Heartland Genetics Services Collaborative

Annual Report

2015-2016

March 2017

Collaborate. Evaluate. Improve.

Interdisciplinary Center for Program Evaluation

HEARTLAND GENETICS SERVICES COLLABORATIVE

University of Nebraska Medical Center

MUNROE-MEYER INSTITUTE

PROGRAM DESCRIPTION: 2015-2016

The Heartland Genetics Services Collaborative (referred to in the remainder of the report as Heartland Collaborative) is a network of representatives (parents, patients, clinicians, researchers, industry representatives, laboratorians, and public officials) from eight states. This 13-year-old Collaborative actively engages with its partners at a regional and national level to increase access to and improve quality of genetic and newborn screening (NBS) services in the region and, at the same time, contribute to projects of national significance. This work is completed under the leadership of the Heartland Collaborative Regional Coordinating Center (HRCC) with planning and direction supported by the Heartland Collaborative Advisory Board and four work groups [e.g., Newborn Screening (NBS), Clinical Services, Early Hearing and Detection Intervention (EHDI), and Advocacy] and through a grant (H46MC24089) from the Health Resources and Services Administration (HRSA). The Heartland Collaborative implemented strategies related to five primary HRSA priorities for this funding cycle:

HRSA Priority 1: Treat in the context of a medical home that provides accessible, family-centered continuous, comprehensive, coordinated, compassionate, and culturally effective care.

HRSA Priority 3: Expand the pool of the genetic service workforce by determining needs and gaps across sectors to provide education and training, with emphasis on allied health providers, other subspecialties, and educators.

HRSA Priority 4: Build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services.

HRSA Priority 8: Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access.

HRSA Priority 10: Any other program priority that addresses the needs of the region and the program goals.

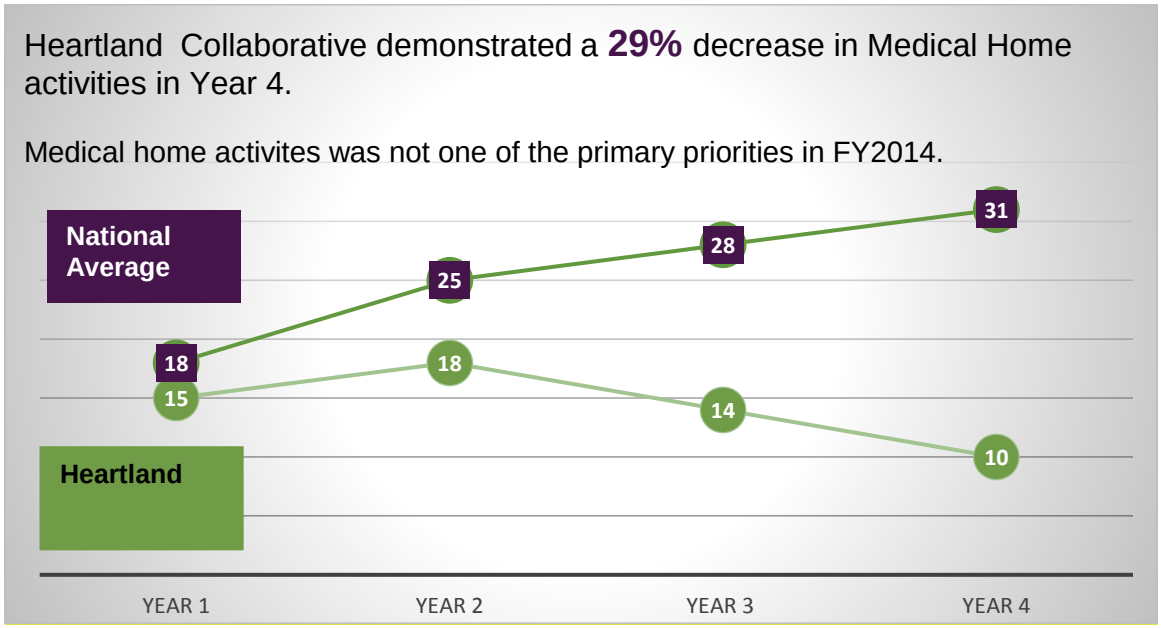
Heartland Collaborative Evaluation Findings

The purpose of this report is to provide a summary of the evaluation findings regarding the Heartland Collaborative's implementation of program activities, its success in accomplishing program outcomes, and performance on HRSA outcome performance measures. A multi-method approach, including qualitative and quantitative methodologies, was used to help inform a continuous improvement process. Built into the evaluation process was the ongoing review of evaluation data based on the Heartland Collaborative's five HRSA priority areas to inform program improvement through reflection and action planning. The results of the evaluation are summarized in the following sections.

HRSA Priority 1: Treat in the context of a medical home that provides accessible, family-centered continuous, comprehensive, coordinated, compassionate, and culturally effective care.

Cross Project Efforts to Support Medical Home

As part of the national evaluation, the Heartland Collaborative rates the degree to which they assisted in developing, supporting, and promoting medical homes for the Maternal Child Health (MCH) populations (HRSA Performance Measure #41). The Heartland Collaborative decreased the number of activities in this area this past year. Activities this year focused primarily on telehealth, transition, Individualize Healthcare Plan (IHP) implementation, access to services, and needs assessment. Based on the work plan of the Heartland Collaborative, medical home was not one of its primary priorities this grant year. Rather, activities that will circle back to supporting the medical home were the focus.



Care Coordination

The *Care Coordination: the Region 4 Midwest Genetics Collaborative developed Empowering Families* training curriculum was implemented for Heartland families this grant year. Region 4 developed this training in partnership with representatives from public health, genetics and primary care providers, parents and consumers of genetics services. The training was built on the premise that families have an important role in the care coordination provided within the medical home. This training focused on providing a training curriculum to help parents better meet the needs of the child and family by working collaboratively with their child's physicians and care providers.

In May 2015, the training was provided in the Heartland region. The purpose of the training was to provide facilitators (both parents and providers) with the skills, knowledge, and resources they need to support parents to coordinate care for children with complex needs in partnership with a medical home. Heartland partnered with Region 4 Midwest to provide a Care Coordination Facilitator Training in the Heartland region. The 24 individuals who participated were from six states (North Dakota, South Dakota, Nebraska, Kansas, Missouri, and Iowa) and became certified facilitators by Region 4 Midwest. One organization sent four participants, of which two were funded by their own organization.

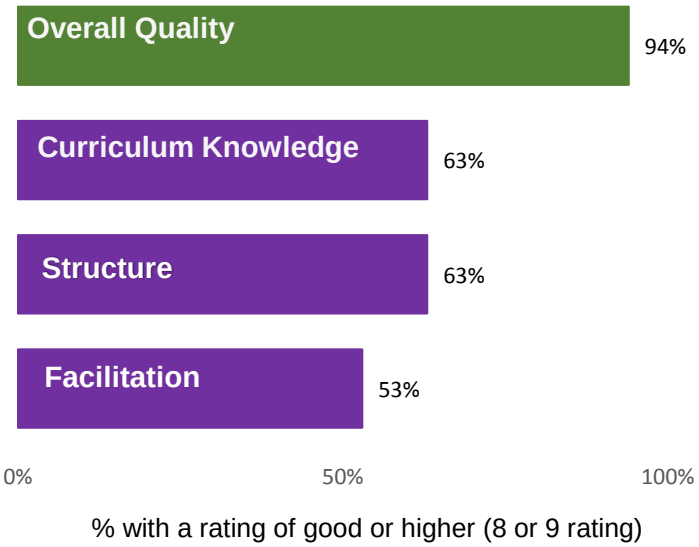
After the May 2015 training, the participating eleven organizations were to provide at least one training in their state by November 1, 2015. In order to facilitate the success of their trainings, Heartland offered small grants to help cover the costs. Seven of the eleven organizations received an award and agreed to conduct another training by May 31, 2016. Nineteen trainings were completed in the Heartland Region during project year 4. Trainings were always facilitated by a parent and were often co-facilitated by a community provider. As of May 2016, 175 parents completed the pre-assessment for the in-person training. Parents were asked to complete a pre-survey to determine their current interface with their child's health care team.

The parents were very excited to **learn new things** and to begin **implementing what they learned**….Many commented that they wished they could have had this training years ago.

…….A parent facilitator

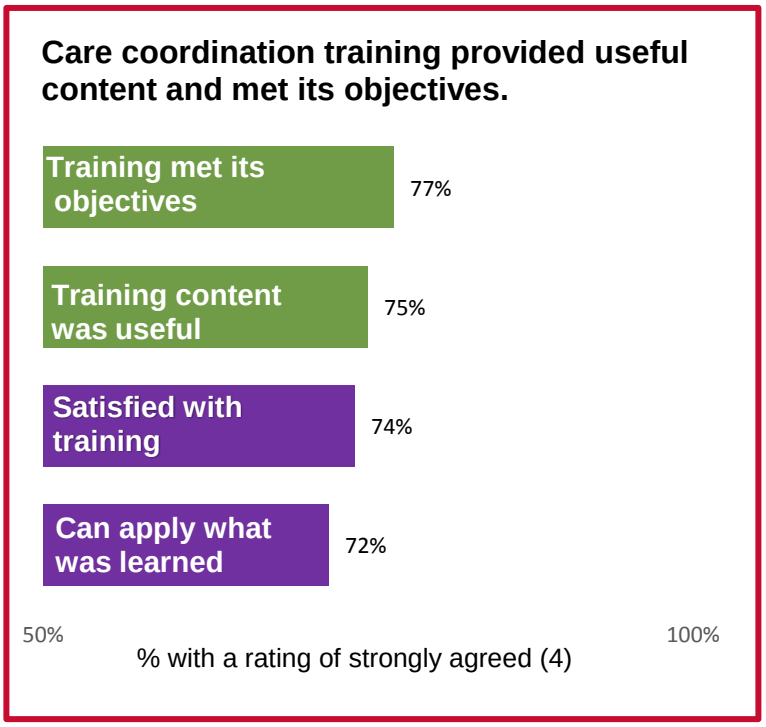
Training fidelity. Each of the facilitators completed a fidelity implementation rating as they implemented the workshop for parents in their community. The assessment was completed to monitor the quality of their training and the degree that it stayed true to the fidelity of the original training. The ratings were based on a nine-point Likert scale. Four key components were evaluated including: 1) overall quality (e.g., participant satisfaction, participant growth); 2) curriculum knowledge (e.g., information on medical home, advocacy, care coordination navigating insurance); 3) structure (e.g., organization of training, adjusts materials for group); and 4) facilitation (e.g., manages group dynamics, facilitates discussion). Most facilitators rated the overall quality of the training positively (a score of eight or nine). The majority reported that they felt comfortable with the curriculum knowledge and navigating the structure of the training process. Several facilitators reported feeling less comfortable in presenting on insurance, the Affordable Care Act (ACA) and related topics. Overall, the facilitators commented that the "structure flowed well" and "families were engaged in the discussion." A few commented that attendance was lower than anticipated, but they were problem-solving ways to increase attendance

The parent facilitators provided high quality training on Care Coordination.



at future trainings. The area of facilitation was the lowest rated. The facilitators commented that they were feeling good overall, "we did a good job of facilitating, but since this was our first time, we have room to improve." Others felt they had credibility, were responsive, and had good pacing and great team dynamics. Areas to improve included timing and working on transitions.

Parent participants' feedback. Parents were asked to complete a post-training assessment at the conclusion of the workshop. A total of 106 parents completed the assessment that was based on a 4-point Likert scale. The majority found the content useful and were satisfied with the training [rated as strongly agreed (4)]. The results found over 90% of the parents were very satisfied with their opportunity to contribute to the training conversations and with the facilitator team. The majority of the families also found they were very satisfied with their opportunities to network with other parents (87%) and learn about local resources (85%). A post-knowledge test was completed as part of the post-survey. The results found most (91%) of the parents received a 90% or higher score on the knowledge assessment. These results suggest that families had acquired the knowledge targeted by the training.



The last part of the survey examined parents' perceptions on the impact of the training on future interactions with their health care team. A small majority (58%) reported that the role in their child's healthcare would change as a result of the training. Actions that parents plan to take because of the training varied greatly with the primary actions reported including:

- Organize medical information;
- Communicate better with their medical team;
- Advocate for their child;
- Use the resources provided;
- Navigate their insurance; and
- Develop a care coordination plan for their child.

Transition Project

The Center for Disabilities at the University of South Dakota (USD) Sanford School of Medicine has collaborated with the Heartland Genetics Services Collaborative to understand and address some of the issues related to developing processes and practices that support successful health care transitions for youth with special health care needs and, specifically, those with genetic conditions. A multi-disciplinary Transition Clinic (***TransitioninAction***) was established to assist adolescents with disabilities or chronic health conditions make the transition from pediatric to adult medical care by assessing and developing a comprehensive, coordinated, patient-determined transition process. The clinic includes interviews, assessments, discussions and activities with medical, education, rehabilitation and adult service personnel. The family member and self-advocate peer mentor are an integral part of the clinic process. A primary focus is the emphasis on the integration of health, education, employment and independent living. A unique feature of the clinic is the addition of work experiences through two to three situational assessment opportunities. The result is a mutual development of effective transition goals and practices.

Findings. Initial data on the clinic was reported on 10 young adults who ranged in age from 16 to 21. The young adults had a variety of different diagnoses such as Down Syndrome Intellectual Disability, Autism and co-occurring health conditions. The young adults and/or their families completed a 9-question satisfaction survey. Overall the rating was a 3.6 (4- strongly agree) suggesting positive satisfaction with the clinic services. A Self-Determination Scale was administered to the young adults, and results found at the pre-test that youth "seldom" or "never set goals or established systematic strategies for achieving tasks. Post-tests show slight increase in self-determination and ability to make adjustments. The findings suggested the greatest challenge was youth making changes and adjustment in their life. One parent reported, "…..has become a different person since the transition clinic. She's doing more on her own; just more independent-she seems older."

> "I hope…that other families will have this **wonderful experience** and to provide another young person the opportunity to use this **great resource** to **assist them as they transition** to the adult world. I highly recommend it! A++."
>
> …..a parent's response

Medical professionals and trainees from a variety of fields including Genetics Counseling and Pediatrics participate in this clinic. The particular role of these students has been to facilitate an hour-long collaboration with the patient [and family] that is used to specifically address their knowledge, current competencies, and activities as they relate to health care transitioning across the lifespan. These medical professionals make specific use of two finalized "products" developed during this project: the *Transition Engagement Guide* and the *Patient Interaction Tool* [informally referred to as "Doc Talk"]. Their participation not only results in a practical and nuanced understanding of the broad impact of health care transitions for this population of youth with genetic conditions and/or special health care needs, but they also gain a concrete sense of their role in this process.

During this past year, five presentations were made regarding this process and an article was published in *The Outreach: A publication of the Center for Disabilities* (Fall 2015). In a separate activity, significant time and effort was expended to create the "scope and sequence" as well as the "content" for learning modules that effectively translate the substance of the "Transitions of Care" course into an on-line curriculum that could be tested and eventually widely disseminated, potentially as a product for CME credit for Practice Improvement [PI] Activities.

HRSA Priority 3: Expand the pool of the genetics service workforce by determining needs and gaps across sectors to provide education and training, with emphasis on allied health providers, other subspecialties and educators.

Early Hearing Detection and Intervention (EHDI) Program Exchange

In the original EHDI Program Exchange Program, EHDI coordinators visited another state program to learn more about that state's processes. A modification to the approach was made during the past two years that involved accomplishing the same goals within interactive workshops. The workshops were structured so there was time for a networking exchange among the participants. A national consultant, Dr. Karl White, the Director of the National Center for Hearing Assessment and Management, participated in both workshops.

In 2016, the second workshop had a series of state presentations. Six EHDI coordinators identified targeted objectives for discussion at the networking section, as the workshop was based on a self-assessment process. Interests were clustered around three primary areas:

- Strategies focused on improving processes related to supporting families (e.g., developing family support networks, improving family resources materials, development of parent surveys);
- Methods to improve their communication strategies for follow-up with families including using texting to communicate with families; and
- Processes related to their interface with early intervention programs.

Results. Interviews were completed with each of the EHDI coordinators. Overall, the participants indicated that having an interactive workshop with content targeted specifically for their group was very valuable and resulted in higher engagement of the participants. Aspects of the format that contributed to its success included:

- Ample time for networking with individuals who were addressing similar challenges;
- An agenda that was informed by the participants; and
- Topics that applied to their practices.

EHDI coordinators indicated that this format benefited them and facilitated their work better than the traditional conference format (e.g., the EHDI national conference). It provided an important avenue for networking that continued outside of the workshop venue. Several commented that the

networking opportunity with a national leader in the field was invaluable, and they would be using many of the resources that he shared. They all recommended that this technical assistance strategy be continued.

Based on interviews and survey data, participants reported that they learned from other state EHDI coordinators, both what worked and did not work. It allowed them to "share ideas and share resources." The EHDI coordinators reported many concrete examples of changes in practices or additions of resources that were adopted or were in the process of being developed by their states because of the information exchanged at these workshops. Examples include system changes (defined a state process for follow-up with physicians, development of a text process for notifying parents); resource development (modified parent resource materials developed by another state); and support services (e.g., family to family match program).

"At conferences, often you say, that sounds like a great idea...however, it is difficult to follow-up. We **will follow-up** from these **workshops**!"

Collaborative Partners Program (CPP)

In 2015-2016, four states (e.g. Arkansas, Oklahoma, Nebraska, and North Dakota) participated in the Heartland Collaborative Partners Project (CPP), which was established by Heartland to promote state activities that would improve one aspect of their NBS system. Each state selected a community participant (e.g. pediatrician) who was interested in learning more about newborn screening (NBS) and perceived him/herself as a change agent who could work with their state NBS coordinator to make a difference. Each state chose a NBS project that became the focus of their work, as well as, attended the American Public Health Laboratories (APHL) Newborn Screening Genetic Testing Symposium (NBSGTS) to meet with the NBS representatives from the Heartland states, increase their knowledge of newborn screening, and provide an opportunity for networking and exchanging of information and resources. Projects included:

1) Improving their system of distributing parent information (NE);
2) Supporting midwives to adopt pulse oximetry screening for home deliveries (OK);
3) Providing Neonatal Intensive Care Unit (NICU) nurses at their children's hospital information on NBS, the appropriate follow-up steps after a NBS is completed; and
4) Discussing new NICU policies related to NBS (AR); and improving proper NBS specimen collection and rejection rates (ND).

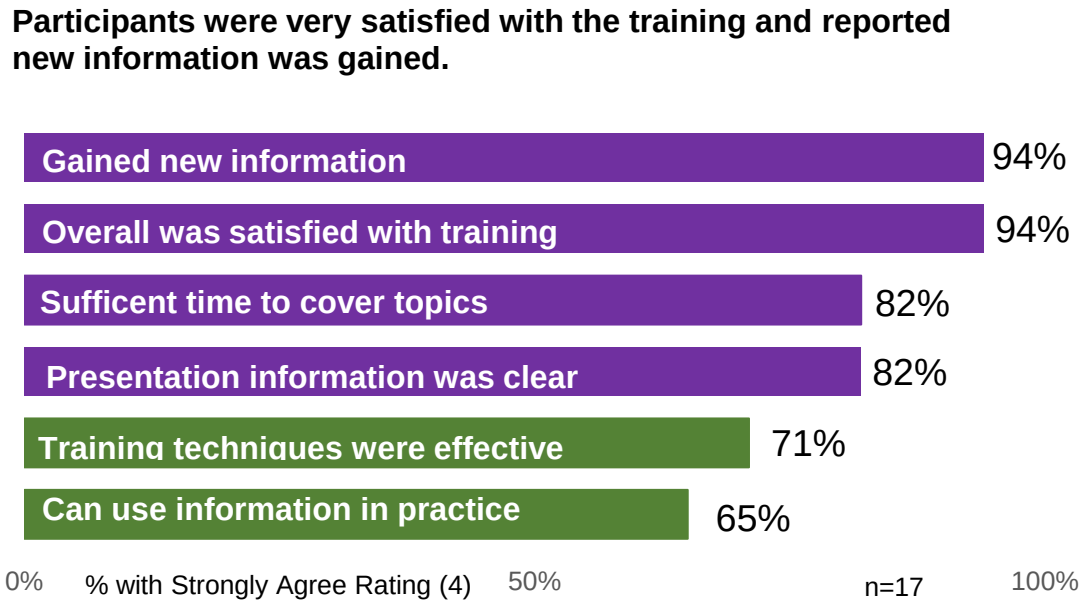
Findings. State participants found the APHL conference to be a very positive experience that increased their awareness of the NBS process. As one participant noted, "I came out of my comfort zone in the world of pediatrics and learned about the impact of NBS." Others cited the parent panels as very insightful. With respect to the state activities, those that implemented a training component received positive ratings from the participants. The result of the satisfaction survey about the state training found that the participants rated the presentation very highly (strongly agreed) with high percentages (93%) reporting that they gained new information.

The following is a description of each state's project and findings.

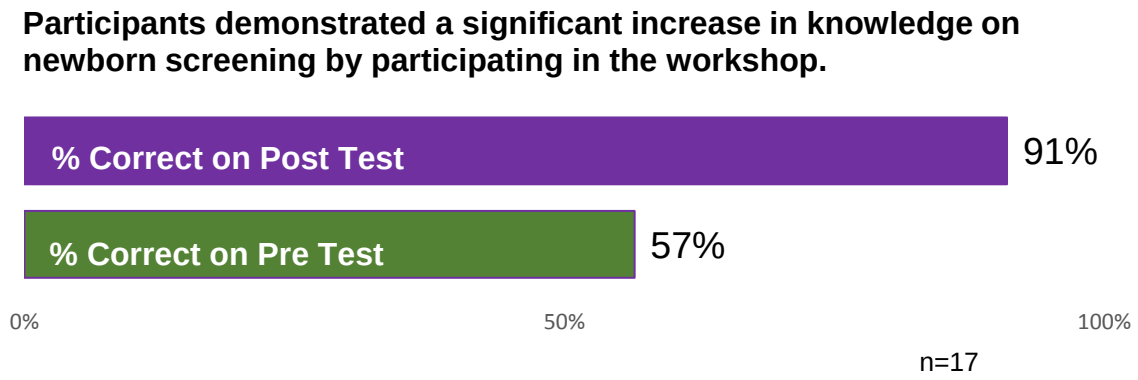
Arkansas

This year, the purpose of the Arkansas project was to provide NICU nurses at Arkansas Children's Hospital information on: 1) Newborn Screening (NBS), 2) the appropriate follow-up steps after a NBS is completed, and 3) discuss new NICU policies related to NBS. This goal was addressed through a training that was offered at two different times. Twenty-seven individuals from the NICU participated in the training in January of 2016. The effectiveness of the training was evaluated through two strategies: 1) evaluation of the participants' perceptions of the helpfulness of the training and 2) pre-post evaluation of participants' knowledge.

Satisfaction results. The results of the satisfaction survey found that high percentages (94%) of participants reported they gained new information as a result of their involvement in the training. They were also highly satisfied with the training and found the information was clearly presented with sufficient time to address the content. Fewer (65%) indicated that the information would be used in their practice. This data would suggest that participants had gained knowledge to a greater extent than their anticipated applied use of the skills. Reasons for this difference are unclear.



Knowledge results. The analyses of the 17 pre-post knowledge assessments found that participants demonstrated a significant increase of knowledge by the end of the training (Pre: mean=56.5; Post: mean=91.2; p<.001, d=1.19). These results suggest the training was effective and resulted in participants learning new information about NBS, which will be helpful to their practices.



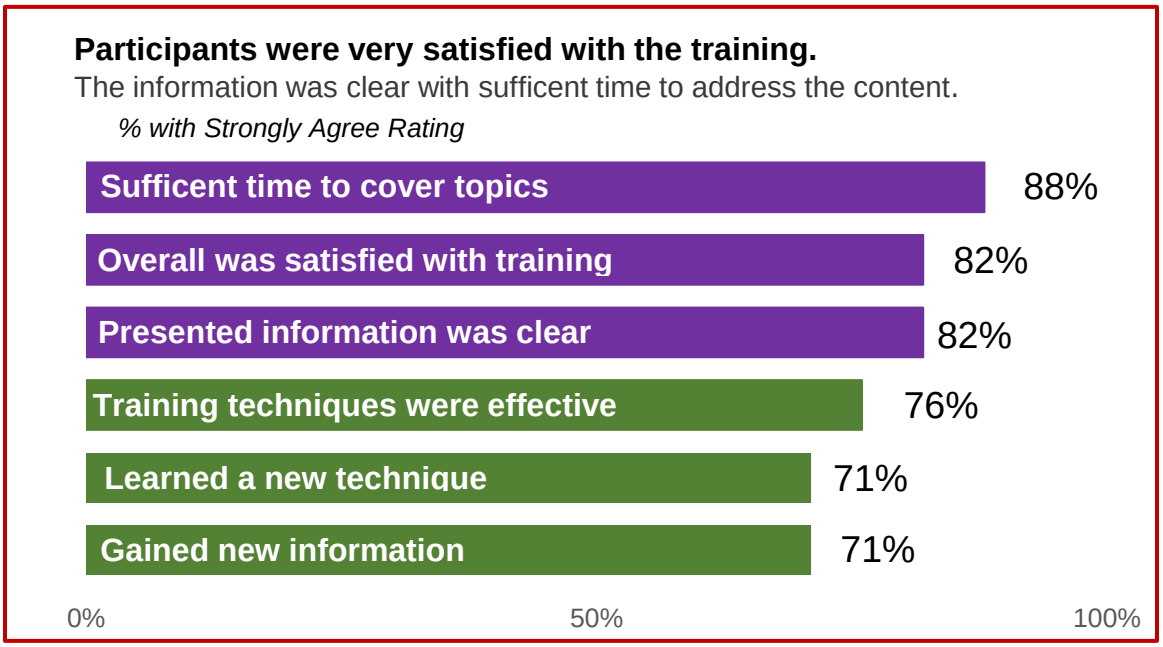
Oklahoma

In July 2013, legislation passed in Oklahoma requiring licensed birthing facilities to perform pulse oximetry screening on every baby to identify newborns that are at-risk for critical congenital heart disease. Homebirths are not required by legislation to provide pulse oximetry screening; however, there was a growing amount of interest among lay midwives in Oklahoma to provide pulse oximetry screening to the families they serve. Barriers for lay midwives to provide the pulse oximetry screen include: 1) proper training on the screening procedure, 2) selection of appropriate equipment and its cost, 3) interpretation of results and 4) lack of a tangible referral process. As many as 100 babies are born with life threatening critical congenital heart disease in Oklahoma every year. While 98% of babies are born in hospitals, some newborns will be delivered at home by a midwife and could have improved outcomes related to early identification and referral for testing through a more comprehensive pulse oximetry-screening program.

Purpose. The purpose of this project was to expand pulse oximetry to the homebirth population within Oklahoma by providing education, policy and procedure development, and referral process for midwives to ensure appropriate and timely diagnostic testing. A task force was established to develop policies and procedures related to pulse oximetry screening. Based on the recommendations of the task force, a statewide training for midwives was provided and a referral process for babies born at home who have an out-of-range pulse oximetry screen result was developed.

82% of the participants demonstrated **increased knowledge** of pulse oximetry screening.

Findings. Pulse oximetry screening training was provided to eighteen individuals. Participants included eleven midwives, six students, and one midwife assistant. Seventeen of the attendees completed both a pre- and post-test to measure knowledge gained from the pre- to post-test score and three maintained the same score.



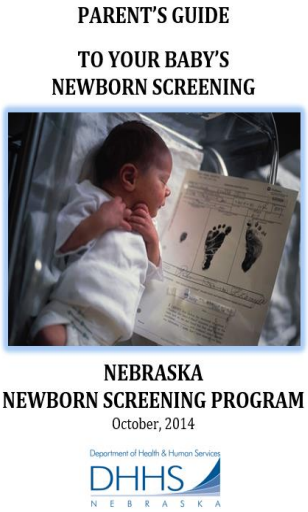
Sixteen participants completed a training evaluation. Fourteen reported they gained new information from the training, and sixteen reported they learned something new to implement in their current practice.

Ten midwives reported they had already purchased pulse oximetry screening equipment, and five were anticipating purchasing equipment in the near future. Three attendees reported, even though they did not purchase the equipment, they did have a referral process in place to ensure the families that they serve would be offered the pulse oximetry screen. The NBS Program plans to measure the number of newborns delivered by a midwife who receives pulse oximetry screening and the number of newborns whose parent or guardian refuses the pulse oximetry screen.

Nebraska

Health care providers in Nebraska are required by law to educate parents about newborn screening. The Nebraska NBS program provides brochures such as “the Parents Guide to Newborn Screening” free of charge to assist in this education. The NBS program tries to increase awareness of the availability of the literature. Many hospitals had not ordered these brochures regularly. It was felt that staff turnover contributes to the problem, as it is difficult for hospitals to remember how to order the literature, including its availability in multiple languages. The purpose of this project was to determine a process that facilitated dissemination of these materials to the appropriate locations for distribution to address this need.

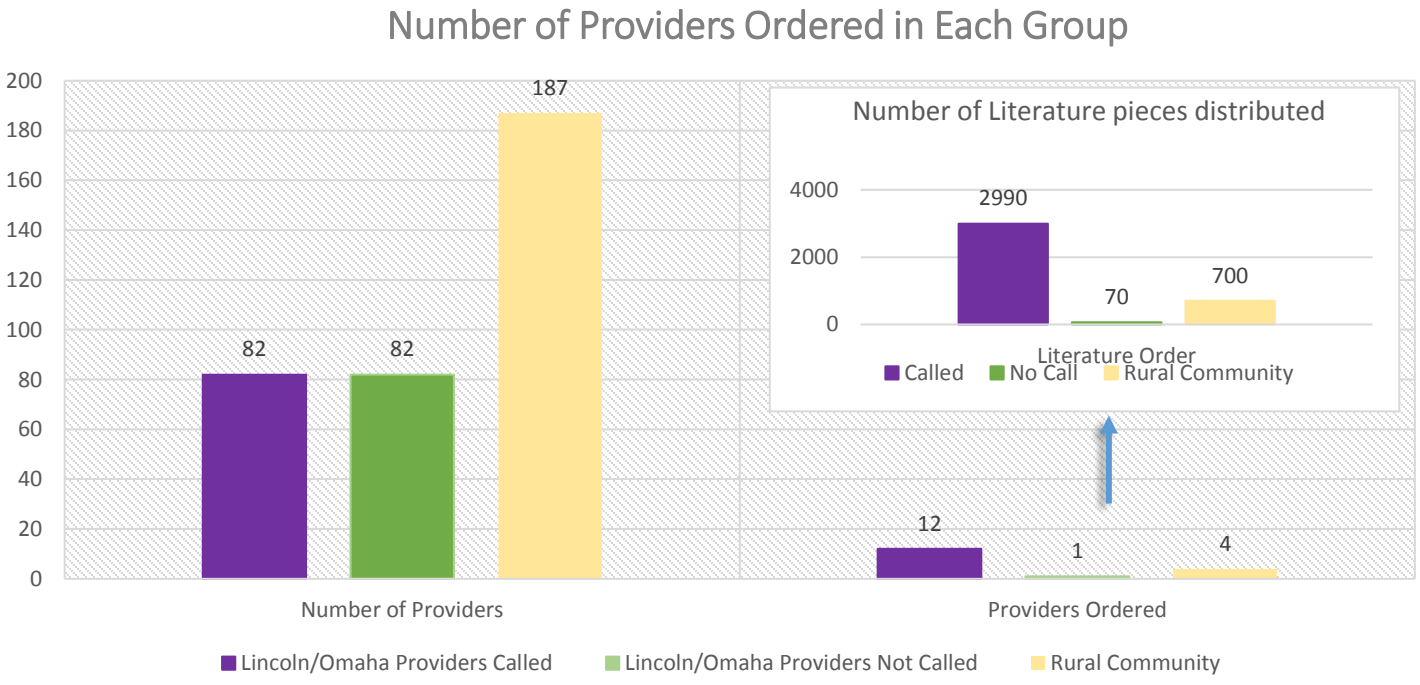
Implementation strategies. A new method for ordering literature online was developed to try to facilitate ordering of educational materials. This system went live on September 2015, and providers were notified of the new system via post cards. To assess use of the new system the NBS program tracked the number of requests made via the online portal during the months of September 2015 through February 2016 versus requests made via phone, fax, and email in the same months from 2012 through 2015. A total of 366 post-cards were delivered to OB/GYN and Family Practices throughout Nebraska. A select number (82) of the practices in the Lincoln and Omaha areas were also called three months later to offer free literature to provide to families and to remind them of the new online ordering system.



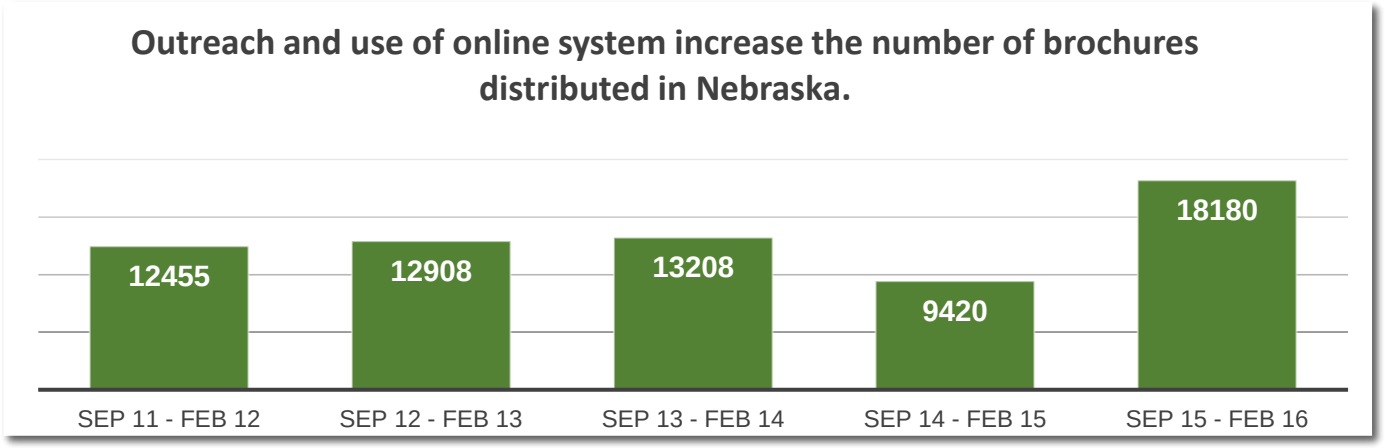
In an attempt to increase awareness and use of the Parent's Guide in languages other than English, a list of the available languages was included in the newly developed online ordering system. It was hoped that the new format would make the translated brochures more obvious and that providers would be encouraged to order and distribute the brochures.

Findings. Of 366 practices contacted, only 17 facilities ordered brochures. Of the 17 facilities that placed orders, 12 had received phone calls to remind them of the availability of education materials. A total of 3,760 materials (700 from rural and 3,070 from urban) requested from the 17 locations (four rural and 13 urban). Of those 3,760 materials:

- 990 were One-Page OB/GYN Fact Sheets (230 of which were Spanish).
- 2,670 were the Parent's Guide to Newborn Screening (120 of which were a foreign language requests: 40 each of Chinese, Vietnamese, and Korean).
- 100 were pamphlets to help patients understand the importance of waiting 24 hours after birth to collect a reliable screen and avoid repeats.



Reviewing the last five years, it was found that the increased outreach and addition of the online ordering system have helped increase the number of brochures shipped during the chosen time frame (September through February). During this timeframe, the birthrate did not significantly change. When comparing the number of brochure orders received from the call list versus the non-call list it was found that those who received a follow-up call were 97% more likely to order than those who did not. These results suggest that follow-up calls are an important factor in increased distribution of brochures.



North Dakota

Purpose. The North Dakota Newborn Screening Program (NDNSP) collaborated with Altru Hospital in Grand Forks to evaluate rejected specimens and educate staff on proper specimen collection and handling to improve rejection rates.

Implementation strategy. A survey of basic newborn screening collection knowledge was given to the staff to provide a baseline on how staff was being trained to collect specimens. Some of the questions asked were:

- At what age should the newborn screening be drawn?
- Where is the best place to draw blood for the test?
- How long should the specimen dry?

Based on the survey results, the newborn screening program director, nurse consultant and lab collector provided additional training. Thirty-two staff members from Altru were present for the training. These staff members included lab staff as well as nursing staff. During this session, the questions that were asked on the pre-test were all answered, as well as, showing the pictures of specimens and identifying specimen quality.

Findings. Prior to the training, data on number of specimens collected at that hospital for the three previous months was collected along with the rejection rates. For July through September there were 473 total specimens (453 being initial and 20 repeat specimens) collected by Altru. There were 26 total rejections or 5.5% rejection rate.

Following the educational session, a post-test was given. Results of both pre- and post-tests were comparted to determine the change in knowledge. Most of the 10 questions on the post-test were answered with 100% accuracy. There were only a few of the specimen identification questions that did not have all answered correctly.

The numbers of rejections in the following 3 months after the educational session were also examined. From October through December 2015, there were 485 total specimens (473 of those being initial screens and 12 being repeat tested). Of those 485 specimens, only four were rejected or 0.82%. This showed a reduction in rejections of 85% from the previous 3 months. The reduction for rejections was attributed to the provision of education to staff. This education focused on what the lab was looking for in a proper specimen and helped to educate the staff on what a rejected specimen was.

Training lab staff resulted in an **85% decrease** in rejected specimens.

5.5% Rejection Rate

.8% Rejection Rate

This facility will continue to be monitored to ensure low reduction rates. Education will be provided again if rejection rates begin to increase. This method of data monitoring, augmented with training, will be provided to all hospitals throughout the state in the future due to the positive outcomes of the project (i.e., increased performance and decreased rates of rejections).

Telegenetics

The Heartland collaborated in partnership with the Western States Region to implement a training series for genetics residents, genetic counseling students and providers using telehealth for the delivery of genetics services.

Two trainings were conducted involving 15 participants, which included, physicians, genetic counselors, special health care needs program, genetic counseling students, a metabolic nurse practitioner, and one director of another telehealth resource center.

A training evaluation was completed by six of the participants. The majority (88%) agreed or strongly agreed that the training met the training objectives. Participants reported the training increased their competence rated to implementing telehealth practices (83%) and 66% indicated that the training could potentially have positive impact on patient outcomes. Long-term follow-up of participants will be conducted in the 2016-2017 grant year to determine more fully how the training influenced participants' practices. Cost and reimbursement were the two primary barriers to implementation of telegenetics that emerged.

Training **increased** participant **competence** in telehealth who anticipated **increased positive patient outcomes.**

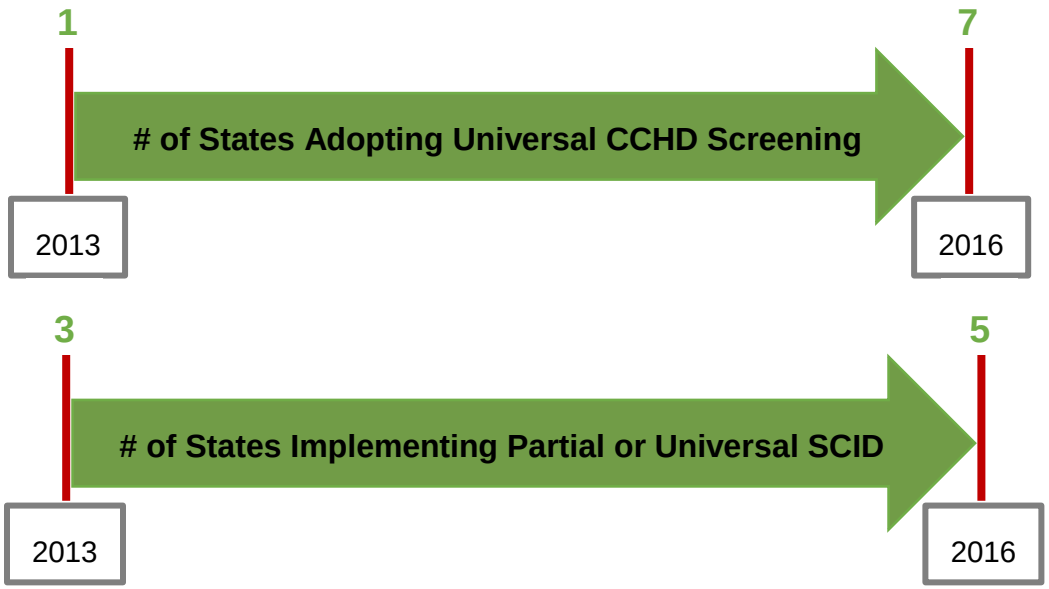
HRSA Priority 4: Build capacity in state public health departments to enhance and sustain the delivery of newborn and child screening and genetic follow-up and treatment services.

Critical Congenital Heart Defect (CCHD) and Severe Combined Immunodeficiency (SCID) Screening for Newborns

Much work has occurred in Heartland Collaborative states to further the implementation of CCHD and SCID screening for newborns. Across the region, states have improved their implementation status of both CCHD and SCID. In order to support the states' work in this area, a SCID Implementation Toolkit was developed and disseminated. It was posted on the Heartland Collaborative website: http://www.heartlandcollaborative.org/scidtoolkit. Slow progress is being made on the adoption of SCID with only four states implementing universal levels of screening for SCID. However, the majority of the states (7 out of 8) in the region have adopted universal CCHD screening. The one state that does not have a mandate, reported that almost 100% of the facilities are screening for CCHD.

Majority of states have adopted universal CCHD screening.

63% of the states are implementing universal screening of SCID.



Collaborative Improvement and Innovation Network for Timeliness in Newborn Screening

Description: Iowa NBS program received an award from NewSTEPS for the planning and implementation of a Collaborative Improvement and Innovation Network (CoIIN) for timeliness in newborn screening. Heartland supported additional states (Kansas, Iowa, Arkansas, Missouri, North Dakota, and Oklahoma) in the region to convene and extend the CoIIN project across the region. The rationale was to enable programs to engage in quality improvement activities through shared learning of evidence-based strategies for improving timeliness within their program's newborn screening system.

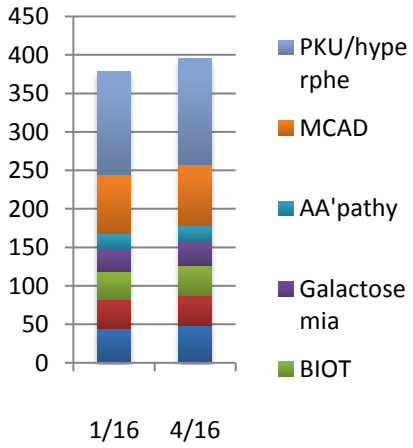
Findings. Participating states convened a CoIIN team of newborn screening stakeholders and met in Kansas City May 5-6, 2016. NewSTEPS facilitator presented on the quality improvement process, states reported on the specific section(s) of Quality Indicator 5 that pertains to their state project, and states shared barriers and strategies. Many states have indicated that they will apply for the next round of awards due in August 2016. All participants ranked the training as valuable or very valuable.

HRSA Priority 8: Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access.

Inborn Errors of Metabolism-Information System (IBEM-IS) Project

The project's purpose is to develop a long-term follow-up database and to track the treatments, health, and developmental outcomes of the patients with inborn errors of metabolism.

In this project, each visit of an enrolled patient is entered into the database. The figure displays, by diagnosis, the cumulative number of patients enrolled (398) through April 2016. The majority of the patients were diagnosed with PKU (31%) or MCAD (20%).



HRSA Priority 10: Any other program priority that addresses the needs of the region and the program goals.

Genetic Services Assessment Project

Description: The Genetic Services Assessment (GSA) is a tool developed for state level public health programs to use in assessing the genetics systems/services in their respective states. The quality metrics cover five domains: (1) State capacity for services; (2) Access; (3) Clinical process and quality improvement; (4) Performance reporting/improvement; and (5) Workforce. Parallel to the continuous refinement of the GSA tool, Heartland has focused on creating cross-collaborative

opportunities for implementation. The tool was implemented with each of the participating regions to facilitate a continuous improvement process in their state.

In 2015-2016, the GSA was fully implemented in the Heartland, as well as in other regions, i.e., NYMAC, SERC, and Mountain States. A modified GSA process was implemented in the Western States and Region 4 Midwest Regions. Participation in the GSA process resulted in states completing needs assessments that identified their strengths and needs related to genetic service delivery in their state. For some of the regions, this was the first time of administration and these results were used to frame a continuous improvement process. The information reported as aggregate and tailored for each state was used as a tool for the states to engage in further needs assessment, cost-benefit analyses, and program design and implementation to enhance access to genetic services, particularly prevention.

This is the second time that Heartland Collaborative states completed the GSA. Compared to the data collected from three years ago, the Heartland made great strides overall, but especially in accomplishing a number of elements that were targeted for improvement at the time of the initial assessment.

Hispanic Families' Access to Genetic Services

Due to the growing Hispanic population (ranging from 49% to 114%) in the Midwest region (2010 census), the Heartland Collaborative supported the initiation of the Hispanic Access Project. The goal of this project was to identify the barriers to accessing genetic services for Hispanic patients and to identify strategies to support genetic service providers in providing culturally competent quality care. In May 2013, Heartland began an initiative called, "Assessing the Barriers to Access for Hispanic Populations within three states: Oklahoma, Nebraska, and Kansas." This initiative stemmed from two main questions:

(1) What are the barriers to accessing genetic services for Hispanic patients?

(2) What can genetic service providers do to provide culturally competent quality care for Hispanic patients?

Heartland received Institutional Review Board (IRB) approval from University of Arkansas Medical Science in April 2014 (IRB# 202 965) to implement a qualitative research project to interview families in the states of Oklahoma, Kansas and Nebraska. Twenty-six Spanish-speaking families with children with genetic or chromosomal conditions were interviewed about their experience in accessing genetic services. The interviews were voluntary and held in Spanish. The study coordinators traveled to all three states to conduct in-person interviews of the caregivers. These interviews were conducted in their homes, local libraries, or family network offices. Since many families were undocumented, no personal identifiers such as names, dates of birth, or mail addresses were collected. All the interviews were transcribed and analyzed in Spanish by the research team.

As a result of this research analysis, the barriers to access to genetic services were identified and eight recommendations were developed. The Heartland Collaborative has formed an inter-regional Hispanic Access Advisory Committee (HAAC) to address the following eight recommendations.

1. Create a regional Hispanic Access Advisory Committee (HAAC) and form partnerships with healthcare providers, educators, early intervention staff, community leaders, family networks (etc.) to develop an interdisciplinary system capable of meeting the needs of Hispanic families with genetic conditions.
2. Develop and provide comprehensive and appropriate education and information relating to genetics and genetic services, for healthcare providers, early intervention programs, family networks, community leaders and Hispanic families with genetic conditions, to meet the patient's healthcare needs.
3. Increase awareness about genetic conditions and services to the Hispanic community including parent support agencies and groups with the purpose of increasing interest/acceptance within the community.
4. Explore the cultural and religious beliefs identified in the Hispanic population that may influence the parents' understanding and acceptance of their child's genetic condition.
5. Develop a more programmatic approach to overcome communication barriers experienced by non-English fluent families.
6. Share information with other agencies and committees on the need to educate Hispanic families on the American health care system.
7. Increase awareness among genetic service providers and staff about cultural beliefs and practices.
8. Establish partnerships among genetic service providers, community based health care systems staff and parent support groups for families with CSHCN.

HAAC met in May 2016 to identify implementation strategies to address each of the recommendations. They prioritized their top three recommendation areas, which were to: 2) provide comprehensive and appropriate education and information relating to genetics and genetic services to community providers; 5) develop programmatic approaches to overcome communication barriers; and 8) develop partnerships across agency and parent support groups for families. This information will be used to help plan future activities of the Heartland Collaborative.

Dissemination of Information and Resources

The Heartland Collaborative used a variety of strategies to disseminate information. One of the key dissemination has been via their website. All Heartland Collaborative project reports are posted on the Heartland Collaborative website, as well as the funded projects. HRSA is interested in how individuals are using the website in light of five priority areas: medical home, NBS capacity building, collaboration, Affordable Care Act, and NBS long term follow-up. Heartland posted material on its website regarding each of these key areas.

Home page visits were slightly decreased from last year; however the unique visits increased by 6% from the previous year. Heartland Collaborative's website had:

3093 unique visits **4036** home page visits.

Heartland Collaborative recorded 10 webinars on a variety of genetic-related topics for a broad spectrum of stakeholders. These are available via YouTube. Heartland Genetics will add additional videos as they become available. The link is:
https://www.youtube.com/user/HeartlandGenetics

Several Heartland staff, consultants, and partner staff have made six invited presentations at national meetings and presented in one poster session. Articles have been published in one newsletter and one refereed journal. These have represented a wide range of topics including transition, role of clinical genetics in the patient-centered medical home, using data as part of the quality improvement process, and the Collaborative Partners Project.

Summary of the Healthcare Coverage Survey 2016 - English and Spanish Combined with Genetic Respondents Only

The Heartland Collaborative conducted a brief online survey to assess the health care insurance coverage access and needs for children with special health care needs in the eight-state region, collecting responses from October 2015 through March 2016. With the onset of the Affordable Care Act, the Heartland was interested in identifying region-specific needs of families in covering health care related expenses.

Respondents

A total of 46 parents who had children with a genetic disorder completed the online survey. Nine percent of the respondents were Spanish speaking. Every state had respondents with the most in Iowa (26%) and the fewest in Kansas (7%).

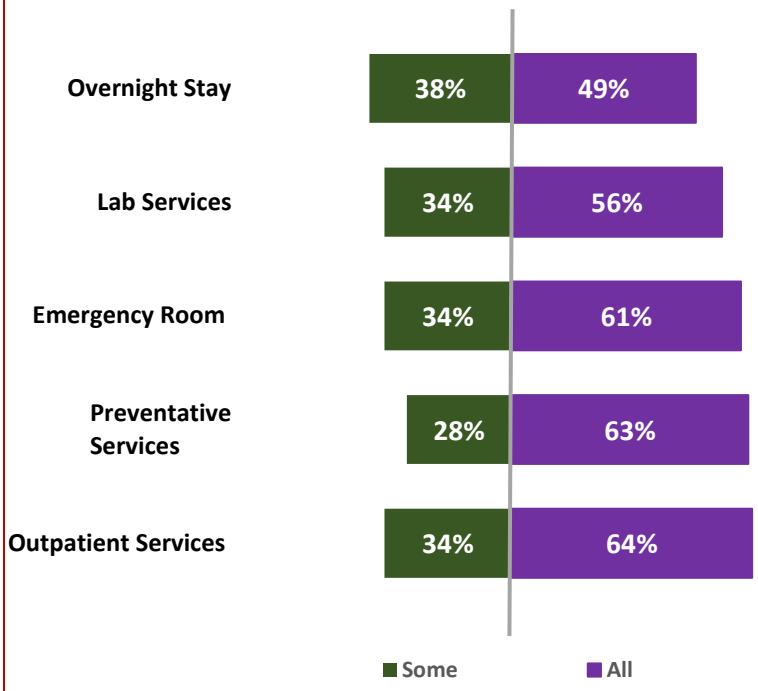
The children and youth represented a wide range of genetic disorders (e.g., PKU, autism, Angelman Syndrome, muscular dystrophy, etc.). Children and youth with Down Syndrome represented the largest percentage (26%) in this sample. The average age of the children was 11 years old with a range from one to 20. Medicaid (65%) and private health insurance (61%) provided health care coverage for most children. Small percentages had an individual policy, state employee health plan, or federal employee health plan.

Findings

Insurance Coverage

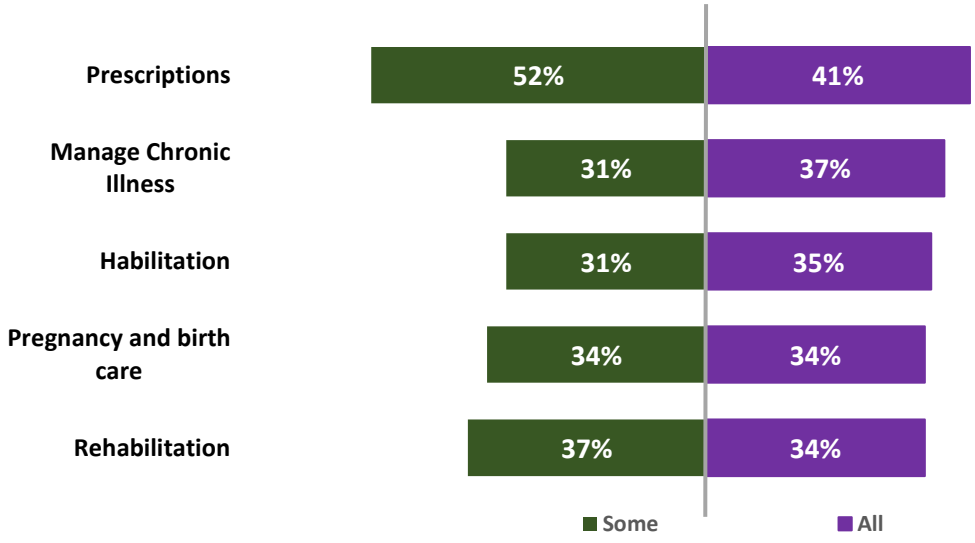
The majority of the families reported that they had insurance to pay for most prevention and direct health services. The following charts review the coverage of direct care services, support services and pediatric support services reported by the families. Dental and vision care were the lowest funded health care services for families. The charts reflect the percentages of individuals that indicated that funding was available for either some or all the services (i.e., full coverage).

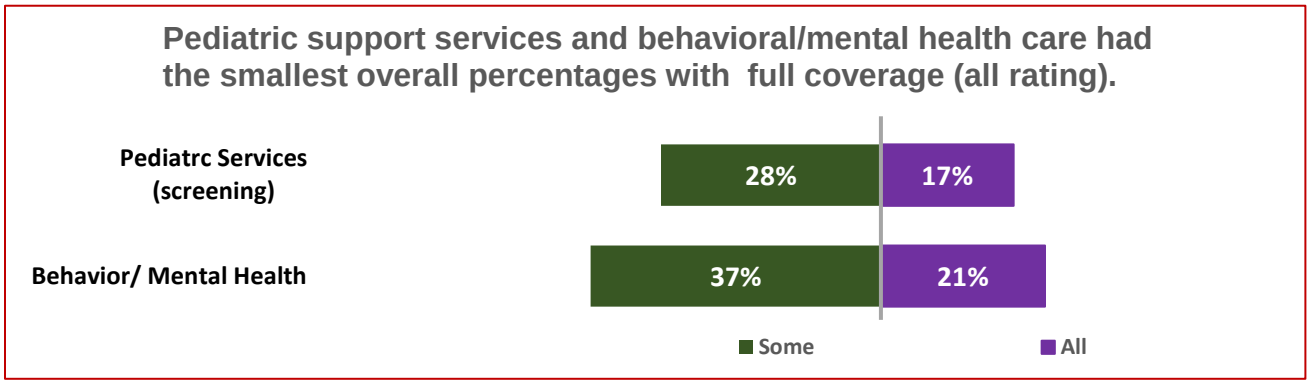
The majority of direct care services had full coverate (all rating) through private insurance or Medicaid.



- **42%** had **dental care paid for** and **32%** had **some** paid for.
- **39%** had **vision care paid for** and **46%** had **some** paid for.

Support services had smaller percentages of families that had full (all rating) coverage.





Health Care Costs

Families reported variability in their health care costs for their child or youth with a genetic disorder.

- Yearly, 55% of the families pay $1,000 or more for insurance coverage and 21% have an annual deductible of $2,500 or more.
- Yearly costs for medical and supportive care are variable across families. For example, 34% pay less than $500 for medical and supportive care, where as 29% pay between $1,000 and $5,000.
- Some families (41%) had difficulty paying for the costs of caring for their child. The most frequently stated costs were co-pays, non-prescription drugs, and deductibles. Examples of other items not covered included equipment, therapy, nutritional formula and chiropractic services.

Access to Services

Few (26%) families have help coordinating their child's care, yet 46% felt that they needed help coordinating their child's care.

37% of families had difficulty accessing services in the last 12 months. Specifically, areas were related to:

- Travel distance (33%)
- Too expensive to pay for what insurance does not cover (26%)
- Long wait lists (24%)
- Providers were not in network (20%)
- Could not identify a provider (15%)

Economic Status of the Family

The economic status of the 47% of the families was affected as a result of having a member cut back or stopped working to care for their child. A total of 41% of the respondents reported having difficulty paying for the costs of caring for their child with 28% delaying seeking care for their child as a direct result of the cost of the deductible.

Health care costs and the needs of their children affect the economic status of the families in the Heartland.

Summary of Heartland Collaborative Data for National Common Measures - YEAR 4

The Heartland Collaborative evaluator and administrative team partnered with other regional collaboratives (RCs) and NCC/RC national evaluation team to identify a core set of common evaluation measures that was used across all the RCs. Heartland Collaborative participated in the NCC/RC sponsored monthly phone conference meetings to support the implementation of the national evaluation plan.

Table 1. Number of Regional Collaborative (RC) partners by stakeholder type and activity

	Providers	Family Organizations	Disease-Specific Organizations	Individual Consumers
Mailing List	**118**	**2**	**2**	**11**
Annual Meeting	**N/A**	**N/A**	**N/A**	**N/A**
Workgroup or Committee	**68**	**0**	**1**	**16**

Definitions
Stakeholder types:

- **Provider –** genetic counselors, physicians, nurses, nutritionists, social workers, public health genetics or newborn screening professionals, or other direct service providers
- **Family Organization –** Family Voices, Family to Family Health Information Centers, Parent to Parent or other family advocacy organizations excluding disease-specific organizations
- **Disease-Specific Organization –** advocacy organizations whose activities are devoted to one or a group of genetic or metabolic conditions
- **Individual Consumer –** individuals who have or are at risk for a genetic condition or family members of same

Activity:

- **Mailing List –** people or organizations who routinely receive emails or postal mailings of information about Collaborative activities
- **Annual Meeting –** people or organizations who attended the Collaborative's yearly meeting, conference or summit of all involved stakeholders (excluding RC-paid staff)
- **Workgroup or Committee –** people or organizations who participated in Collaborative funded projects (excluding RC-paid staff)

Table 2: Number of Education and Training Sessions and Number of Participants						
HRSA Priorities	In-person meetings	In-person participants	Webinars	Webinar participants	Teleconferences	Teleconference participants
1. Treat in the context of a medical home	**15**	**135**	**3**	**46**		
2. Cultural competency and diversity in outreach projects	**1**	**11**	**2**	**17**		
3. Expand the pool of the genetic service workforce						
4. Build state public health department capacity	**7**	**120**	**3**	**48**		
5. Strengthen public-private partnerships						
6. Collaborate and partner with HRSA MCHB-funded programs that promote the scaling up of effective practices						
7. Improve insurance coverage policy and reimbursement – Affordable Care Act Implementation	**1**	**3**				
8. Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access.						
9. Address emergency preparedness						
10. Others not in RFA –						
Telemedicine	**2**	**15**				
Regional model development			**1**	**9**		
Family Resources in Genetics			**2**	**37**		
Advocate Leader Program	**1**	**9**				
TOTAL sessions/participants	**27**	**293**	**11**	**157**		

Table 3. WEBSITES AND SOCIAL MEDIA						
Home page visits Total : 4,036 **(Using Google Analytics)**						
Unique visits Total : 3,265 **(Using Google Analytics)**						
	Medical Home	**Newborn Screening Capacity Building**	**Collaborations**	**Affordable Care Act Implementation**	**Newborn Screening Long Term Follow up**	**Transition from pediatric to adult care**
RC website has pages that address these topics (Y/N)	Y	Y	Y	Y	Y	Y
SOCIAL MEDIA						
RC uses Social Media (Y/N)						
If yes, please indicate type AND Number Of unique followers as of May 31, 2016:	FACEBOOK: 165 TWITTER: ____NA___ PINTEREST: ___NA__ OTHER: _YouTube: Heartland Genetics provides recorded10 n webinars on a variety of Genetic related topics for a broad spectrum of stakeholders. This year Heartland Genetics added one additional video; The link is: https://www.youtube.com/user/HeartlandGenetics					

Table 4 NEWBORN SCREENING ACTIVITIES		
STATE status (List by State) using the four categories: **Universal:** Screening is provided for all newborns **Partial:** Screening is being provided under pilot studies or on a voluntary basis by some hospitals **Planned:** State is considering **No Activity:** Not under consideration:	**CCHD** **7: Nebraska, Iowa, Missouri, South Dakota, North Dakota, Oklahoma, Arkansas** **1: Kansas***	**SCID** **5: Nebraska, Iowa, Oklahoma, Arkansas; South Dakota** **3: Missouri, Kansas, North Dakota***
	***Kansas is screening almost 100% without a mandate.**	***** Kansas will start pilots summer of 2016** **Missouri will have population based pilots s Fall 2016** **North Dakota will mandate screening July 1, 2016**

Supplement 1: SUMMARY OF RC PRIORITIES - as of May 31, 2016

HRSA Priorities	Insert an X for RC activities that address the priority area
1. Treat in the context of a medical home	**X**
2. Cultural competency and diversity in outreach projects	**X**
3. Expand the pool of the genetic service workforce	
4. Build state public health department capacity	**X**
5. Strengthen public-private partnerships	
6. Collaborate and partner with HRSA MCHB-funded programs that promote the scaling up of effective practices	
7. Improve insurance coverage policy and reimbursement	
8. Expand state and regional collaborative systems of cohorts of patients for long-term monitoring and analysis of follow-up and treatment for provider and/or patient access.	**X**
9. Address emergency preparedness	
Others not in RFA – Transition/ Genetics Systems Assessment; Telemed	**X**

Evaluation Report prepared by
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The University of Nebraska Medical Center's
Munroe-Meyer Institute: A University Center of
Excellence for Developmental Disabilities

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