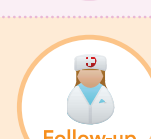
This test is called pulse oximetry. It checks the amount of oxygen in the baby's blood.

Low blood oxygen may be a sign of a heart condition.



Results

If the baby has low levels of blood oxygen: Test again 1 and 2 hours after the first test.



Follow-up

All heart screening results should be reported to the baby's provider.

Positive screen:

- ✓ Provider is notified.
- ✓ Provider follows up with baby's family and refers the baby immediately to a pediatric cardiologist for:
 - ✓ More testing, like an echocardiogram
 - ✓ Surgery, if needed, to repair a heart condition

Negative screen:

- ✓ Baby is released from the hospital and no additional testing is needed.



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This resource was developed by funding from the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS) under grant number U22MC24078 for \$850,000.

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Acronyms

AAMC: Association of American Medical Colleges	LPDR: Longitudinal Pediatric Data Resource
AAP: American Academy of Pediatrics	LSD: Lysosomal Storage Diseases
ACHDNC: Advisory Committee on Heritable Disorders in Newborns & Children	MCHB: Maternal & Child Health Bureau
AHA: American Hospital Association	MOU: Memorandums of Understanding
AMA: American Medical Association	NBS: Newborn screening
ACOG: American College of Obstetricians & Gynecologists	NBSGT Symposium: Newborn Screening and Genetic Testing Symposium
APHL: Association of Public Health Laboratories	NBSTRN: Newborn Screening Translational Research Network
ACMG: American College of Medical Genetics	NCC: National Coordinating Center for the Regional Genetic Service Collaboratives
API: Application Programming Interface	NewSTEPS: Newborn Screening Technical assistance & Evaluation Program
ASTHO: Association of State & Territorial Health Officials	NHLBI: National Heart, Lung, and Blood Institute
AMCHP: Association of Maternal & Child Health Programs	NICHD: National Institute for Child Health & Development
BDR: Birth Defects Registry	NICHQ: National Initiative for Children's Healthcare Quality
CDC: Centers for Disease Control & Prevention	NICU: Neonatal Intensive Care Unit
CFF: Cystic Fibrosis Foundation	NIH: National Institutes of Health
CLSI: Clinical & Laboratory Standards Institute	NLM: National Library of Medicine
CCHD: Critical Congenital Heart Disease	NLTN: National Laboratory Training Network
CMS: Content Management System	OHRP: Office of Human Research Protection
DBS: Dried blood spots	PDSA: Plan-Do-Study-Act
EHDI: Early Hearing Detection & Intervention	PEAS: Performance Evaluation & Assessment Scheme
FISMA: Federal Information Security Management Act	PHI: Personal Health Information
GA: Genetic Alliance	QA/QC: Quality Assurance/ Quality Control
HIPAA: Health Insurance Portability & Accountability Act	QI: Quality Indicators
HIT: Health Information Technology	RC: Regional Genetics Collaboratives
HL7: Health Level 7	RUSP: Recommended Uniform Screening Panel
HRSA: Health Resources & Services Administration	SCID: Severe Combined Immunodeficiency
HHS: Health & Human Services	SDSA: Study-Do-Study-Act
IHI: Institute for Health Improvement	SIMD: Society for Inherited Metabolic Disorders
IT: Information Technology	SNOMED-CT: Systematized Nomenclature of Medicine – Clinical Terms
LIMS: Laboratory Information Management Systems	STFU: Short Term Follow Up
LOINC: Logical Observation Identifiers, Names & Codes	TA: Technical Assistance
LTFU: Long Term Follow Up	VDBR: Virtual Dried Blood Spot Repository

Appendix C: UNBS Learning Community Surveys

UNBS Pre-Survey

Please complete your feedback by end of day August 31. To refresh your memory of the purpose and aim for the Unite Newborn Screening-Learning Community (UNBS-LC):

Purpose

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

AIM

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

Due to the size of the LC, your responses will not be anonymous. However, results from the survey will only be shared in aggregate. No individual responses will be shared.

1. For this LC, which state do you represent?
 - a. Louisiana
 - b. Indiana
 - c. Michigan
 - d. South Dakota

2. What role best represents you on the LC?
 - a. Dried blood (DBS) spot staff
 - b. Early Hearing Detection and Intervention (EHDI) staff
 - c. Critical Congenital Heart Disease staff/representative
 - d. DBS spot parent
 - e. EHDI parent

3. Prior to participation how would you rate the collaboration (e.g., consistent communication, working together on projects, brainstorming solutions to a problem) between EHDI and DBS?
 - a. In place, working well
 - b. In place, needs improvement
 - c. Plan in place to develop/establish
 - d. Not in place
 - e. I don't know

*If answered a, b, or c on Q2, answer Q4, Q5, & Q6

4. Prior to participation in the UNBS-LC, what was your program's ability to share data between DBS and EHDI (e.g., data system, Excel, other data applications)?
 - a. In place, working well
 - b. In place, needs improvement
 - c. Plan in place to develop/establish
 - d. Not in place
 - e. I don't know

5. Prior to participation in the UNBS-LC, what was your DBS or EHDl program's ability to share data with a family support organization (e.g., data system, Excel, other data applications)?
- a. In place, working well
 - b. In place, needs improvement
 - c. Plan in place to develop/establish
 - d. Not in place
 - e. I don't know
6. Prior to participation in the UNBS-LC, what was inclusion of families in your DBS or EHDl program?
- a. In place, working well
 - b. In place, needs improvement
 - c. Plan in place to develop/establish
 - d. Not in place
 - e. I don't know

*If answered d or e on Q2, answer Q7

7. How involved are you with your state's DBS or EHDl program? (mark all that apply)
- a. I am not involved with this program but would like to be.
 - b. I am not involved with this program and would not like to be.
 - c. I have visited their website.
 - d. I follow them on social media.
 - e. I have participated in their activities or programs.
 - f. I am an EHDl or DBS family leader (for example, builds partnerships, advocates for DHH children in the larger community, participates on advisory committees).
 - g. Other: _____
8. How do you rate your knowledge of quality improvement?
- a. Excellent
 - b. Very Good
 - c. Good
 - d. Fair
 - e. Poor
9. I feel confident using quality improvement methodology.
- a. Strongly agree
 - b. Agree
 - c. Disagree
 - d. Strongly disagree
10. Name at least one outcome you would like to accomplish during this LC.

UNBS Post-Survey

Hello, a big THANK YOU all for your time, energy, expertise, and willingness to come together to improve the collaboration between DBS, EHDI, and CCHD programs!

Please complete this evaluation of the collective work we have done.

Complete your feedback by end of day Monday, June 24, 2024.

To refresh your memory:

1. The purpose of the LC was to serve as a way for DBS and EHDI peers to both learn and share successful uniting NBS program strategies and spread them throughout the newborn screening system.
2. The Aim of the LC was, by June 30, 2024, the UNBS-LC will develop a document of promising practices for DBS and EHDI collaboration.

1. What role best represents you on the LC?
 - a. Dried blood (DBS) spot staff
 - b. Early Hearing Detection and Intervention (EHDI) staff
 - c. Critical Congenital Heart Disease staff/representative
 - d. DBS spot parent
 - e. EHDI parent

2. I learned new information about the other newborn screening programs as part of my participation in UNBS-LC.
 - a. Strongly agree
 - b. Agree
 - c. Disagree
 - d. Strongly disagree

3. After participation in the LC, how would you rate the collaboration (e.g., consistent communication, working together on projects, brainstorming solutions to a problem) between EHDI and DBS?
 - a. In place, working well
 - b. In place, needs improvement
 - c. Plan in place to develop/establish
 - d. Not in place
 - e. I don't know

4. After participation in the UNBS-LC, how would you rate the inclusion of families in your EHDI program?
 - a. In place, working well
 - b. In place, needs improvement
 - c. Plan in place to develop/establish
 - d. Not in place
 - e. I don't know

5. After participation in the LC, how do you rate your knowledge of quality improvement?
 - a. Excellent
 - b. Very Good
 - c. Good
 - d. Fair
 - e. Poor

6. The UNBS-LC leaders were responsive to our team's needs.
 - a. Strongly agree
 - b. Agree
 - c. Disagree
 - d. Strongly disagree

7. Participation in UNBS-LC was worth my time.
 - a. Strongly agree
 - b. Agree
 - c. Disagree
 - d. Strongly disagree

8. Our DBS, EHDI, and CCHD teams plan to continue working together after the conclusion of this LC.
 - a. Strongly agree
 - b. Agree
 - c. Disagree
 - d. Strongly disagree

9. The LC lasted from September 2023-June 2024 (10 months). The amount of time for the LC was
 - a. Sufficient at 10 months
 - b. Should have been shorter (<10 months)
 - c. Should have been longer (11-12 months)
 - d. Should have been longer (13-18 months)
 - e. Other, please specify_____

10. Each team was provided \$30,000 to compensate for time and materials spent on the LC. Was the amount of funding provided
 - a. Sufficient
 - b. More than needed
 - c. Not as much as needed (if this is selected, enter amount of funding that would have been preferable)

11. Please list at least one strength related to participation in the UNBS- LC.

12. When thinking through the LC process (in-person kick-off, bimonthly LC sessions, bimonthly individual check-ins, duration of LC, etc.), share any thoughts on how to improve the LC process for future participants.

Parent Education Material

Evaluation Check List:

- Is the material "caregiver friendly" or too technical?
- Are parents provided materials in writing at the time of diagnosis?
- Ensure all materials are at 5th grade education level. (see website below)
 - o Tip: Use Word editing feature to evaluate.
- Do you have materials with state and national resources?
 - o Examples: Patient support groups, treatment support, clinic links, insurance availability (CSHCS, Medicaid, etc.), treatment manufacturers, etc.
- Do you have updated and active websites and links to the above resources?
- Do you have materials available in different languages?
- Do you have caregiver to caregiver support or resources to connect caregivers and patients?
- Are resources available on your clinic website or the IDOH site?
 - o May think about how available resources can be accessed and if clinic website update would be helpful.
 - o Send to us at IDOH to add to our site.
- Do you have a variety of resources available at many life or diagnostic stages?
 - o What to expect resources, age-based resources, common FAQ resources, check lists, diagnosis specific needs, etc.
- Do you have your facility's contact information with all necessary clinic numbers, emails, and staff information on your forms?
 - o Make this easy for families to hold onto or have access too at all times (business card, photo, sticker, etc)
- Are these resources clean and clear (not blurry, slanted, etc.) copies and within the last 2-3 years?
- Is this too much, too little information? Can you edit in real time what you provide depending on patient/caregiver needs while also ensuring they are getting the information necessary.

This is also a known rubric that may be used and useful: <https://www.ahrq.gov/health-literacy/patient-education/pemat-p.html>

Appendix E: Louisiana Materials

Letter to potential focus group participants

You completed a survey about joining our focus group on Newborn Screening in Louisiana. This group is hosted by the Bureau of Family Health (BFH). It will help us to better understand the support families need before the birth of their child. It will also help us understand how to support families if Newborn Screening shows their child needs further testing.

My name is _____. I am a parent of a child who was identified _____ as part of Louisiana's Newborn Screening program. Our goal is to improve newborn screening information that families like yours and mine receive.

There are four people who will be leading the focus groups. They are: myself, another parent, and two representatives from the Bureau of Family Health (BFH).

Please, follow the link below.

All information is private. You will be asked if you agree to participate. You will also be asked for information about family and life experiences. Lastly, you will be asked to choose the date you want to attend. The dates you will be asked to choose from are:

Wednesday, November 29, 2023 from 7:30-8:30 p.m.

Saturday, December 2, 2023 from 9:30-10:30 a.m.

Thursday, December 7, 2023 from 12:00-1:00 p.m.

<https://forms.gle/9UT2BPNaqEmuWrif9>

Thank you again for joining us. Please let us know if you have any questions. You can email us at laehdi@la.gov, or call (504) 568-2876.

Kindly,

DBS Parent Representative

EHDI Parent Representative

LA EHDI Program Manager

Heelstick Program Manager

LA Focus Group Discussion Guide

Focus group dates were shared with potential focus group members. Participants will be asked to choose their availability and note preferences in the notes section. Participants will be asked to sign forms acknowledging sessions will be recorded on Zoom but their personal information will be de-identified when analysis is conducted on the information gathered.

The following discussion guide includes the questions that will be asked during the focus group discussions geared toward understanding barriers to parent understanding of follow-up from newborn screening in the state of Louisiana. All of the focus group participants have completed a survey about newborn screening and their experiences in Louisiana. All of the focus group participants have at least one child who is identified as deaf or hard of hearing (DHH) or who has a disorder diagnosed through newborn heel stick/dried bloodspot.

This discussion guide has been broken down by stages. The focus group will begin with a welcome, introduction of moderators and notetakers and a reminder of the purpose of the focus group. Because the focus groups are conducted virtually, Zoom etiquette will be reviewed with participants. The third stage will be questions for participants. All questions are geared toward personal newborn screening experiences, including knowledge about newborn screening prior to their child's birth, their screening experience and information provided following a newborn screen. The focus group will conclude with time allowing the group members to ask any questions or add any additional comments. Using this discussion guide should produce focus group times of approximately one hour.

Welcome participants and explain the purpose of the session.

Thank you so much for being here. My name is _____, and I am the program manager for the Early Hearing Detection and Intervention program. We are currently working as part of a collaborative learning community to bring newborn hearing screening and our heel stick/dried blood spot programs together to better support Louisiana families. Today, we are leading this session on behalf of the Louisiana Bureau of Family Health, and our collaborative working on understanding any barriers parents may experience regarding newborn screening, particularly following up when further testing is needed. We hope to understand what may keep families from quickly following up after a newborn screening test that needs further testing, and what can be done to improve timeliness in that follow-up.

Also joining is my colleague with BFH, _____, and two of our amazing and invested parents, _____ and _____. Would you all like to introduce yourselves, briefly?

Invite parents to introduce themselves.

We are going to ask you some questions and have a conversation with you today about your perspectives on and experiences with the newborn screening process in Louisiana. Your participation in this focus group is voluntary—which means you do not have to participate if you do not want to. If there are any questions that you do not want to answer, you do not have to, and you can stop participating at any time.

We will be audio-visually recording what is said so we do not miss anything important and so we can go back and listen to the information again if we forget something. Because we are recording, we will not be using names or other identifying information during the session. This will take us about 60-minutes. And we will take some notes during our conversation. Does anyone have any questions so far?

Ok. We will start recording.

Review Zoom Etiquette Guidelines

Before we get started, let's review a few helpful Zoom tips. Please remember to:

- a. Find a quiet place where you are alone: To help make sure we are keeping what's said in this session private, please find a place where you are not around others who may hear the session, or please consider using headphones.
- b. Mute your microphone: To help keep background noise to a minimum, make sure you mute your microphone when you are not speaking. Be mindful of background noise: When your microphone is not muted, avoid activities that could create additional noise, such as shuffling papers. Also remember to turn your phone on vibrate or silent.
- c. Turn your camera on, we want to see your face! If you choose to use a web camera, be sure it is in a stable position and focused on eye level, if possible. Doing so helps create a more direct sense of engagement with other participants.
- d. Limit distractions: You can make it easier to focus on the meeting by turning off notifications, closing or minimizing running apps, and muting your smartphone. Try to avoid driving or moving from room to room.

Focus Group Questions

Parent

Before we start, I would like to remind you that there are no right or wrong answers in this discussion. Please answer the questions based on your own comfort level and experiences. We are interested in knowing what each of you think, so please feel free to be open to share your point of view. It is very important that we hear everyone's opinions. As a courtesy and to ensure confidentiality, please do not share what is discussed today with people outside of this group. We also ask that you put your cell phones on either vibrate or silent.

1. When do you first recall learning about newborn hearing and heel stick screening in general? What were you told about it?
2. What kind of experience did you have with your child's newborn hearing and heel stick screening process? (question to probe responses could include - Was your child born in a hospital, or home birth?)
3. What do you remember being told after your child passed or needed further testing for their newborn hearing or heel stick screen? Were you given instructions including a date/time you needed to go for follow-up testing? (could ask were the instructions verbal or written or both?)

Parent Representative 2

4. What information were you given about the rescreening process, or need to go for more testing? And who provided the information?
5. Tell us about problems with follow-up (such as lack of understanding the need, not being told to do so or where to go, transportation, etc.) How could this process be better?

6. Do you have anything else you would like to share about your personal experiences with newborn hearing and/or heel stick screening today?
7. Do you have any thoughts about how to improve the information parents receive about newborn screenings in Louisiana? What kind of information do you feel you needed before giving birth that could have made the process less intimidating?

Conclusion of the Session

Thank you again for talking with us and sharing your thoughts. Do you have any questions for us now?

Immediately following closure, please complete the short evaluation of today's session at this link. It is posted in the chat.

EHDI Staff

You will also receive a Docusign in your email with a log and form to indicate if you would like payment via mail by check or via direct deposit. For your time, you are compensated for the initial survey completion, the focus group today, and completion of the evaluation. You can complete this on your phone now and submit.

If you have any questions later, please contact us via email or phone afterward. We really appreciate your feedback and help. Thanks again for taking the time to talk with us today.

Evaluation: Newborn Screening Parent Focus Group

1. Email
2. What is your name?
3. Which date did you participate in the focus group on Newborn Screening?
4. How did you learn about the focus group?
 - a. Phone call
 - b. Email
 - c. Social Media
 - d. Other:
5. Did the facilitators review Zoom etiquette guidelines prior to beginning the session?
 - a. Yes
 - b. No
6. Did the facilitators clearly explain the expectations for the focus group?
 - a. Yes
 - b. No
7. Do you have anything else you would like to share about your personal experiences with newborn hearing and/or heel stick screening today?
8. Would you be interested in serving as a parent reviewer of any family-facing material we develop to improve parent understanding of the newborn screening process?

Birth Class Newborn Screening Post Test

1. Who is completing this form?
2. How many times have you or your partner given birth?
3. Newborn screening is...
 - a. a test given 1 minute after, and then 5 minutes after birth to quickly check a baby's health.
 - b. tests performed 24-28 hours after birth that test babies for conditions that need support
 - c. a vitamin k shot given soon after birth to prevent bleeding in babies
 - d. none of the above
 - e. I don't know
4. There are three parts to newborn screening.
 - a. True
 - b. False
5. Most babies born in the United States do not get newborn screening.
 - a. True
 - b. False
6. Newborn screening is important because babies can look healthy at birth, but still have a condition that can cause serious health problems.
 - a. True
 - b. False
7. Newborn screening usually occurs 1 month after birth.
 - a. True
 - b. False
8. Many conditions that are found through newborn screening can be treated.
 - a. True
 - b. False
9. The blood spot test takes a blood sample from a baby's arm.
 - a. True
 - b. False
10. A light sensor placed on a baby's finger measures oxygen in a baby's blood and can detect some heart problems.
 - a. True
 - b. False
11. The result of "needs further testing" on the newborn hearing screening means a baby will need more hearing testing.
 - a. True
 - b. False
12. Follow-up testing is not important and does not need to be done quickly.
 - a. True
 - b. False

What Families Need to Know

What are newborn screenings and why are they important?

Newborn screenings are state health services and part of the many things that will happen after a baby is born. Newborn screenings are important to help ensure babies have the healthiest possible start in life.

Newborn screenings are important because they identify areas where your baby may need extra support. Newborn hearing screening, for example, ensures early opportunity for communication and language support for babies who are identified as deaf or hard of hearing. Testing a baby's blood may show if they need a special diet or other early treatment for genetic or metabolic conditions. Heart screening shows if a baby has an infection, breathing problems, or heart defect which all require further medical support.

The following information will help parents, caregivers, and families learn more about what to expect from newborn screenings in Louisiana. The Louisiana Department of Health, Office of Public Health, and Bureau of Family Health are here to support you, your child, and your family.

All states have systems to screen newborns for certain conditions.

More than 1 in 300 babies have a condition detectable by newborn screening.
babysfirsttest.org

Newborn screening, or Baby's First Test, has three parts.

These tests usually take place at your bedside or in the nursery. These tests will not harm your baby.



Blood: A small blood sample is taken from your baby's heel and placed on a special paper card. It is then sent to a laboratory to see if there are any genetic or metabolic conditions that may need care right away.



Heart: A small, light sensor placed on your baby's hand or foot measures the amount of oxygen in your baby's blood. It can help detect heart problems.



Ears: Hearing screening equipment will be used to quickly and safely test your baby's hearing. This screening will let you know if your baby will need more testing when you leave the hospital.



The results from your baby's blood screening can take a few days. If the result is abnormal, you will be contacted by your baby's doctor or the state Newborn Screening Program. The results of the heart screening are immediate and the nursery staff will explain the results and any next steps you need to take, including a follow up appointment. The results of the hearing screening are immediate and will either be "pass" or "further testing needed." Nursery staff will explain the results. If further testing is needed, an appointment will be scheduled before you leave the hospital.

Do you want to learn more about newborn screening?

Scan the QR codes or visit the websites to get started!

Frequently asked questions are on the back of this page.



Expectinghealth.org - A digital learning book for expectant parents about newborn screening.

Babysfirsttest.org - Newborn screening information by state and resources for families with rare health conditions.

Newbornscreening.hrsa.gov - Newborn screening information by state and information about conditions that may be found.

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LOUISIANA NEWBORN SCREENING: Frequently Asked Questions

Do I have to ask for my newborn to be screened?

No. It is standard hospital procedure to screen every baby. You do have the right to opt out of screening.

When does newborn screening happen?

Screening usually takes place 24-48 hours after a baby is born.

Will my baby still get screened if I am not giving birth at a hospital (i.e. at home or a birthing center)?

The blood, heart, and hearing screening *may* be completed by a licensed midwife. If the screening cannot be completed in the home or birth center, you should work with a doctor to arrange a blood sample (also called heel stick) screening within the first few days after birth. A newborn hearing screening should also be completed as soon as possible, and no later than one month of age.

What kind of conditions are screened using my baby's blood sample?

Over 30 conditions are screened for using the heel stick. You can find out exactly which ones by using the QR code below for the Louisiana Department of Health (LDH) Newborn Screening program.

How will I find out about the results of my baby's newborn screenings?

Hearing and heart results and next steps (such as an appointment for outpatient screening) are provided at the hospital before you and your baby are discharged. For heel stick, in most cases, you will not hear from your baby's doctor or the screening program unless further testing is needed. If you would like to confirm the results of your baby's screening, contact your pediatrician.

Does an abnormal result on the heel stick or heart screen mean my baby is sick?

Not necessarily, but there is a possibility your baby has a condition that will need special care right away. For example, phenylketonuria (PKU), caused by an enzyme defect, requires babies to have a special diet. Without treatment, PKU can affect the brain and cause developmental delays. It is very important that you follow up with your baby's doctor, attend scheduled follow-up appointments, and follow recommendations from your baby's provider to be sure your baby is receiving the care they need.

Does "needs further testing" on the hearing screen mean my child is deaf or hard of hearing (D/HH)?

Not necessarily, but there is a possibility - it is very important that you bring your baby for their outpatient screening and any other testing that is recommended to confirm your child's hearing levels after you leave the hospital. It is also important that you know help is immediately available if your baby is identified as D/HH to ensure your baby and family are supported. Follow the QR code below for the LDH Early Hearing Detection and Intervention (EHDI) program to learn more.

What is cytomegalovirus (CMV)?

Your baby's doctor should test for cytomegalovirus (CMV) if your baby needs more hearing testing after their newborn hearing screening, or if certain other symptoms are present. CMV, a congenital condition (meaning present at birth), is not a part of the newborn screening panel. The timeframe for testing for congenital CMV is limited and should be completed as soon as possible before your baby is 3 weeks old. You can learn more about Louisiana's CMV screening law, [Act 177](#), or about congenital CMV at www.nationalcmv.org.

What happens to my baby's blood sample after the screening is done?

Blood spot cards are kept in the state laboratory for a minimum of one year, and then destroyed.



LDH Newborn Screening Program webpage:

ldh.la.gov/page/newborn-screening

Newborn Screening Program Manager Phone: (504) 568-8254



LDH Early Hearing Detection and Intervention Program webpage:

ldh.la.gov/page/LouisianaEHDI

EHDI Program Manager Phone: (504) 568-2876



4/2024

Midwife Training Agenda

9:00 AM Welcome & Housekeeping

9:15 AM Dried Blood Spot Screening

9:45 AM Michigan Bio Trust for Health

10:05 AM Parent Education

10:25 AM BREAK Everyone

10:40 AM EHDI - Overview of Early Hearing Detection and Intervention Program

11:10 AM CCHD - Critical Congenital Heart Disease

11:30 AM LUNCH Everyone

Attendees break into groups of 3 or 4 to attend sessions.

12:30 - 2:50 All Topics run simultaneously 15 minutes with 5 min switch

Session A EHDI- BASICS How to screen

Session B EHDI -Communicating results to parents & EHDI

Session C Ordering NBS cards/brochures and Drying/Mailing specimens

Session D Collecting blood spots

Session E Filling out card & receiving and communicating results

Session F Educating families on choices after screening

Session G CCHD Algorithm and Results Reporting

2:50 -3:30 Final Thoughts & Wrap-up Everyone

Michigan Midwife Training Pre-Survey

- 1) First Name_____
- 2) Last Name_____
- 3) Email_____
- 4) Best Phone number_____
- 5) Company/Practice affiliation _____
- 6) Address_____
- 7) Please select your community-based birth role:
 - Certified nurse midwife
 - Certified professional midwife
 - Midwife student/assistant

- 8) Do you have hands on prior experience collecting the following types of newborn screens:
 - Yes No Blood spot
 - Yes No Hearing screen
 - Yes No Pulse oximetry screen

- 9) Do you have hands on prior experience doing the following:
 - Yes No Guiding parents through the BioTrust consent process
 - Yes No Ordering and paying for blood spot cards
 - Yes No Educating parents about newborn screening

Please Rate you comfort level doing the following:	Not very comfortable	Very comfortable
- Collecting blood spot screens	0 1 2 3 4 5	
- Collecting hearing screens	0 1 2 3 4 5	
- Collecting Pulse oximetry screens	0 1 2 3 4 5	
- Guiding parents through the BioTrust consent process	0 1 2 3 4 5	
- Ordering and paying for blood spot cards	0 1 2 3 4 5	
- Educating parents about newborn screening	0 1 2 3 4 5	

Michigan Midwife Training Post-Survey

- 1) Please select your community-based birth role:
 - Certified nurse midwife
 - Certified professional midwife
 - Midwife student/assistant

- 2) Do you have hands on prior experience collecting the following types of newborn screens:
 - Yes No Blood spot
 - Yes No Hearing screen
 - Yes No Pulse oximetry screen

- 3) Do you have hands on prior experience doing the following:
 - Yes No Guiding parents through the BioTrust consent process
 - Yes No Ordering and paying for blood spot cards
 - Yes No Educating parents about newborn screening

- 4) Please Rate you comfort level doing the following:

	Not very comfortable		Very comfortable
- Collecting blood spot screens	0	1 2 3 4 5	
- Collecting hearing screens	0	1 2 3 4 5	
- Collecting Pulse oximetry screens	0	1 2 3 4 5	
- Guiding parents through the BioTrust consent process	0	1 2 3 4 5	
- Ordering and paying for blood spot cards	0	1 2 3 4 5	
- Educating parents about newborn screening	0	1 2 3 4 5	

- 5) The training was relevant to your role and responsibilities (select one):
Strongly disagree Somewhat disagree Neutral Somewhat agree Strongly agree

- 6) The trainers effectively communicated the information (select one):
Strongly disagree Somewhat disagree Neutral Somewhat agree Strongly agree

- 7) The training sessions were engaging and kept my interest (select one):
Strongly disagree Somewhat disagree Neutral Somewhat agree Strongly agree

- 8) The training met my expectations (select one):
Strongly disagree Somewhat disagree Neutral Somewhat agree Strongly agree

- 9) Would you recommend this training to your colleagues? Yes No

- 10) Please provide comments on how the training could be improved:

- 11) What specific aspects of the training contributed most to your learning experience?

South Dakota Provider Survey

1. With which organization are you associated?
 - a. South Dakota Department of Health
 - b. Sanford Children's Specialty Clinic
 - c. State Hygienic Laboratory at the University of Iowa
 - d. University of South Dakota

2. Newborn screening is
 - a. A test given 1 minute after and then 5 minutes after birth to quickly check a baby's health
 - b. Test performed 24-28 hours after birth that test babies for conditions that need support
 - c. A vitamin k shot given after birth to prevent bleeding in babies
 - d. None of the above
 - e. I do not know

3. Do you recall communicating with a South Dakota UNITE team member regarding newborn screening in South Dakota between August 2023 and May 2024?
 - a. Yes
 - b. No

4. When communicating with a South Dakota UNITE team member, did you learn about the newborn screening process in South Dakota?
 - a. Agree
 - b. Somewhat Agree
 - c. Somewhat Disagree
 - d. Disagree

5. Is your role/organization part of the newborn screening process in South Dakota?
 - a. Yes
 - b. No

6. The newborn screening process in South Dakota involves many organizations?
 - a. True
 - b. False

7. Most babies born in South Dakota receive newborn screening.
 - a. True
 - b. False

8. There are three parts to newborn screening.
 - a. True
 - b. False

9. Which organization in South Dakota collects newborn screening data?
- SD Department of Health
 - Sanford Children's Specialty Clinic
 - State Hygienic Laboratory at the University of Iowa
 - University of South Dakota
 - Birthing Hospitals
 - Physicians/healthcare providers
 - Parents/caregivers
10. Newborn screening usually occurs one month after birth.
- True
 - False
11. Follow-up testing is not important and does not need to be done quickly.
- True
 - False
12. Select your level of understanding of each entity's role in the newborn screening process in South Dakota.
- South Dakota Department of Health
 - I understand this entity's role
 - I somewhat understand this entity's role
 - I do not understand this entity's role
 - This entity does not have a role
 - Sanford Children's Specialty Clinic
 - I understand this entity's role
 - I somewhat understand this entity's role
 - I do not understand this entity's role
 - This entity does not have a role
 - State Hygienic Laboratory at the University of Iowa
 - I understand this entity's role
 - I somewhat understand this entity's role
 - I do not understand this entity's role
 - This entity does not have a role
 - University of South Dakota
 - I understand this entity's role
 - I somewhat understand this entity's role
 - I do not understand this entity's role
 - This entity does not have a role

e. Birthing hospitals

- i. I understand this entity's role
- ii. I somewhat understand this entity's role
- iii. I do not understand this entity's role
- iv. This entity does not have a role

f. Physicians/healthcare providers

- i. I understand this entity's role
- ii. I somewhat understand this entity's role
- iii. I do not understand this entity's role
- iv. This entity does not have a role

g. Parents/caregivers/families of newborns

- i. I understand this entity's role
- ii. I somewhat understand this entity's role
- iii. I do not understand this entity's role
- iv. This entity does not have a role

Audiologists are often the first professionals to deliver the diagnosis of hearing loss, so we have provided some strategies for delivering the message.

Interaction

- Prepare in advance and know the family's background. Reactions vary considerably and will be influenced by several factors. When are they learning about the hearing loss? Is it during the newborn hearing screen? Is this a later identification? Have they suspected that there was a problem? Is there a history of hearing loss in the family? Is the family a member of the Deaf culture?
- Meet in a comfortable setting.
- Allow enough time to meet.
- Be careful not to provide too much information. Answer questions briefly and directly. You may need to repeat the same information later when they are emotionally ready to hear and understand it.
- Be prepared for a variety of reactions from families. Professionals need to read people's body language and facial expressions. If a family has shut down because of the shock of the diagnosis, be sensitive to that and reconvene later.
- Offer referrals. Know that some families will be ready to interact with others, and some will not. Be sensitive to either situation and ask again later if needed. Summarize the session with a brief plan for the next step. Knowing what to expect next can be comforting to families.

Results

- Must be understandable to families.
- Concisely state the meaning of results.
- Terminology should always be clearly explained.
- List critical information and immediate action items.
- Include appropriate contact information for follow-up questions.
- Be clear when further follow-up is necessary.

Reports

- Writing should be at or below an 8th-grade reading level.
- Use plain language <https://www.plainlanguage.gov/guidelines/>
- Highlight, change the font color, CAPITALIZE, underline, or bold important points to stand out.
- Place summaries and action items before results, as some will not read the whole report.

References
Baby's First Test. (2010). Plain Language Recommendations for Reporting Newborn Screening Results.



NEWBORN SCREENING

Saving Babies' Lives

FOR ADDITIONAL INFORMATION

Visit with your health care provider

Call the South Dakota Department of Health Newborn Screening Program at 1-800-738-2301

Scan the QR code below for additional resources



SOUTH DAKOTA DEPARTMENT OF HEALTH
Newborn Screening Program
email: dohnewbornscreening@state.sd.us

REGARDING SCREENING

What is Newborn Screening?

All newborns in South Dakota are required by law to have a blood test shortly after birth to screen for metabolic and other inherited disorders. The newborn screening helps identify babies who may have one of these disorders.

Why should my baby be screened?

Even if your baby looks healthy, he/she may have one of these disorders. Although these disorders are rare, they are usually serious. With early diagnosis and medical treatment, complications may be prevented. Without treatment babies with these disorders could suffer intellectual disabilities, seizures, or even death.

How will my baby be tested?

A few drops of blood from your baby's heel is all that is needed to test your baby. It is recommended that the test be performed 24-48 hours after birth.

When do I get the screening results?

Generally, parents are notified only if retesting or further testing is needed. You can ask about the results when you take your baby in for a regular check-up.

What if my baby needs to be re-tested?

If your baby's doctor asks you to bring your baby in for retesting or further testing, do so as soon as possible.

There are 3 main reasons why a repeat screening test may be needed: (1) There was a problem with the sample, (2) The test was done prior to 24 hours of age, or (3) The test result was abnormal. Generally, if the results of the repeat screening test are also abnormal, the doctor will discuss the need for further treatment or testing. It is important that your hospital and doctor have your correct address and phone number to contact you.

What happens to the blood spots after screening?

Most of the dried blood is used up during testing. The leftover blood spots are destroyed with 60 days. They are not used for research.

South Dakota law requires hospitals, doctors, and midwives to tell you about newborn screening. Because screening is so important, all babies should have these screens. If you don't want your baby screened, you must sign the refusal form. Ask your midwife or doctor for the form. Newborn screening can save your baby's life. The possible health risks of not screening are serious.

KREW'S STORY

After Krew was born, we were told about the newborn blood spot screening test. It's a simple heel prick for a spot of blood that is sent to a lab to check for metabolic and genetic disorders. Things were going great on our first full day at home until we got a call from the hospital. Something had come back abnormal on Krew's newborn screening. They told us it was a genetic condition called MCAD (Medium-chain acyl-CoA dehydrogenase). If this inherited condition is not found and treated quickly, it can cause low blood sugar, seizures, breathing difficulties, coma, and even death.



The newborn screening truly changed our lives and saved our baby's life.

The hospital had us come back and Krew was admitted for 24 hours to monitor her blood sugar. Her diagnosis was confirmed. As first-time parents, we were overwhelmed and terrified of what could have happened had this not been caught by newborn screening. Our genetics team was fantastic giving us all the information and resources we needed to ensure that Krew would continue to live a healthy and happy life. The newborn screening truly changed our lives and saved our baby's life. As parents we are the best advocates for our children and choosing to do the newborn screening was easily one of the best decisions we have ever made. It truly has been lifesaving.

— MANDY S. MOM OF KREW KAY

X-ALD and Hearing

ADDED TO SD NEWBORN SCREENING PROTOCOLS

In consultation with the South Dakota Newborn Screening Advisory Committee, the South Dakota Department of Health has added X-ALD (X-linked adrenoleukodystrophy) to South Dakota's newborn screening panel. Additionally, all babies born in South Dakota will be required to have an initial hearing screening before leaving the hospital or by one month of age.



EFFECTIVE JUNE 3, 2024, ALL NEWBORNS BORN IN SOUTH DAKOTA WILL BE SCREENED FOR X-ALD AND HEARING.

X-ALD (X-Linked Adrenoleukodystrophy):

X-ALD is a rare genetic condition that can cause problems in the brain and adrenal glands. Without treatment, these problems can worsen quickly in babies and may become fatal.

Deafness or Hard of Hearing: This occurs when any part of the ear does not function in the usual way. If not identified and acted upon, this can affect a child's ability to develop communication, language, social skills, and learning abilities.

99%

of all South Dakota newborns are screened by the SD Newborn Screening Program

