Improving Systems: Changing Futures

Engaging Title V, Families and Clinical Partners in Improving the System of Care for Children and Youth with Special Healthcare Needs

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Acronyms

AAP	American Academy of Pediatrics
AMCHP	Association of Maternal and Child Health Programs
CYSHCNs	Children with Special Healthcare Needs
CYSHCN	Children and Youth with Special Healthcare Needs
EHDI	Early Hearing Loss detection and Intervention
ENT	Ear, Nose and Throat Specialist; Otorhinolaryngologist
HRSA	Health Resources and Services Administration
IHI	Institute for Healthcare Improvement
JCIH	Joint Committee on Infant Hearing
MCH	Maternal and Child Health
MCHB	Maternal and Child Health Bureau
MFI	Model for Improvement
NHS	Newborn Hearing Screening
NICHQ	National Initiative for Children's Healthcare Quality
PCP	Primary Care Provider
PDSA	Plan-Do-Study-Act
QI	Quality Improvement
TTX	Table Top Exercise

Executive Summary

Almost one in five children in the United States has special healthcare needs; however, only 18% of those children receive services in a high-quality care system (Strickland, 2011). Improving the quality of care in early life, especially for the most vulnerable children, takes on additional urgency because of our increased understanding of the importance of the early years for health over the entire lifespan.

In 2007, the federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration contracted with the National Initiative for Children's Healthcare Quality (NICHQ) to lead an initiative that applied quality improvement principles to the system of care for children and youth with special healthcare needs (CYSHCNs). The project sought to improve the health and well being of CYSHCNs and their families by building the capacity of Title V programs, in concert with other state-based partners, to create and sustain effective community-based systems of care. The Improving the System of Care for Children and Youth with Special Healthcare Needs project worked in three phases to achieve its aim:

1. Identify successful existing strategies within state systems that enhance care and service delivery, and use those strategies to inform a framework for systems improvement.
2. Work with state Title V leaders, clinical teams and families to apply the framework for improvement to two "real-world" programs- services for children with epilepsy and for infants needing follow-up after newborn hearing screening.
3. Evaluate the impact of the initiative both on its ability to identify, test and spread successful system change strategies, and its impact on the integration of quality improvement activities in state Title V programs.

The project engaged 22 teams from 17 states in two consecutive Learning Collaboratives based on the Breakthrough Series Model. An additional 18 state grantee teams were funded by HRSA-MCHB to participate in an abbreviated form of QI training called *Jumpstart*. These teams applied the training to address a variety of topics, including implementation of structured developmental screening in the medical home and transition planning. Both methods appeared successful in training Title V leaders in QI methodology.

Project faculty working with Title V leaders developed a new tool, the *Title V Index*, to provide a framework for Title V programs to reflect on their own capacity to make and sustain system change. Modeled after the Medical Home Index, the Title V Index identified six care domains, with five levels of achievement for each domain and included a list of "change strategies" applicable to each domain that state teams could test. Title V leaders used the Index to self-assess their capacity accomplishing sustainable change in their states and then to select change strategies to build that capacity. The project also aligned these strategies with change ideas being trialed by clinical teams, making it easier for Title V leaders and clinical teams to see how their work was related. Title V leaders saw great value in their role as facilitators of system improvement, and planned to apply the QI methods they had learned to other programs for CYSHCNs.

Improvement teams conducted small tests of system change using "PDSA" or "Plan-Do-Study-Act" cycles, and reported on promising change strategies. For teams addressing the care of children with epilepsy, these changes included providing written medication plans, medication side-effect lists, seizure action plans and care plans. Some teams trialed the use of "flash drives" containing care plans that families could carry with them to appointments and youth could wear as "flash-drive bracelets." Teams working to improve follow up for newborns referred after hearing screening, promising strategies included correctly identifying and verifying the PCP before discharge from the birth hospital, obtaining two contact numbers from families needing follow-up, providing written and verbal screening results to families, and using a spreadsheet data-tracking system with outreach to families who did not attend follow-up appointments.

Teams working on improving the newborn hearing screening and follow-up system struggled with small case numbers. The Collaborative used a promising strategy called a "Table Top Exercise," widely used by public health agencies in preparing for rare events (such as disasters), to address this issue. Teams reviewed written summaries of realistic case scenarios and used them to test how a "virtual patient" would progress through the care system. Using this non-judgmental tool, both epilepsy and NHS teams identified gaps in the care process that could influence quality. Teams also worked to improve primary care-specialist communication, finding that communication needed to be conceptualized as a three-way process among family, PCP and Specialist. Structured referral letters and involvement of families in defining questions for specialists emerged as new strategies for further testing.

Teams with strong leadership, a designated team member for data reporting, who had regular team meetings and high attendance on monthly check-in calls were more engaged with the QI work and generally showed greater progress. All teams struggled to collect and report data. Teams that involved and engaged family partners as part of their work developed strategies that led to improvement. Families led efforts to develop a Family Partner Guide to introduce parent partners to QI work. Families, Title V and clinical Collaborative chairs reflected positively on the "mutual mentoring" relationship that had developed during the Collaborative among participants as they worked together to improve the system of care for CYSHCNs.

Introduction

Almost one in five children in the United States has special health care needs, but only 18% are receiving services in a high-quality care system (Strickland, 2011). Improving this system of care is a Healthy People 2020 goal and a priority for the Maternal and Child Health Bureau (MCHB) Division of Services for Children with Special Health Needs at the Health Resources and Services Administration (HRSA).

Children with special healthcare needs (CYSHCNs) have chronic physical, developmental, behavioral or emotional conditions, needing health and related services of a type or amount beyond that required by children generally (Newacheck, 1998). The MCHB strives to build and sustain community-based systems of care—that is, a health care system that is accessible to families with few restrictions—to address these needs. However, developing community-based systems of care is a significant challenge for providers and families. At the state level, responsibility for planning and developing these systems lies with Maternal and Child Health (MCH) and CYSHCN programs, supported historically through Title V MCH Program of the 1935 Social Security Act and administered through annual block grants. Over the years, changes in health, education and social policy, together with an increase in the number of children identified with chronic conditions, and changes in the nature of those conditions, have resulted in an increasingly complex service system characterized by large gaps in some areas of care, and a general fragmentation in organizational structure (McPherson, 1998).

In 2007, the MCHB contracted with the National Initiative for Children's Healthcare Quality (NICHQ) to lead an initiative that applied quality improvement principles to the system of care for CYSHCNs. The project sought to improve the health and well-being of CYSHCNs and their families through building the capacity of State Title V programs, in concert with other state-based partners, to create and sustain effective community-based systems of care for this population. The initiative focused on transforming the health care component of the system through spread of the medical home, and through improved communication and strengthened co-management relationships between the medical home and specialty care. The project worked in three phases to achieve its aim:

1. Identify successful existing strategies within state systems that enhance the delivery of health care and other community services, and use those strategies to inform a framework for systems improvement.
2. Work with state Title V leaders and clinical teams to apply the framework for improvement to two "real-world" programs- services for children with Epilepsy, and Follow-Up after Newborn Hearing Screening.
3. Evaluate the impact of the initiative, both in terms of its ability to identify, test and spread successful system change strategies, and its impact on the integration of quality improvement activities in state Title V programs.

The project built on three previous MCHB cooperative agreements which funded Learning Collaboratives on the Medical Home, Newborn Hearing Screening and Follow-Up, and Project Access-Epilepsy. These Learning Collaboratives provided a rich foundation of promising change strategies to inform this work. In contrast to most pediatric quality improvement initiatives that focus on care within individual hospitals, clinics or groups of practices, this initiative sought to improve entire statewide systems, and to strengthen links not just within the healthcare sector, but also with education and early intervention services.

Newborn Hearing Screening

Newborn hearing screening is one of only seven preventive services for children recommended by the U.S. Preventive Services Task Force. More than 95% U.S. newborns are now screened for hearing loss at birth, a tremendous public health achievement. Yet, the success of the screening program depends on more than the initial screen (Russ, 2010). The Joint Committee on Infant Hearing has set three national goals:

- Screening should be completed before one month of age;
- Diagnostic testing completed before age three months; and
- Intervention and treatment should commence before age six months.

Although the first goal is close to being met, recent data from the Centers for Disease Control and Prevention suggest that up to 50% of newborns that do not pass the hearing screen never have a documented diagnosis. Of children confirmed to have a permanent hearing loss, almost one-quarter are not enrolled in early intervention by the age of six months (CDC, 2008).

Reports in the literature, and our own experience in prior Collaboratives, have identified system gaps and barriers that threaten the success of the screening program. Although primary care providers (PCPs) have close contact with infants in the first year of life, and view themselves as responsible for guiding families through the diagnostic process, too often they lack timely access to the results of screening and diagnostic tests. Only about two in 100 newborns do not pass their hearing screen, and only one-to-three in 1000 newborns will prove to have a permanent hearing loss (Russ, 2010). Consequently, most PCPs have limited experience with managing children that need specialized testing and follow-up, and lack knowledge of local services for children who are deaf or hard of hearing.

In addition, there is a recognized national shortage of pediatric audiologists trained in the specialized testing required for very young children, resulting in some regions in waiting lists for audiologic evaluation, and requiring families to travel long distances to access testing services.

Most children who are deaf or hard of hearing are born into families with no history of the condition (Russ, 2010). These families must quickly acquire the ability to navigate a complex care system, including multiple appointments with professionals from different disciplines, in multiple locations. Families also face decisions—should their child be fit with hearing aids? Should they consider a cochlear implant? Should intervention focus on the acquisition of sign language, and/or adopting a listening and spoken language approach to language development? Families discover that their child's management depends on the integration of care across health and education sectors, yet these services are scattered across a confusing array of institutions and organizations, with limited communication between them.

Epilepsy

Epilepsy is the most common childhood neurological condition, affecting about six in 1000 U.S. children (Murphy, 1995). In addition to the challenge of seizure control, children with epilepsy may have additional conditions such as learning disabilities, ADHD, and anxiety that can negatively influence developmental progress and emotional health (Jones, 2008; Dunn, 2003; Dunn, 2009). Medications used to treat the condition can have significant side-effects that affect quality of life. About 30% of those living with epilepsy do not respond to available medications and continue to have recurrent seizures that affect activities of daily life. As children with epilepsy grow to adulthood, psychological distress, loneliness, difficulties with adjustment and coping and stigma perception appear to contribute significantly to quality of life outcomes, regardless of physical condition (Suurmeijer, 2001).

Families of children with epilepsy report challenges in obtaining information to help them better understand their child's diagnosis and treatment (Aytch, 2001). Lack of knowledge about the condition, and concerns about how to respond when the child has a seizure can harm the child's experience in educational and social settings. Epilepsy is a heterogeneous condition, requiring careful diagnostic testing and tailoring of therapy to the child's individual needs. Most existing care models for children with epilepsy involve shared management between the child's primary care provider and a specialist neurologist. PCPs often have limited experience with managing patients with epilepsy, a problem made more acute by the expanding options for medical and surgical epilepsy management that have become available over the last two decades.

Despite clear need for specialist input to care, families report significant difficulties with access to specialist services. There is a national shortage of pediatric neurologists, and a shortfall of new graduates entering the specialty (Bale, 2009). Even when families do obtain specialist care, communication and coordination between primary care and specialists is frequently sub-optimal. Families have expressed a desire for more self-management tools that can help them to organize their child's care across different settings, and to facilitate communication between the many professionals involved with their child's treatment (The Epilepsy Foundation, 2011).

Both follow-up after newborn hearing screening, and the care of children with epilepsy, highlight cross-cutting service needs for the CYSHCNs population. Both require effective medical homes and enhanced linkages with community-based and specialist services. Both face challenges with delayed or limited access to specialists. Both are greatly facilitated by the deep engagement of families.

MCHB has articulated six core performance measures for the system of care for all CYSHCNs , including children with epilepsy and children with hearing loss. These are:

- All CYSHCNs will receive coordinated ongoing comprehensive care within a medical home.
- All families of CYSHCNs will have adequate private and/or public insurance and financing to pay for the services they need.
- All children will be screened early and continuously for special health care needs.
- Services for CYSHCNs will be organized in ways that families can easily use them.
- Families of CYSHCNs will partner in decision-making at all levels, and will be satisfied with the services they receive.
- All CYSHCNs will receive the services necessary to make appropriate transitions to adult health care, work and independence.

Engaging Title V leadership in this work provided an opportunity both to advance the content work itself, and to enhance Title V's capabilities to sustain successful system improvements and to spread quality improvement methodology to other programs and activities. This report summarizes the joint work undertaken by these three partners—Title V, clinical teams and families—to improve state systems of care for CYSHCNs using a quality improvement approach.

Improving the System of Care for CYSHCNs: The Approach

Based on experience in previous Collaboratives, we adopted three tightly linked frameworks to guide this initiative: The Care Model for Child Health, The Breakthrough Series Model, and The Model for Improvement.

The Care Model for Child Health

Cal Sia, M.D. initially articulated the concept of the medical home for children with complex medical needs, social concerns, or both. The attributes of the medical home, as first defined by Sia and later endorsed by the American Academy of Pediatrics and the Maternal and Child Health Bureau, are that care be accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally competent. (American Academy of Pediatrics, 2002).

Although expressing an oft desired ideal, the medical home model did not initially achieve widespread adoption or implementation. Believing that providing more operational guidance to practices seeking to become medical homes would accelerate adoption, NICHQ and the Center for Medical Home Improvement, with support from the Maternal and Child Health Bureau, integrated the medical home concept with the chronic care model, developed by Ed Wagner to specify an approach to care for individuals with specific chronic conditions. (Coleman, 2009; Homer 2009). This integrated framework, termed the Care Model for Child Health in a Medical Home, had six key components:

- Health care organizational leadership
- Community outreach and engagement of community resources.
- Patient registries and other supportive information technology
- Decision support
- A redesigned system of care delivery and
- Partnership in care between provider and family

The model emphasizes a "prepared pro-active" team approach to care, and an informed and activated family functioning in partnership with the care providers.

Care Model for Child Health
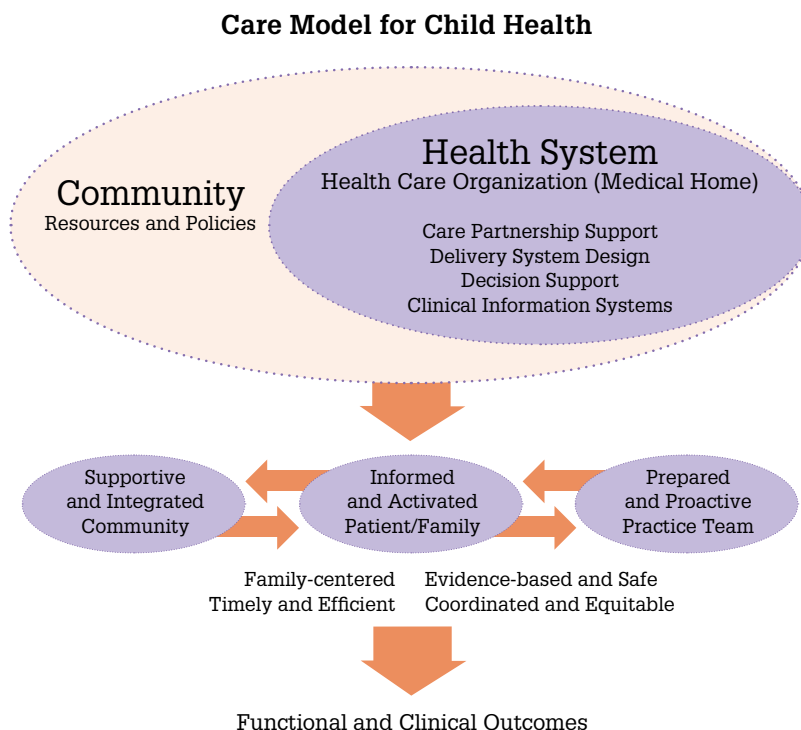
The following section elaborates on the individual elements of the care model for child health.

Decision Support

Patients and PCPs need access to best available evidence and experience at the point of care. Although for more common conditions PCP's can be expected to maintain that expertise or embed it through standardized encounter forms (either paper or templates in electronic health records) or intermittent consultation, for the care of individuals with these two conditions, information between PCP, specialist and family needs to be timely and accurate and flow seamlessly. Prior collaborative work from NICHQ, IHI and NICHQ faculty identified several strategies to increase access to specialists, including: advanced access scheduling by specialists (citation), use of service agreements between PCP's and specialists outlining specific roles and responsibilities in general, back transfer of stable patients from specialists to PCP's to free up scarce resources, expanded use of advanced practice nurses within specialty sites and use of specific co-management plans for individual patients. Use of electronic templates and fax back forms can improve timeliness and completeness of communication between primary care and specialists as well.

Planned Interactions (delivery system design)

For children with epilepsy and other special health care needs, encounters should occur not only when the child is having difficulty but also when the child is stable. Such encounters can be used to monitor medications, address school performance and discuss the impact of the child's condition on the family. Other aspects of preventive care (immunizations, oral health, diet) can also be addressed.

The care team for children with either condition will necessarily be broader than the physician and parent alone, but include appropriate professionals from a variety of disciplines. These professionals need work as a team, with clearly delineated roles and responsibilities and mechanisms for communication.

Care Partnership Support

In an ideal care system, prepared and pro-active care teams interact with fully informed and activated families to partner in the child's care. Provision of information and, of greater impact, shared plans and common goals, better enable families to manage the health and care of their child. For example, the PCP should have a record of each newborn's hearing screen result, and be prepared to discuss that result with the family. Families that need to take their child for diagnostic audiologic evaluation need instructions on how to prepare their child for the evaluation, to maximize the chance of successful test completion and then action based on the results.

An important system goal for families is fully informed decision making. Tools such as the Ottawa Decision Guide can help families consider the advantages and disadvantages of different decision paths, e.g., whether to consider cochlear implantation.

NICHQ has emphasized the importance of parent partnership in care by modeling parent and patient participation in the collaborative process. The prior collaboratives all required every team to include at least one parent partner as part of the improvement work. Parent partners have made significant contributions to the development of a range of self-management tools. Families of children with epilepsy have supported the development of seizure action plans, written care plans, and medication lists. Families have embraced new technology to explore innovative approaches to improving communication with providers e.g., use of flash drives worn as bracelets that contained an electronic version of the child's medical history that could be accessed in an emergency. For follow-up after newborn hearing screening, families used roadmaps to guide them through the diagnostic and intervention processes, and checklists to ensure they have received all recommended.

Assistance in care coordination is another key element of care partnership support. Although in fact parents and caregivers provide the bulk of care coordination, children with complex special health care needs and their families benefit from active assistance in organizing services for the benefit of the child. Care plans are a key tool in care coordination, as are accurate and timely lists of community and clinical resources.

Community Outreach and Engagement of Community Resources

Community partnerships have been embedded in Collaborative improvement work from the start through partnerships with The Epilepsy Foundation, Family Voices, Hands and Voices and others. Documentation of community resources, with targeted communication about key resources and parent-to-parent guides to facilitate access to resources, has shown promising results in prior Collaborative work. Health care professionals can also raise the awareness and capacity of communities to address the needs of children with special health care needs.

Patient Registries and Other Supportive Information Technology

State newborn hearing screening programs are working towards the development of real-time data tracking mechanisms that will allow all newborns that are referred after hearing screening to be tracked through the diagnostic and intervention processes, yet few states have achieved this goal. Smaller-scale data tracking spreadsheets provide a useful mechanism to follow babies form one region or institution, triggering intervention when families do not receive recommended services within the expected time frame.

Practices have also used registries to manage populations of children with specific conditions as well as children and youth with special health care needs more broadly. NICHQ defined the elements of such a registry specifically for the care of children with epilepsy in the prior learning collaborative.

Health Care Organizational Leadership

The sine qua non for success in undertaking organizational change and improvement is organizational commitment and leadership. This requires articulation of a vision for change, establishing effective coalitions and partnerships, providing adequate resources for change initiatives, highlighting early successes and embedding successes in the organizational infrastructure. Leadership also requires the use of measures to track and demonstrate progress.

Breakthrough Series Learning Collaborative

The Breakthrough Series Model, developed by the Institute for Healthcare Improvement, provide a structured sequence of activities that can be used to engage quality improvement experts, faculty, leaders, clinicians, and families to make major, rapid changes in order to produce breakthrough results: lowering costs and improving outcomes simultaneously. A typical Collaborative begins with an expert group identifying the key changes required to drive improvement in a topic, and translating these changes into goals and measures. Organizations are then recruited; these organizations identify improvement teams to participate directly in the program. Teams undertake a self-assessment prior to attending any training sessions, and also set aims for their own organization. Teams then attend three face-to-face Learning Sessions, during which they both learn "content," and learn and practice the process of making changes. The project team supports the organizational teams by hosting a listserv for discussion; conference calls; and review of monthly data and text reports.

For this collaborative, the Breakthrough Series approach was modified for working with Title V leaders and CYSHCN by recruiting two Parent Chairs to coach the teams and by integrating Title V CYSCHN Directors into the collaborative supplemented by additional training and support. By involving Title V leaders, the collaborative sought to improve the support system to frontline clinical teams and develop the capacity of Title V itself in quality improvement.

The Breakthrough Series Model
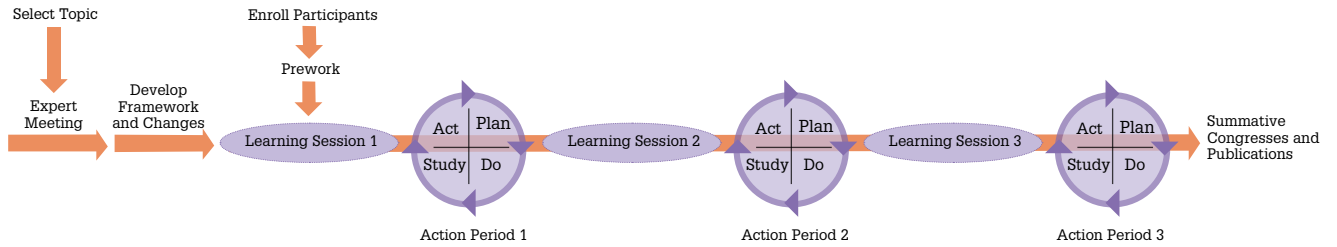
Model for Improvement

The Model for Improvement was developed by Thomas Nolan and colleagues at Associates in Process Improvement. The model identifies 4 key tasks of process improvement:

- Set specific and measurable aims.
- Track measures of improvement over time.
- Identify key changes that result in desired improvements.
- Test key changes in a series of "Plan-Do-Study-Act" or "PDSA" cycles during which teams learn how to apply key changes in their own organizations at increasing scale and over a diverse set of conditions.

Model for Improvement
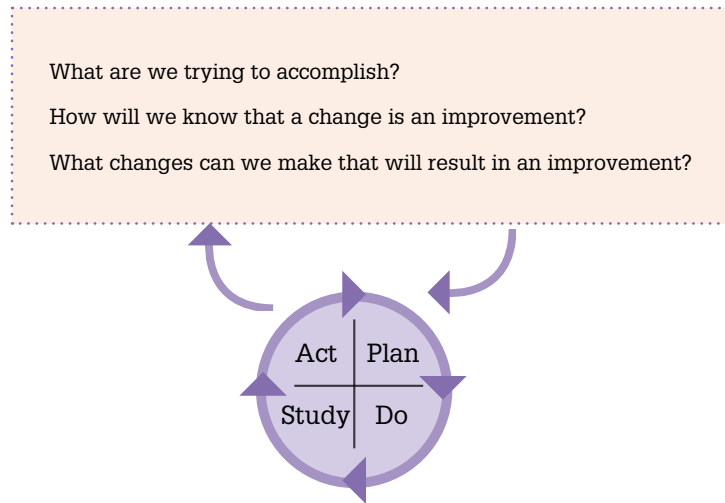
Planning Phase

Based on experience with prior Collaboratives, MCHB in collaboration with NICHQ was able to draw on work that had applied the Care Model for Child Health in a Medical Home and the Model for Improvement to the process of follow-up after newborn hearing screening, and the care of children with epilepsy. In addition, NICHQ undertook a program of planned discovery to identify key elements of state led improvement initiatives associated with success.

Expert meeting

In preparation for the meeting, NICHQ staff reviewed literature of successful state programs to improve systems of care, and conducted key informant interviews of program leaders. Based on this input, NICHQ developed a draft listing of the key determinants of having an effective system.

The culmination of the discovery phase was the expert meeting held in Washington D.C. in February 2008 to review and refine the proposed curricula for the Title V arm of the Collaborative. Invited experts included clinicians, Title V program directors, Title V consultants, representatives from the Association of Maternal and Child Health Programs (AMCHP), the Center for Medical Home Improvement, the AAP, Family Voices, and other parent advocates. Following the expert meeting and during the first Collaborative, six key drivers of Title V performance in systems improvement work were identified:

- Strategic leadership
- Partnership across public and private sectors
- Commitment to quality improvement
- Use of all available resources
- Coordination of service delivery
- Data infrastructure

These then formed the basis for recommendations for changes that state Title V leaders could undertake in order to improve their effectiveness in driving system improvement for CYSHCN.

Expert Faculty

For both rounds of the learning collaborative, Four Faculty Chairs were appointed: two Parent Co-Chairs, a Clinical Chair and a Title V Chair. For the second learning collaborative, a second Title V expert, a pediatric neurologist, and an Audiologist were added to the faculty. Faculty played an active role in team recruitment, teaching and mentoring, assessing team progress and recommending interventions.

Aims, Changes and Measures

Setting Aims

The mission of the project was to improve the health and well-being of CYSHCNs and their families through enhancing the capacity of state Title V programs—in concert with other state partners—to create and sustain effective community-based systems of care for this population. The NHS and Epilepsy components aimed to achieve breakthrough improvements in each of their systems of care. In addition, each participating state team was instructed to craft its own aim statement that reflected state priorities for improvement and included quantifiable goals. The Title V component of the Collaborative aimed to enable state Title V programs to:

- Provide support for clinical teams in improvement work
- Serve as resources in quality improvement initiatives
- Be active participants in tests of change and innovations in state level work
- Be agents of change for clinical improvement for CYSHCNs throughout the state

The Driver Diagram: Key Processes That Can Drive System Improvement

In the second learning collaborative, in collaboration with content experts, NICHQ created pictorial representations of desired outcomes and the key system components (drivers) needed to achieve them. As the project progressed, the driver diagram was adjusted to achieve better alignment with MCHB core outcomes.

Creating a Change Package

For each secondary driver, NICHQ identified key processes of care contributing to that driver, and created a "change package" of promising strategies that could be trialed by clinical teams in an effort to enhance those processes. For example, for NHS an important first step to achieving a medical home model of care was the correct identification of the child's PCP prior to discharge from the birthing hospital. An error in documentation of the PCP could result in the child's PCP failing to receive a copy of the screening result, and contribute to delays in follow-up. Teams could trial collecting this information when families register for the birth admission, or have the screener check with the family that the correct PCP was documented. For epilepsy, the joint development of a written care plan among the specialist, PCP and family was regarded as a key process in ensuring that parents were actively involved in care. Clinical teams were encouraged to trial different models of care plan creation, including having parents and PCP set aside time to create the plan during a clinic visit, or creating an electronic template of the plan that parents and providers could all contribute to.

Given the prominent role of Title V in this Collaborative, we wanted to encourage teams to consider practical ways in which that leadership could support quality improvement efforts at the clinical interface. For each change strategy suggested for the clinical teams, we created an aligned strategy that could be trialed by state leadership. For example, to promote use of written care plans, state Title V leaders could create templates of quality plans, and make them available via web-based resource for providers and families to customize.

Table 1 shows some key examples of change strategies for NHS and Epilepsy. The full versions of each Change Package are included in **Appendix A**.

Table 1. Sample Aligned Change Strategies

	Clinical Change Idea	Title V Change Idea
Newborn Hearing Screening	Birth hospital obtains and documents correct PCP name from family	Promote identification of PCP prior to delivery with prenatal providers and professional organizations.
	Provide "just in time" information to PCP/MH about follow-up for infants that "refer" after newborn hearing screen.	Customize AAP "Guidelines for Medical Providers" with state resources and make available to providers and families.
	Hospital staff schedule follow-up appointments after screening before leaving birth hospital.	Work with PCP and audiology practices on new approaches to making appointments, e.g., use of web-based appointment systems.
Epilepsy	Medical provider administers Pediatric Symptom Checklist to screen for cognitive, behavioral or emotional problems among children with epilepsy	Assure provider awareness of available services for children that screen positive.
	Providers use fax-back or electronic form for transfer of information from specialist to PCP.	Collect and disseminate fax-back templates and other practice-level tools to support flow of information among providers.
	Medical teams develop list of meaningful community resources with family input.	Create and maintain statewide searchable family resource directory

Driver Diagram for Follow-Up After Newborn Hearing Screening

Key Processes

P1. Medical home
- S1a. Identify PCP
- S1b. Inform PCP
- S1c. PCP Specialist Family Communication

P2. Public or Private Insurance
- S2a. Share Insurance Options
- S2b. Facilitate Enrolment
- S2c. Advocate for Coverage
- S2d. Provide Supplement Coverage

P3. Reliable Hearing Screening and Follow Up
- S3a. Screening by 1 Month
- S3b. Audiological Eval by 3 Months
- S3c. EI by 6 Months
- S3c. High-risk Infants Screened
- S3c. Sreeen for Additional Conditions

P4. Parents Are Informed About Service Access
- S4a. Map Service Options
- S4b. Track Patients for Follow-up

P5. Parents Are Involved and Active
- S5a. Survey Parent Satisfaction
- S5b. Parent Representation (EDHI etc)

P6. Transition Plans Are In Place
- S6a. Link Patients to adult Providers

Optimal Outcomes for Patients and Families

Measures

A series of key process measures was developed for both Epilepsy and NHS components of the project. Each measure had a defined numerator and denominator. These included:

Epilepsy

Proportion of children with epilepsy
- With home medication list/card
- Screened for medication side effects
- Family understands medication side effects
- With a care/management plan
- With a seizure action plan
- Screened for learning/behavioral and mental health problems
- With timely labs and test results
- With a medical home
- With a transition plan to adult care
- With language preference documented
- With race/ethnicity documented
- Visited emergency department since last office visit

Additional process measures:
- Time to third available new appointment with neurologist
- Proportion of patients with epilepsy entered into the epilepsy registry
- Proportion of patients entered into epilepsy registry with all key components complete

Newborn Hearing Screening

Proportion of newborns
- Screened by one month of age
- With hearing screen result available in chart at time of first PCP visit
- With verified PCP
- With 2nd contact number documented

Proportion of newborns that are referred on screening
- With completed audiologic evaluation by age 3 months
- With PCP/MH notified of diagnostic test result
- Given a care plan/ roadmap
- With language preference documented
- With race/ethnicity documented
- Unable to find by age three months
- Unable to find at one year
- With no documented second screen

Proportion of infants with proven hearing loss
- Offered amplification by age three months
- Offered intervention by age six months
- Completed IFSP by age six months

Additional process measures
- Time to third available new audiology appointment
- Median age at completion of audiologic evaluation for screen refers
- Median age offered intervention for infants with proven hearing loss

For Learning Collaborative B, the following measures were added:

Epilepsy
- Proportion of visits to neurology specialist with referral letter from PCP available
- Proportion of families of children with epilepsy offered support services
- Proportion of children with epilepsy with documented EEG result
- Proportion of children referred for CT/MRI with result documented
- Proportion of children with epilepsy with verified financial support/insurance coverage

Newborn Hearing Screening
- Proportion of screen "refers" with verified financial support/ insurance coverage
- EHDI System Reliability Measure: proportion of system screening/ follow up opportunities successfully completed for all infants in target population
- Proportion of infants with hearing screening result documented in PCP record within two days of discharge from birthing hospital

Applying the Framework for Improvement to Follow-Up after Newborn Hearing Screening and Epilepsy: Learning Collaboratives A and B

Learning Collaborative A

Eleven states, with a total of 14 teams participated in LC-A between February and December 2008 (see **Table 2**). This Collaborative included teams representing two very different conditions – newborn hearing loss and epilepsy. A virtual office or Extranet, hosted by the Institute for Healthcare Improvement (IHI) at www.ihi.org/extranet was used as a tool to facilitate data and document sharing, and provide a virtual project workspace. During the Pre-work period (February-April 2008) each team collected baseline data, prepared a "storyboard" about the system of care in their state and their proposed improvement aim statement, and conducted a "walk-through" exercise designed to help participants view their system from the perspective of a parent/family.

Teams traveled to three in-person Learning Sessions, separated by action periods in which they applied quality improvement techniques to making "small tests of change" to their care delivery systems. Teams participated in coaching calls in which they shared experiences and lessons learned. Throughout the action periods, teams returned data monthly on project measures and on descriptions of their PDSAs to the Extranet. Project staff rated teams on their progress.

Learning Collaborative B

Between March 2009 and September 2010, the eight Epilepsy state teams from LC-A continued their work, while eight new states participated in Newborn Hearing Screening Quality Improvement work (see **Table 2**). LC-B followed the same format as LC-A with three face-to-face Learning Sessions interspersed with three action periods.

Table 2. Team Participants in the Improving the System of Care for CYSHCNs Collaborative

Epilepsy	Newborn Hearing Screening (A)	Newborn Hearing Screening (B)
California (Northern)	Colorado	Hawaii
Florida	Utah	Illinois
Maine	Massachusetts	Indiana
Nevada	Nevada	Iowa
New Hampshire	Minnesota	Maine
New York	New York	New Hampshire
Washington	Washington	North Carolina
		Virginia

Jumpstart

In addition to the learning Collaboratives that addressed epilepsy and newborn hearing screening, MCHB also funded Jumpstart, a separate training for second group of MCHB funded grantees in the methods of quality improvement linked to a project of their choosing. This second training initiative sought to test whether providing Quality Improvement (QI) training alone, with some level of technical assistance to these grantees that were working in partnership with their State Title V, could develop QI capacity within Title V successfully.

Eighteen state grantees funded under the Division's initiative " h State Implementation Grants for Improving the System of Services for CYSHCNs were brought together with the aim of improving their ability to use continuous quality improvement as a strategy for developing statewide service systems. The project was divided into two cohorts that were six months apart, and included eight grantees in the first cohort (January - September 2010) and ten grantees in the second cohort (June - March 2011). NICHQ had an opportunity to incorporate feedback received from the first Jumpstart Session to make improvements to the curriculum and design of the second Jumpstart Session. Jumpstart participants are listed in **Table 3**.

Table 3. Jumpstart Participants

State Grantees 1	State Grantees 2
State Grantees 1	State Grantees 2
Colorado	Illinois
Connecticut	Indiana
Maryland	Kansas
Michigan	Mississippi
Nebraska	Missouri
Nevada	New Jersey
North Dakota	Vermont
Pennsylvania	Virginia
District of Columbia	West Virginia

Each group was brought together for an abbreviated, two-day training in the model for improvement, then worked on a quality improvement project with input from NICHQ via a series of coaching calls. NICHQ customized measures with each team to monitor progress toward stated aims. Teams worked on a variety of topic areas including adding non-token youth and family members to participate in the process of medical home system establishment (Colorado); transition planning (Connecticut, Kansas); implementation of structured developmental screening in the medical home (Maryland, Nebraska); and provision of written care plans (Michigan).

Components of the Improving the System of Care (ISC) Project

MCHB/NICHQ

| LCA | Title V | LCB | Title V | JUMPSTART | Title V | PHASE III |

LCA
1. Monograph
2. Toolkit
3. Report/Summary
4. Presentation of Results
5. Learning Collaboratives

Clinical Teams
Epilepsy:
Florida, New Hampshire, Maine, Washington, New York, Dartmouth, USC, Nevada

Newborn Hearing:
Utah, Colorado, New York, Nevada, Massachusetts, Minnesota, Washington

LCB
1. Monograph
2. Toolkit
3. Report/Summary
4. Presentation of Results
5. Learning Collaboratives

Clinical Teams
Epilepsy:
Florida, New Hampshire, Maine, Washington, New York, USC

Newborn Hearing:
Hawaii, Illinois, Indiana, Iowa, Maine, North Carolina, Virginia

JUMPSTART
1. Site Visit Reports
2. Summary
3. Jumpstart

State Teams
Colorado, Connecticut, Illinois, Indiana, Kansas, Maryland, Michigan, Mississippi, Missouri, Nebraska, Nevada, North Dakota, Pennsylvania, Virginia, Washington DC, West Virginia, Vermont

PHASE III
1. Evaluation
2. Monograph
3. Clinical Toolkit
4. Parent Toolkit
5. Report/Summary
6. Final Report
7. Dissemination
8. Presentation of Results

Lessons Learned

Role of Title V in Quality Improvement: Learning Collaborative and Jumpstart Experiences

One of the ways in which this collaborative differed from prior collaboratives was the stronger emphasis on Title V involvement. Title V representatives took leadership roles in each improvement team. Each Title V leader was trained in quality improvement methodology and gained new skills that could be applied to multiple programs and services for CYSHCNs. Jumpstart provided a more intensive time-limited model for training Title V leaders in QI. Jumpstart teams worked on a wide variety of CYSHCNs QI projects, whereas the ISC collaborative focused on epilepsy and newborn hearing screening. Both models appeared successful in training participants in the basics of QI. Jumpstart required less of a time commitment from busy Title V leaders, but provided less opportunity for in-depth clinical improvement work. Both approaches encountered challenges with data collection to monitor improvement. Title V leaders found the concept of "small tests of change" challenging, as they are used to making changes that affect whole communities and whole states rather than short-term small-scale trials of changes on just a few cases. Most Title V leaders also expressed interest in learning about other QI activities, in addition to traditional learning Collaboratives, that could be applied at state level.

"Participation in the learning Collaborative provided Title V leaders an opportunity to learn about quality improvement, to see quality improvement in action as part of their work with the clinical teams, and then to apply these new skills to their broader state-level work."
–State Title V leader

Partnering with Families and Clinical Teams in QI Work

The ISC collaborative emphasized the three-way partnership among Title V, Clinical teams and Families in contributing to QI. Involvement of Title V gave a "big picture" perspective to the QI work, and enhanced opportunities for "spread" of successful change strategies. Families contributed a "consumer" perspective, and insights on how the whole "system" of care worked for their family's needs. This helped clinicians to see how what was happening in their own institution contributed to a wider care system for families. This shifted the improvement emphasis from "how can we improve care in our institution?" to "how can we improve the system?" including hand-offs between providers and disciplines.

"At the end of the day, if the system is not working for the 'end-user,' families, then the system that has been built cannot be successful."
–Janet DesGeorges, Parent Chair

"In my view, family-professional partnerships are the way forward in quality improvement work. Families have first-hand knowledge of how the system is working or not working for them 'on the ground.' The best way to find out where the problems are is to talk with families. They know the roadblocks, and can often suggest solutions….sometimes things I, as a provider, wouldn't have thought of."
–Shirley Russ MD, Clinical Chair

Title V Index

The Title V Index was developed during the ISC Collaborative in response to the need to provide Title V with a "big picture" framework for Title V programs to reflect on their own capacity to make and sustain changes in systems of care for CYSHCNs. The index, modeled after the Medical Home Index, identified six areas or domains critical to systems improvement capacity within Title V programs. These domains helped Title V leaders think about what would be needed at the state level for successful quality improvement. These domains are:

- Strategic Leadership
- Partnerships across Public and Private Sectors
- Quality Improvement Knowledge
- Use of Available Resources
- Coordination of Service Delivery
- Use of Data Infrastructure

For each of the six domains there is a brief description corresponding to levels of achievement from Planning through Preliminary Action Steps, Implementation, and Mastery and Sustainability. Title V leaders were encouraged to use the tool to self-rate the improvement capacity of their programs, as well as to monitor progress in the work being performed by the ISC clinical teams, and by the state grantees in Jumpstart. A full description of the Index is included in **Appendix B**.

Outside of the collaborative, Title V leaders have also used the Index as the framework for a State Program Needs Assessment; a framework to describe a CYSHCN Program as part of a grant application; to conduct periodic Program Assessments (mid-course review); as a tool for State Program Strategic Planning; Staff Development; and to guide the Title V program's vision, mission and goal setting.

"My state Title V Program continues to use the Title V Index as a tool to assess how it's doing within each of the domains and to identify areas for attention. For example, we routinely reflect on our leadership role. We also ask how we can expand our partnerships, what is our capacity to support quality improvement, and how can we more effectively integrate and use data."
–State Title V Leader

"Title V Index was most helpful for our program back home by using it to advocate for workforce development, to educate administrators and leadership why we do what we do and how."
–State Title V leader

## Prioritizing and Aligning Change Strategies

Improvement requires change, but not all changes lead to improvement. A change concept is a general notion or approach that has been found useful in developing more specific ideas for change that lead to improvement. Examples of change concepts include "eliminate waste," "improve work flow," and "focus on product or service." Title V leaders working in the ISC Collaborative generated a list of "change ideas" or "change strategies" to try by selecting change concepts for each of the Title V Index domains. For example, under the leadership domain there is a change concept "Change the Work Environment" and one change strategy is to "identify, develop and mentor peers for leadership positions."

The Collaborative also developed an 'Aligned' Change Package. 'Alignment' refers to the consistency among the teams aim and goals, change activity, measures, and project plan. A well-aligned team has an aim with a clear set of numerical goals, it is posting data on measures that correspond to each of its goals, it reports changes and activity related to each goal, and its project plan includes projected testing and implementation work for those goals and measures.

Each of the six CYSHCNs national performance outcomes was identified as a primary driver of system change (see six performance measures on page 10). For each primary driver, secondary drivers were identified that support change, together with corresponding specific change ideas. The Aligned Change Packages for both Newborn Hearing Screening and Epilepsy components of the ISC Collaborative are included in **Appendix A**. Through the development of these "Aligned Change Packages" the "collection of good ideas" from the learning collaborative was "aligned" with the drivers for change for the Epilepsy and Newborn Hearing Screening clinical teams, making it easier for teams to see how their work was contributing to the MCHB's core outcomes. Further, for each secondary driver, change ideas were listed that could be tried by the clinical teams alongside corresponding change ideas that could be tried at the Title V level. So, the change package also aligned the work of Title V with the work of the clinical teams, making it easier for both contributors to see that they were working on the same types of system improvement but at different levels within the system.

The level of alignment was important for achieving results in this Collaborative, as shown for Learning Collaborative B below. States wanting to adopt the aligned change framework could also use this approach to inform their measurement development strategy, i.e., measures could be developed that were applicable both at the clinical team (micro) and state (macro) levels.

Alignment versus Improvement
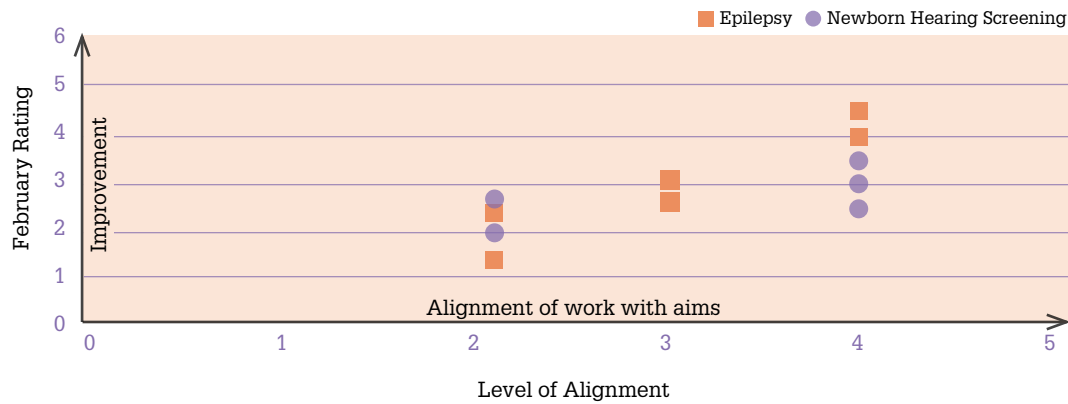
> *"Aligning the change ideas for the clinical teams with those for the state Title V leaders made it easier for everyone to understand how their roles were connected. Lining all of this up with the six MCHB core outcomes helped everyone to see that this QI project was part of our core work, not something being added on as an extra."*

Future of Title V and QI

Title V leaders envisaged applying QI methods to other programs for CYSHCNs in their states. Many struggled with competing time priorities, presenting challenges for their full participation in these initiatives. For example, several Title V leaders needed to devote significant time to the co-occurring H1N1 epidemic. While competing time priorities are likely to continue to pose challenges, Title V leaders also saw great value in their role as facilitators of systems improvement.

> *"Participation also led to improved collaborative partnerships among Title V, families, providers and other state and local organizations forming the basis for future quality improvement work."*
> *–Lynda Honberg, Maternal and Child Health Bureau*

Tackling Two Topics—Epilepsy and Newborn Hearing Screening—in One Collaborative

Advantages

Epilepsy and Newborn Hearing Screening are two discrete topics, brought together in one collaborative largely due to the existence of groundwork laid by prior HRSA-MCHB funded initiatives. Despite the clear distinctions, epilepsy and childhood hearing loss share important features. Each reflects a condition that can carry a degree of "stigma" in some sectors of society, and both reflect conditions that are poorly understood among those who have had little experience with these diagnoses. Both follow-up after newborn screening and services for children with epilepsy require a high degree of coordination among families, primary care providers and specialists, and between healthcare services and educational services including early intervention and schools. Each, at least in theory, would benefit from a medical home model of care, and each can be affected by common system barriers such as lack of health insurance, lack of good information-sharing across services and by cultural and linguistic barriers. Consequently, there are real opportunities for cross-topic learning, and for the application of successful change strategies from one topic to the other.

Disadvantages

There are important differences between the topics. Follow-up after newborn hearing screening is focused on the care of infants. Children with epilepsy can present and require treatment at any age. Follow-up after newborn hearing screening has established well-articulated, legislatively specified goals to which states are held accountable. As a complex clinical topic not under the oversight and direction of public health, epilepsy management has no such legal mandate. Evolving science and rarity of specific conditions has also resulted in less clear articulation of guidelines by professional organizations. Newborn hearing screening has established performance goals; for epilepsy the six MCHB core outcomes provide targets, but they are not condition-specific. These differences posed significant challenges for addressing both topics in one collaborative.

Participants commented that they found it difficult to focus on aspects of care specific to each topic in the context of the collaborative. Although some measures were common to both topics, many were specific, and also suffered from a relative lack of focus. Although participants were split during some parts of the learning sessions into epilepsy and newborn hearing screening tracks, and were also largely separated for coaching calls, some participants commented that they found some presentations at the sessions less relevant for them. Family representatives particularly found the inclusion of both topics challenging, and the connections between the two hard to identify. Overall, most participants expressed a preference for single-condition focused collaboratives. However, there were some shared learnings across newborn hearing screening and epilepsy teams. For example, the newborn hearing screening family roadmap concept was adopted and modified by some epilepsy teams.

Examples of Change Strategies and Specific PDSAs

The following are just a few examples of the type of work undertaken in the Collaboratives. The examples below show some evidence of an improvement in the process of care. Most of these changes were accomplished through the use of iterative tests of change, starting on a small scale and ultimately expanding in scope and permanence.

> *"Small tests of change and PDSA cycles are a foreign concept for most of us—you have to change your way of thinking."*
> *–State Collaborative Team Member*

> *"It's OK to do a PDSA, find it doesn't work and abandon the idea…because a change has worked well in one setting doesn't necessarily mean it will work well in another."*
> *–State Collaborative Team Member*

Epilepsy

Written Medication Lists

Keeping an updated copy of each child's <u>medication list</u> in the case record, and ensuring that the family also has an updated written medication list at each visit, are promising tools for improving the system of care for children with epilepsy. Written lists hold promise for reducing mistakes in recalling names and dosages of medication, and provide the family with a written record of medications that can be shown to other providers as needed.

Florida's Team, under the leadership of the Miami area epilepsy foundation, sought to increase the use of written medication lists so that, ultimately, all families of children with epilepsy would have an up to date list. They started by identifying existing forms used elsewhere, and then modified it for use in their context. They tried it with one patient seeing a specific neurologist. Based on the first experience, they modified the form so that it was kept on a card and tried it again. As it became easier to use, they expanded its use to multiple providers in a single clinic, and then expanding its use to multiple clinics. At the end of the first learning collaborative, 65% of children known to the regional Epilepsy Foundation were using a written management plan. Their goal now is to increase use to 95%.

Proportion of Children with Epilepsy with Written Medication List (Florida)
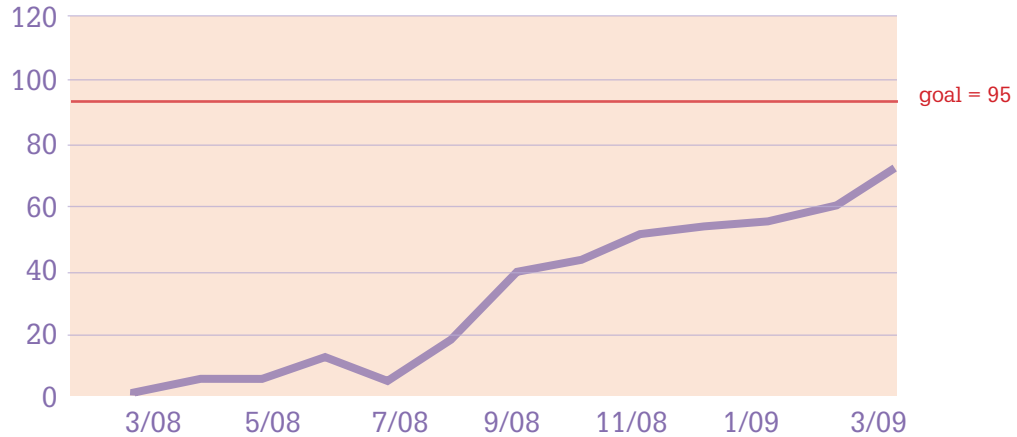
"My sixteen-year-old daughter was diagnosed with epilepsy when she was three months old, and in those sixteen years she has been on over eighteen anti-epileptic medications and combinations of medications. Many of the drugs have complicated names and spellings, most have to be titrated carefully, and dosing is often confusing and variable. Confusion is added when we visit multiple specialists and have to coordinate information about our child for each provider. Family leaders determined that having a wallet-sized medication list, something that can be easily downloaded and filled out, as well as carried in a wallet or purse, is extremely helpful for the overall organization of the child's care."
*–Elizabeth Aquino, Parent Chair*

Written Care Plan and USB Flash Drive Downloaded Care Plan
Several sites worked on increasing the use of written care plans. A written care plan for each child with epilepsy is a promising tool for improving communication between PCP, specialists and family, and provides the family with a place to keep all relevant information about their child's condition and care. Two broad approaches were used—a care notebook and a digital strategy, such as a flash drive. In some settings, these were combined with families able to have one, the other or both depending on their preferences. Some families like to carry their care notebooks with them; however, other families and some youth have expressed interest in having a digital version of their care plan downloaded onto a USB flash drive that could be carried with them to appointments. Providers could view the care plan, update it via computer, and re-load the updated care plan onto the USB port.

"As family members, do we feel like we are the only ones who have the 'big picture' when it comes to our child's healthcare? Do the different providers in our lives have information from one another so they can collaborate on the care for our child? We can help by carrying a care notebook with key reports and test results, and by signing a release form to allow intervention services to talk with our primary care doctors. If we can put systems in place that help this sharing of information, everyone will benefit."
–Parent

Proportion of Families of Children with Epilepsy with a Written Care Plan and a USB Flash Drive Digital Care Plan (Florida)
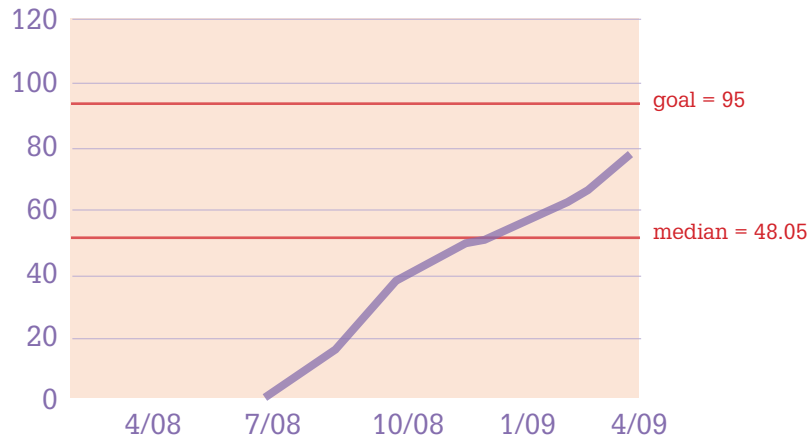
Learning, Behavioral and Mental Health Screening

Children with epilepsy can be at increased risk of learning, behavioral and mental health problems, yet they rarely have formal screening using a validated tool for these conditions. PCPs often report time limitations that prevent them from undertaking this type of screening at office visits. One site found that assigning responsibility to their case manager enabled ready use of one validated tool, the Pediatric Symptom Checklist and, during the course of the collaborative were able to increase use such at 75% of children at that site underwent screening.

Additional testing is needed to expand the use of such tools to different sites with different configurations of staff, as well as to also address the referral and follow up process to assure that children and families benefit from this information.

Proportion of Children with Epilepsy Screened with Pediatric Symptom Checklist by Case Manager (Florida)
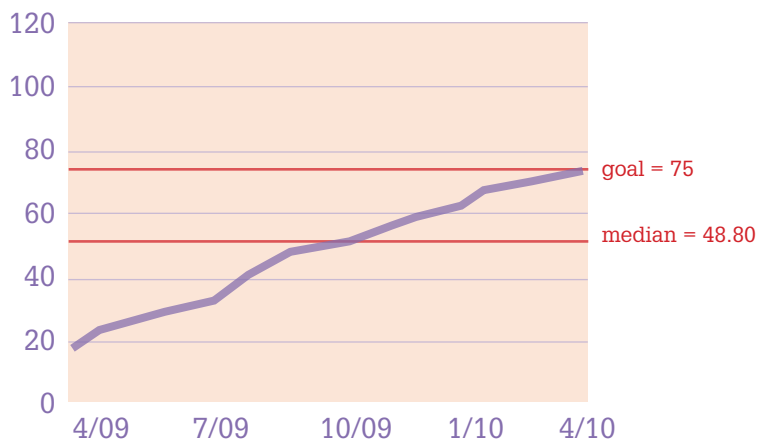
Newborn Hearing Screening

Collecting Multiple Contact Numbers

Families with newborns are a very mobile population. If the family moves shortly after the infant's birth and changes telephone numbers, neither the birth hospital nor the state EHDI program may be able to contact the family. In addition, if the family misses a follow-up appointment for audiologic evaluation after a "refer" (i.e., an abnormal result or a "fail") on a newborn hearing screen, lack of correct contact information may result in the family being lost to follow-up. Because this simple change was shown in the initial hearing screening learning collaborative to lead to improved follow up and lower resource use needed to make follow up calls, several teams worked on implementing this through the use of tests of change in the mechanism for collecting more than one contact number for each infant that referred on newborn hearing screening.

Because this change is relatively simple, teams were able to achieve relatively high levels of performance.

> *"If you win the lottery, how can we reach you? You wouldn't want to be unavailable if you just won a million dollars, would you? Likewise, your medical home needs updated information to get in touch with you!"*
> *–Janet DesGeorges, Parent Chair*

Proportion of Newborns that "Refer" on Screening with Multiple Contact Numbers (Utah)
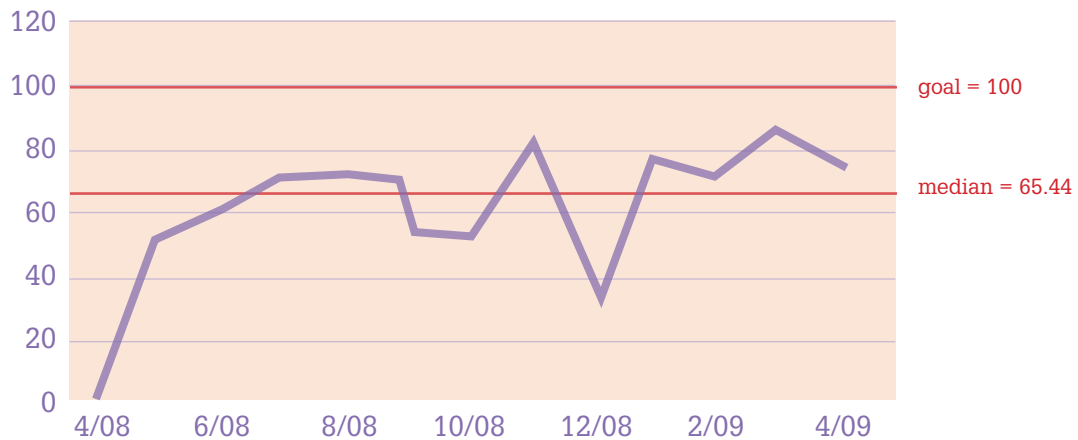
Working with Special Populations: Babies in the NICU

Some babies appear to be at increased risk of missing the initial hearing screen, despite high overall rates of screening in the U.S. Two such populations are homebirths and babies treated in Neonatal Intensive Care Units that transfer to other hospitals prior to discharge. In the first collaborative, Massachusetts chose to focus some if its quality improvement efforts on these more vulnerable populations and, through repeated efforts to improve documentation and actual care processes, improved screening from 88% to 95%. .

**Proportion of NICU "transfer" Babies with Documented Screen
by One Month (Massachusetts)**
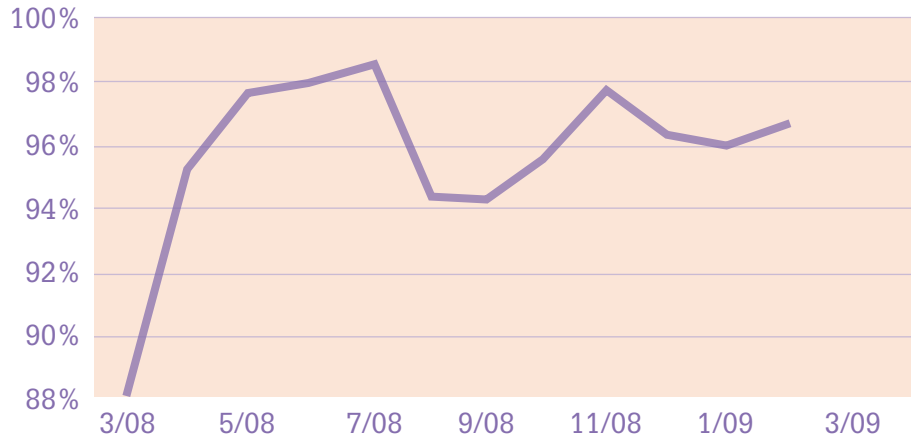
Maine also focused on babies in the NICU, this time focusing on the process for collecting information on hearing loss risk factors among babies that were screened. The Joint Committee on Infant Hearing (JCIH, 2007) recommends that babies with certain risk factors that pass the newborn hearing screen receive closer audiologic surveillance in the early years due to increased risk of onset of hearing loss after the newborn period. The Maine team achieved evidence of improvement in their sample.

Proportion of NICU Babies with Hearing Screen with Risk Factors Assessed (Maine)
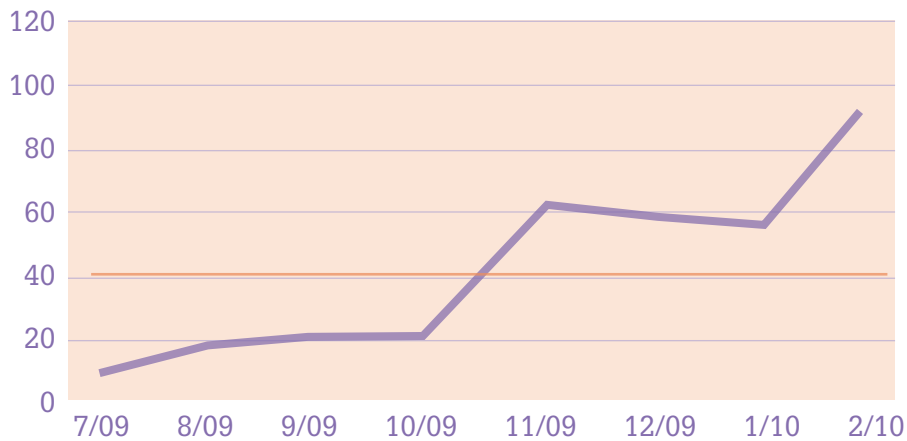
Examples of Change Strategies Tried by More Than One Team and/or Spread

Some change strategies were trialed by multiple teams, indicating a high degree of team belief that that change strategy would result in an improvement. While more data are needed to determine the true impact of each of these change strategies on the overall quality of the care process, these changes are listed here:

Epilepsy
- Provision of care plans (notebook and USB-flash drive)
- Provision of written medication lists
- Provision of seizure action plans
- Screening for medication side-effects
- Linking families with a medical home
- Transition plan to adult care

Newborn Hearing Screening
- Verifying PCP at birth hospital
- Obtaining multiple contact numbers for family
- Faxing results of hearing screen to PCP
- Faxing results of audiologic evaluation to PCP

Table Top Exercise (TTX)

For quality improvement initiatives in general, the more frequently changes can be tested, the more rapidly improvement can occur. QI initiatives aimed at improving care for relatively rare conditions are hampered because care processes are not exercised enough to provide sufficient opportunities for testing. One promising route to addressing this problem is use of a table-top exercise (TTX). The TTX is widely used by public agencies preparing for disastrous events such as hurricanes or floods. A TTX brings together representatives from different agencies and organizations that need to coordinate their actions in the case of a rare event, but do not regularly work together. This situation is analogous to hospital staff, PCPs, audiologists and interventionists who all care for children with hearing loss, and PCPs and specialists, school and intervention agencies that all work with children with epilepsy.

In the Collaborative, we trialed use of a TTX for both epilepsy and newborn hearing screening systems. We created written summaries of realistic case scenarios that could present to the system of care. Each scenario was divided into modules that cover a sequence of events (e.g. birth to newborn hearing screening, screening to diagnosis, diagnosis to intervention) followed by a series of open-ended probe questions designed to challenge participants to think through the process and available resources in such a way as to identify poorly-defined procedures or gaps in care. We conducted TTX sessions with state teams where all stakeholders (hospital staff, PCPs, ENTs, audiologists, interventionists and families) got together around a table and discussed how the "virtual patient" would move through the care system. Through the TTX exercise both state epilepsy and state newborn hearing screening teams identified gaps in the care process that could impact care quality.

The TTX is a non-judgmental tool that can be applied early in the planning for a community-based improvement project to identify parts of the care process most in need of improvement. It can also be applied at practice level to clarify common care processes such as referrals and communication between PCPs and specialists.

"We looked at areas of the Hearing System that needed development, for example, partnering with primary care provider organizations and promoting the role of Title V. We discovered that many of the members of the Medical Home Advisory Board did not know what Title V was or who was responsible for Newborn Hearing Screening and follow-up."
–State Title V Team Member

PCP-Specialist Communication

One focus of the ISC Collaborative was on improving the process of PCP-Specialist communication. Families reported a number of examples where this communication was delayed, or not adequate to drive quality care. A workgroup comprising project faculty and national care coordination experts analyzed the care coordination process and suggested improvement strategies. Care coordination requires explicit planning: what, who, how, where and when. Many tools exist to improve PCP-Specialist communication, but none are required. Even basic forms of communication such as the referral letter lack a standardized format, and are seldom reviewed for inclusion of key elements. One important conclusion the group reached was that a discussion of PCP-Specialist communication was incomplete without discussion of communication with the family. In fact, participants agreed that the focus should be on three-way communication: Family, PCP, and Specialist. Communications involving only any two of these three parties might not be adequate to drive quality care. However, this should not mean that families must necessarily take on the role of the primary communicator between PCP and specialist. Studies have shown that about one-third of families feel uncomfortable assuming such a role, and only one-third of PCPs are comfortable with families in this role (Stille, 2007).

The group identified key elements of communication:

PCP to Specialist:
- Clarifying the type of request, e.g., consultation, collaboration, transfer of care, parent or other third party request for referral
- Summary of history of specific problem
- Identifying what questions the consultation should answer
- Special instructions for office staff, e.g., urgency of referral

Specialist to PCP:
- Findings from visit: examination, diagnostic tests and lab results
- Diagnosis or differential diagnosis
- Management recommendations
- Answers to PCP questions
- Recommendation for further review/visits
- Summary of information given to family

Clarify preferred methods of communication for:
- PCP to contact specialist
- Specialist to contact PCP
- Providers to contact family
- Family to contact providers

The Collaborative tested tools to improve three-way communication among the family, PCP and specialist including written care plans, medication lists, seizure action plans contained in care notebooks, or carried on USB flash drives.

Because of the limited engagement of PCPs in the program, the teams identified but did not test promising change strategies for improving communication:

- Use of letter templates
- Checklist of minimum key elements of communication
- Pre-visit family contact forms
- Pre-visit management meetings (prepared, proactive practices)
- Families contributing to the referral letter sent from PCP to specialist, e.g., identifying family's concerns and questions
- Copies of PCP-Specialist communications given to families

> *"Families who take a pro-active approach with the professionals who serve them have better outcomes for their children."*
> *–State Collaborative Team Member*

Characteristics of More vs. Less Engaged Improvement Teams

Some state improvement teams did more testing, and made more progress in system improvement than others. Characteristics of teams that were more engaged with the improvement process essentially reflect those already reported in the literature: strong leadership, attention of the facilitator to organizing regular team meetings and conference calls, and designation of a team "data expert" responsible for collecting data and reporting measures to the Extranet. Attendance on conference calls and monthly data reporting were also features of more engaged teams, together with the setting of clear, measurable aims, and alignment of aims and change strategies. Teams working on epilepsy participated in both parts of the ISC Collaborative, whereas teams working on newborn hearing screening each participated in only one. Teams appeared to "gain momentum" over time, with epilepsy teams doing stronger work in the second half of the Collaborative. This trend suggested that repeated exposures to QI training and reinforcement of earlier concepts might be contributing to better performance.

Data Collection

Collection of data to monitor the effects of tests of change on the system of care is a vital component of quality improvement. Teams in the ISC collaborative reported on a range of project measures each month to the Extranet. Teams were encouraged to report on about 20 cases for each measure. Some PDSAs required that teams collect additional data on small numbers, e.g., three to five cases in which the change was initially tested.

Extranet Use and Data Challenges

All but two state teams reported data to the Extranet. No team attempted reporting on all measures. In retrospect, the large number of measures suggested for the project resulted in a diffusion of effort in collecting any one measure. This made aggregation of data from different state teams challenging. Team feedback suggested difficulties with correct definition and interpretation of measures. For newborn hearing screening particularly, there were problems with small numbers of cases. For example, even a large birth hospital with 5,000 deliveries per year and a "refer" rate on newborn hearing screening of two percent would see only 100 screen refers per year, or two per week. One in ten or fewer of these newborns will prove to have permanent hearing loss, meaning that following cases prospectively through screening, diagnosis and intervention will not yield sufficient numbers for testing change strategies. Similarly, a PCP with an average-sized practice will only see one case of hearing loss every one-to-two years, which

limits the priority the practice is able to give to system improvements targeted at this condition. Individual teams reported promising improvements on individual measures related to the process of care. However, in part due to small numbers, the core hearing screening follow-up measures of diagnosis by three months and entry to early intervention by age six months did not show improvement.

Use of "Opportunities Measure" in NHS Improvement Initiatives

In the second half of the ISC Collaborative, teams working on newborn hearing screening were introduced to an additional measure of system function known as the "Opportunities Measure." Teams using the measure followed a cohort of infants through the screening and diagnostic systems. The first "opportunity for care" was receiving the screen itself, with a score of 1 given for timely receipt of the screen by the target age of one month. The second "opportunity" was the receipt of a re-screen; the third, audiologic diagnostic evaluation by age three months and so on. Infants that were screened by one month and passed, had only one "opportunity for care," but the opportunity was achieved, giving a score of 1/1 or 100%. An infant who referred on screening but did not receive a follow-up screen would have a score of ½ and so on. The attraction of this measure is that it provides a "single metric" by which the quality of any infant's overall care can be gauged, and by summing scores at population level, gives a measure of overall system quality.

An electronic tracking template was constructed for teams to use for following infants' progress through the system. Teams recorded each infant's name, date of birth, screening, diagnostic and intervention history. Other measures of system quality that could be added to the basic "opportunities measure" and incorporated into the scoring system included 1) PCP verified at birth hospital (1 point for yes, 0 for no); 2) multiple contact numbers documented; 3) language preference documented; and 4) care plan or "NHS family roadmap" reviewed with family. Teams using the measure reported that they found the concept of a single metric reflecting system performance very helpful. Reporting on the measure resulted in some teams realizing that their system of care was working less well than they had estimated. Somewhat perversely, some teams found that their "opportunities measure" fell in the first few months of use, as teams gained skill in correct utilization of the measure. While no conclusions can be drawn from this brief trial about the real utility of this measure as a reflection of system quality, faculty concluded that it held promise and was worthy of future testing.

Some teams also used the tracking template provided as a means of tracking infants through their care system in "real time" and intervening at the first sign of system failure, e.g., calling the family if they missed their re-screening or diagnostic evaluation appointments. States constructing larger, electronic data tracking systems for newborn hearing screening might wish to consider constructing these systems with a similar tracking template in a way that could be used to provide some type of "opportunities measure" reflecting system quality.

Use of Epilepsy Registry

A registry is a listing of patients that includes specific information about them and their care. A condition-specific registry can simplify patient tracking, allow for pro-active, planned care, and for recording and monitoring of delivery of evidence-based care components. A well-kept registry can be used to monitor outcomes, and facilitate participation in CQI activities with a defined patient population. Prototype registries can be paper-based or electronic. Registries that are integrated with patient electronic health records require senior administrative support. Patients for inclusion in the registry can be identified by ICD-9 code. Registry fields for patients with epilepsy could include demographics, health outcomes (number of emergency department visits since last office visit, number of unplanned hospitalizations since last visit, number of missed school days since last visit, number seizures since last visit) and elements of planned care.

Epilepsy teams received training on the registry concept, and were encouraged to test a prototype version. Although teams were enthusiastic about the idea, there was insufficient reporting on registry usage to draw any conclusions about its utility. This remains a care strategy likely worthy of further study in specialty practices seeing substantial numbers of children with epilepsy. The registry strategy may also work better in practices equipped with electronic medical records.

Role of Families in Quality Improvement

In keeping with HRSA-MCHB and NICHQ's commitment to family involvement in all levels of QI work, each state team was required to include at least one and preferably two parents in its improvement team. Most of the parents were new to QI work, and for many professionals it was the first time they had worked with families outside of clinical encounters. Most parents had initial challenges with the "language of quality improvement." They noted that improvement advisors and faculty used a number of terms and acronyms on the assumption that these terms were well understood, when in fact their meaning was often obscure. Frequent use of this terminology meant that parents felt less engaged in sessions.

Parent-Led Initiatives/Changes

ISC parent co-chairs led an initiative to develop a Family Partner Guide. Designed for use by parent partners new to collaborative work, the guide includes an overview the learning collaborative model, an explanation of the role of the parent chairs, examples of past parent participation and opportunities for involvement. The guide also contains an explanation of commonly used acronyms.

Parents in the ISC collaborative also built on parent-led initiatives from prior Collaboratives to further test and customize tools developed to enhance care coordination and improve professional-parent communication. These tools included care notebooks and seizure action plans for children with epilepsy, and the family roadmap for follow-up after newborn hearing screening.

> *"Families want to be involved in quality improvement, not just in a 'token' way, but actively suggesting and leading improvement initiatives."*
> *–Shirley Russ MD, Clinical Chair*

> *"After professionals develop a product aimed at informing and helping families, they often ask for input from family leaders, whether it is to review drafts, give feedback, or worse, 'rubber stamp' it so they can say they had families involved in its development. In contrast, the family-driven model of involvement is a process in which family leaders take primary responsibility for developing the product, and then ask for input from others."*
> *–Janet DesGeorges, Parent Chair*

Parent Reflections

> *"Parent involvement/leadership is often at its most powerful not as an element in a scope of work or on a 'to do' list, but in its very essence: understanding and sharing our journey with our kids. We as family partners bring to the table our life experiences, our children's joys and challenges, and our 'perspective' on what a system should be doing or not doing to make it better for the next family that comes along. We are also being asked not only to represent our own life experiences, but to embody the life stories and 'journeys' of other families. We believe that parents and professionals bring complementary expertise to the quality improvement process."*
> *–Janet DesGeorges and Elizabeth Aquino, Parent Chairs*

Professional Experiences of Working with Parents and Families in QI Work

For many professionals the experience of working alongside families in quality improvement work was new and required a period of adjustment. Some professionals were hesitant to "ask too much" of families, realizing that many were volunteering their time, and not wishing to over-burden them. Families, however, sought an active role in the improvement process, wishing to suggest innovations and often spearhead trialing them. Professionals valued the passion and commitment that families brought to the QI task. Professionals also understood that frequently families' experiences of the existing care system had been negative ones, and that they needed to work to overcome some negative stereotypes.

The parent and professional co-chairs used the phrase "mutual mentoring" to describe the way in which they worked closely together. Each was able to "mentor" the others about the system of care from their own vantage point.

> *"As a state-level team, along with our community quality improvement teams, we have identified the partnership and perspective of families within the process as the most critical element to the success of our work."*
> *–State Title V Leader*

> *"Unless the strategies professionals use are developed hand-in-hand with families, they likely will fall short. The time and initial effort it takes to truly integrate families into a practice development strategy is well worth it."*
> *–Carolyn Green MD, Neurology Chair*

Conclusion

The Improving the System of Care (ISC) for CYSHCNs Collaborative provided a successful framework for partnerships among state Title V leaders, clinical teams and families in quality improvement work. Jumpstart provided a successful alternative format for training Title V state grantees and leaders in QI methodology. The collaborative made significant progress in developing a conceptual framework for Title V programs to evaluate their capacity for improvement activities. The collaborative also identified and trialed a number of tools that Title V leaders could use in this work, and a fund of change strategies for leaders to draw on. Families initiated and led a number of "small tests of system change" including further trialing of communication tools such as the Family Newborn Hearing Screening Roadmap, and the use of care notebooks and seizure action plans. The ISC project also tested ways to improve links with the medical home such as ensuring correct identification of the PCP prior to discharge from the birth hospital, and gaining families' permission to share intervention data with their PCP.

Participants recommended that future Collaboratives focus on a smaller number of measures, and create a plan for each team to collect data on sufficient numbers of cases for meaningful month-to-month comparisons to be made. Despite some useful cross-learning, many participants expressed a preference for single-condition focused Collaboratives. The Family Partner Guide provides an orientation for new families participating in pediatric QI activities. The web-based toolkit will be available as a resource for all Title V leaders, family representatives, and providers working to improve the system of care for CYSHCNs.

> *"Applying Quality Improvement methodology not just to one or two individual practices, but to the whole system of care, offers real hope for widespread change. I am convinced that it is only by working together— families, providers, administrators, and policymakers—that we will be able to develop the high quality care system that we all seek."*

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Appendix A: Epilepsy Change Package

Primary Driver #1: All CYSHCN will receive coordinated ongoing comprehensive care within a medical home as exemplified by reliable systems of care.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Decision Support: Reliable execution of protocol/ guidelines (and education)	C1a. Medical teams develop and place template for standing orders for routine labs, diagnostic tests on the chart for patients.	T1a(i). Convene and support ongoing stakeholder consortium/coalition in on local, regional and/or state basis aimed at achievement of the 6 MCHB outcomes.
		T1a(ii). Promote/support committee on children with disabilities/special health care needs of state AAP chapter as vehicle for disseminating practice-level medical home change strategies.
		T1a(iii). Identify and disseminate office-based practice improvements through coalition/consortium, web, AAP chapter, other mechanisms. Collect and disseminate referral fax-back templates and other practice-level tools to support smooth flow of information among providers.
	C1b. Medical provider administers Pediatric Symptom Checklist (Parent or Youth version) at annual well child visits age 4 and older to screen for cognitive, behavioral or emotional problems.	T1b(i). Collaborate with AAP chapter & Medicaid to promote and create incentives for universal screening and feedback when screening is incomplete (model in many states).
		T1b(ii). Assure provider awareness of available services for children who screen positive for EBD problems.
		T1b(iii). Collaborate with Parent to Parent HICs and other parent organizations to build parent awareness and expectation of appropriate screening and understanding of meaning of positive screen.
		T1b(iv). Support parent to parent education forums on child development.
	C1c. Medical team contacts patients/ families who have ceased to request prescription refills or "did not show" for scheduled visit to provide extra supports.	T1c(i). Publicize state 1-800 number as source of assistance to families of CYSHCN facing barriers (financial, immigration, psychosocial, other) to care.
		T1c(ii). Provide/promote/support medical home care coordination with capacity to seek out and address barriers to care.
		T1c(iii). Promote/provide broad array of family supports statewide (transportation, respite).
	C1d. Medical practices use timely, proactive follow-up for more complex cases, in cases where there is no self-reporting, or when treatment plan/ medication is new or has changed.	T1d(i). Provide/promote/support medical home care coordination with capacity to seek out and address barriers to care.
	C1e. Clinicians work with Title V and insurers by reporting delays and obstacles to access. (Examples: authorizations needed for referrals, payment and scheduling appointments; delay to all specialty providers, including ENT, genetics, audiology, hear aid providers).	T1e(i). Determine and respond if systemic factors contribute to delays. Troubleshoot systemic causes of undue delay.
		T1e(ii). Collaborate with families and providers to monitor time from prescription to receipt of items/services requiring Medicaid prior.
		T1e(iii). Provide/promote/support medical home care coordination with capacity to seek out and address barriers to care.

Primary Driver #1 (continued): All CYSHCN will receive coordinated ongoing comprehensive care within a medical home as exemplified by reliable systems of care.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S2. Delivery System Design: access, cycle time, timely feedback	C2a. Medical practices build service agreements, co-management plans, between primary and specialty care include core competencies, referral guidelines, communication and expectations for access.	T2a(i). Convene and support ongoing stakeholder consortium/coalition on local, regional and/or state basis aimed at achievement of the 6 MCHB outcomes.
		T2a(ii). Promote/support committee on children with special healthcare needs of state AAP chapter as vehicle for disseminating practice-level medical home change strategies.
		T2a(iii). Identify and disseminate office-based practice improvements through coalition/consortium, web, AAP chapter, other mechanisms. Collect and disseminate referral fax-back templates and other practice-level tools to support smooth flow of information among providers.
		T2a(iv).Provide/promote/support medical home care coordination withcapacity to serve as link among providers.
	C2b. Medical practices establish bimonthly case conferences using common cases.	T2b(i). Provide/promote/support medical home care coordination with capacity to serve as link among providers
	C2c. Specialist spends half day doing mini-clinics with primary care teams.	T2c(i). Provide/promote/support medical home care coordination with capacity to serve as link among providers.
	C1d. Medical practices use timely, proactive follow-up for more complex cases, in cases where there is no self-reporting, or when treatment plan/ medication is new or has changed.	T2d(i). Familiarize families with medical home concept.
		T2d(ii). Create buy-in among family leaders for medical home as alternative to dependence on specialists for regular care.
	C2e. Families have group visit for parents of newly diagnosed children to reinforce new knowledge, reduce fears and misperceptions about condition and medication, addressing common questions and safety concerns.	T2e(i). Collaborate with Parent to Parent HICs and other parent organizations to build parent awareness.
		T2e(ii). Develop (or adopt applicable models) state care notebook template to be available to parents via medical home or website. Seizure action plan can be incorporated into notebook.
		T2e(iii). Seek funding for distribution of notebooks to families.
		T2e(iv). Disseminate notebook via the web.
	C2f. Improvement team and Senior Leader agree on how improvement project information is to be provided to senior leader on a regular basis.	T2f,g,h(i). Promote and/or initiate collaborative learning as vehicle for quality improvement. T2f,g,h(ii). Provide TA and facilitation to practice level and local improvement teams.
	C2g. Medical providers integrate measures on quality of epilepsy care w/ other org measures.	T2f,g,h(iii). Engage payers in quality improvement efforts. T2f,g,h(iv). Familiarize legislative champions with QI efforts.
	C2h. Medical providers use teach-back or "closing the loop" techniques to assess understanding.	

Primary Driver #1 (continued): All CYSHCN will receive coordinated ongoing comprehensive care within a medical home as exemplified by reliable systems of care.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S3. Information Systems: Registry functions; referral support	C3a. Medical practices populate and use the Epilepsy Registry to organize patient info and complete reports about key elements of good care.	T3a(i). Assure provider awareness of available services for children who screen positive for EBD problems.
		T3a(ii). Promote and/or initiate collaborative learning as vehicle for quality improvement.
		T3a(iii). Provide TA and facilitation to practice level and local improvement team.
S4. Health Care Organization: inter-provider communication and coordination of services	C4a. Medical practices use nurse practitioners or other mid level providers to complement the care of pediatric neurologists, such as Use Primary Nurse Practitioners for follow-up visits or alternate visits between specialist and nurse practitioner.	T4a(i). Familiarize families with medical home concept.
		T4a(ii). Create buy-in among family leaders for medical home as alternative to dependence on specialists for regular care.
	C4b. Providers use Fax Back or Electronic Form for efficient transfer of information from specialists to PCP including outcomes of the visit, plan for next labs, visit, follow-up and with whom. Fax form within 24 hours of visit and supply copy to family.	T4b(i). Collect and disseminate referral fax-back templates and other practice-level tools to support smooth flow of information among providers.
	C4c. Medical providers champion the development of co-management plans between primary and specialty care groups.	T4c(i). Work with state AAP chapter to identify and disseminate materials on co-management models as appropriate. (See c1bii, c1f.ei).
		T4c(ii). Work with F2F HICs to get buy-in of family leaders & familiarize families w/ co-management concept.
	C4d. Practices develop a primary care provider (PCP) network tied to tertiary centers. Ex:1 day/month sub-specialist goes to the PCP site to train PCP's and provide direct care to children.	T4d(i). Work with Medicaid and private payers to establish mechanism for coverage of collaborative visits.
		T4d(ii). Provide or support care coordination to facilitate shared visits as needed.
S5. Medical Home provides patient centered care	C5a.Medical provider identifies at family or family's physician first contact to office if the family does not speak English as primary language, and arranges for translator to be present at time of visit.	T5a(i). Identify and publicize state resources for interpretation.
		T5a(ii). Identify unmet interpretation needs at clinic and community level.
		T5a(iii). Work with coalition/consortium to enhance interpretation capacity statewide.

Primary Driver #2: All families of CYSHCN will have adequate private and/or public insurance to pay for the services they need.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Provide financial assistance for coverage as needed	C1a. Medical team identifies community resources that provide financial assistance for children with epilepsy; provide a summary of resources to practices.	T1a(i). Establish ongoing accessible mechanism (e.g. website, online guide) to make providers, agencies and families aware of eligibility and benefits provided by public programs and private financing resources. Assure frequent updates and publicize via outreach efforts.
		T1a(ii). Assure (provide/support/train) care coordinators or other front-line personnel to carry out individualized benefits counseling.
		T1a(iii). Work with clinical teams/parents to identify financial burdens (e.g. high cost medications) particular to raising child with epilepsy and find resources available to address those specific needs.
		T1a(iv). Publicize state 1-800 number as source of assistance to families of CYSHCN facing barriers (financial, immigration, psychosocial, other) to care.
	C1b. Medical team verifies appointment, insurance, and referral information in advance of any visit to clinician.	T1b(i). Collect and disseminate referral fax-back templates and other practice-level tools to support smooth flow of information among providers.
		T1b(ii). Promote/support committee on children with disabilities/special health care needs of state AAP chapter as vehicle for disseminating practice-level and system wide medical home change strategies.
		T1b(iii). Update AAP and its disability committee on state-level financing policies.
	C1c. Families and providers advocate for government/insurance changes give access to specialty care for all- (i.e. insurance coverage for brand name medications and medications not typically approved for seizure control, reimbursement for care coordination, expand coverage for mental health visits.	T1c(i). Convene and support ongoing stakeholder consortium/coalition in on local, regional and/or state basis aimed at achievement of the 6 MCHB outcomes.
		T1c(ii). Make comprehensive financing at the state level a focus of consortium activity.
		T1c(iii). Conduct regular scan of web and other sources to identify new and promising policy models nationally for funding of needed services.
		T1c(iv). Support (financially or through publicity) websites providing up-to-date information on relevant policy initiatives.
	C1d. Medical practices have open contracts with every insurer in the area (so that specialist visits are covered).	T1d(i). Convene and support ongoing stake holder consortium/coalition in local, regional and/or state basis aimed at achievement of the 6 MCHB outcomes; educate providers and payers.
		T1d(ii). Educate providers and payers through stakeholder coalition/ consortium. Use relationship with state Medicaid to promote supportive language in Medicaid managed care contracts (models in several states).
	C1e. Medical teams use Title V to help maximize insurance benefits.	T1e(i). Provide or identify point person on Title V staff to troubleshoot barriers to adequate coverage at the structural or systems level.
		T1e(ii). Provide training for customer service personnel at Medicaid and major private insurance companies to respond appropriately to calls from families of children with epilepsy and other special health care needs.
	C1f. Streamline authorizations needed for referrals, payment and scheduling appointments; eliminate delay to all specialty providers.	T1f(i). Identify and disseminate office-based practice improvements through coalition/consortium, web, AAP chapter, other mechanisms for stakeholder communication.

Primary Driver #3: All children will be screened early and continuously for special healthcare needs

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Promote community acceptance and understanding of patient needs	C1a. Families get info about epilepsy into school health curriculum — a school nurse can facilitate, can use Take Charge of Facts developed by EF.	T1a(i). Convene and support ongoing stakeholder consortium/coalition on local, regional and/or state basis aimed at achievement of the 6 MCHB outcomes.
		T1a(ii). Promote/support committee on children with special healthcare needs of state AAP chapter as vehicle for disseminating practice-level medical home strategies.
		T1a(iii). Use National Survey of CYSHCN data and local studies to create awareness among stakeholders, general public and policymakers of gaps and fragmentation among services; publish annual report; convene statewide annual conference; build informed base within legislature.
S2. Timely diagnosis of epilepsy	C2a. Medical teams develop and place template for standing orders for routine labs, diagnostic tests on the chart for patients.	T2a(i). Collaborate with AAP chapter to promote and Medicaid to create incentives for universal screening and feedback to practice when screening is incomplete.
	C2b. Streamline authorizations needed for referrals, payment and scheduling appointments; eliminate delay to all specialty providers.	T2a(ii). Promote use of CAHMI screener to identify CYSHCN in pediatric primary care.
	C2c. Clinicians work with Title V and insurers by reporting delays and obstacles to access. (Examples: authorizations needed for providers).	T2a(iii). Collaborate with Parent to Parent HICs and other parent organizations to build parent awareness and expectation of appropriate screening and of entitlement to follow-up diagnosis and treatment under EPSDT.

Primary Driver #4: Services for children with special healthcare needs and their families will be organized in ways that families can use them easily.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Link to agencies providing condition-specific equip, meds, etc.	C1a. Medical teams develop list of meaningful community resources for patients, families, and staff w/ input from families.	T1a(i). Create (or support) and maintain statewide searchable, family resource directory. Identify and implement strategies to maximize consumer and provider access to database and to make it easy for users to correct or update information.
	C1b. Medical provider asks family permission for EF to proactively call family to personally introduce and explain their services.	T1b(i). Assure (provide, support, train) care coordinators or other front-line personnel to serve as easy access points for families seeking information about clinical settings.
S2. Coordinate referrals to non-medical providers	C2a. Families get info about epilepsy into school health curriculum — a school nurse can facilitate, can use Take Charge of Facts developed by EF.	T2a(i). Partner with state education agency to establish state program to build capacity of school RNS to support CYSHCN in school.
		T2a(ii). Develop standardized protocol and accompanying form to guide safe and supportive integration of CYSHCN in school.
		T2a(iii). Develop standardized protocol and accompanying form to guide safe and supportive integration of CYSHCN in school.
		T2a(iv). Provide training to school RNs on care of CYSHCN in school.
	C2b. Families review information/ guidelines in school nurse manuals (use parent experts to help review).	T2b(i). Support and publicize work of PTP HICs and other parent organizations to train/inform parents on IDEA rights and on strategies for effective collaboration with school personnel.

Primary Driver #5: Families of CYSHCN partner in decision making at all levels and are satisfied with the services they receive, resulting in active well-informed patient and family.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Patients use care documentation, care plans and goals	C1a. Families utilize EF affiliate to coordinate care plan and IEP for child with epilepsy.	T1a(i). Engage state education agency and LEAs in local and state coalitions/consortia.
		T1a(ii). Partner w/ state education agency to establish state program to build capacity of school RNS to support CYSHCN in school.
		T1a(iii). Develop standardized protocol and accompanying form to guide safe and supportive integration of CYSHCN in school (Project SchoolCare and MASSTART model in MA, similar models elsewhere).
		T1a(iv). Develop standardized protocol to link school RNs or other responsible school personnel to medical home (asthma plan in MA links school, medical home, specialist, family).
		T1a(v). Provide training to school RNs on care of CYSHCN in school.
	C1b. Early in relationship, make a plan with family for "graduation" to adult care (see transition to adult care package).	T1b(i). Work with state chapter of AAP and medical society to identify adult providers with interest and/or expertise in serving as medical home.
		T1b(ii). Engage payers in discussion of financing issues related to transition (e.g. possibility of engagement with two primary care providers during transition period).
		T1b(iii). Convene and support ongoing stakeholder consortium/coalition in on local, regional and/or state basis aimed at achievement of the 6 MCHB outcomes.
		T1b(iv). Make comprehensive financing at the state level a focus of consortium activity.
		T1b(v). Conduct regular scan of web and other sources to identify new and promising policy models nationally for funding of needed services.
		T1b(vi). Support (financially or through publicity) websites providing up-to-date information on relevant policy initiatives.
	C1c. Families distribute templates and instructions to encourage families to keep a Care Notebook.	T1c(i). Develop (or borrow/steal) state care notebook template (many models available) to be available to parents via medical home or website. Seizure action plan can be incorporated into notebook.
		T1c(ii). Seek funding for distribution of notebooks to families.
		T1c(iii). Disseminate notebook via the web.
	C1d. Medical teams develop a seizure action plan for all patients with epilepsy.	T1d(i). Promote and/or initiate collaborative learning as vehicle for quality improvement.
		T1d(ii). Provide TA and facilitation to practice level and local improvement team.

Primary Driver #5 (continued): Families of CYSHCN partner in decision making at all levels and are satisfied with the services they receive, resulting in active well-informed patient and family.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S2. Families have early awareness of needs and get services early S2. Timely diagnosis of epilepsy	C2a. Practices use EF for information packets and resource lists for families.	T2a(i). Establish ongoing, accessible mechanism (e.g. website, online guide) to make providers, agencies and families aware of eligibility and benefits provided by public programs and private financing resources. Assure frequent updates and publicize via outreach efforts.
		T2a(ii). Develop (or borrow/steal) state care notebook template (many models available) to be available to parents via medical home or website. Seizure action plan can be incorporated into notebook.
		T2a(iii). Seek funding for distribution of notebooks to families.
		T2a(iv). Disseminate notebook via the web.
	C2b. Experienced families work with medical providers to create phone guidelines for less experienced families with the intended result being efficient calls which lead quickly to the family receiving their desired results and the provider having a positive attitude for responding to future calls quickly.	T2b(i). Establish ongoing, accessible mechanism (e.g. website, online guide) to make providers, agencies and families aware of eligibility and benefits provided by public programs and private financing resources. Assure frequent updates and publicize via outreach efforts
		T2b(ii). Develop (or borrow/steal) state care notebook template (many models available) to be available to parents via medical home or website. Seizure action plan can be incorporated into notebook.
		T2b(iii). Seek funding for distribution of notebooks to families.
		T2b(iv). Disseminate notebook via the web.
	C2c. Medical providers reinforce family involvement by explaining that management is not an exact science and involves adjusting of medication and doses and requires information that only a family could give to have the best results.	T2c(i). Collaborate with Parent to Parent HICs and other parent organizations to build parent awareness around involvement in system of care at all levels.
	C2d. Medical practices support family feedback mechanisms and participation in improvement activities for youth with epilepsy.	T2d(i). Collaborate with Parent to Parent HICs and other parent organizations to build parent awareness around involvement in system of care at all levels.

Primary Driver #5 (continued): Families of CYSHCN partner in decision making at all levels and are satisfied with the services they receive, resulting in active well-informed patient and family.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S3. Families use support networks (Web, Family Voices, etc.) for unbiased info	C3a. Families work with EF affiliate or other organization to create a peer/parent support group with a proactive referral process.	T3a(i). Collaborate with F2F HICs and/or other appropriate family organization, provide TA on family engagement models.
	C3b. Use e-communities on EF website, for kids/peers & for parents.	
	C3c. Families facilitate a Parent to Parent Group for newly diagnosed children.	T3c(i). Collaborate with F2F HICs and/or other appropriate family organization, provide TA on family engagement models.
	C3d. Medical providers refer those who want/would benefit from further or different assistance such as such as education classes, support groups, group visits, home nurse visits, parent-to-Parent, etc.	T3d(i). Convene and support ongoing stakeholder consortium/coalition in on local, regional and/or state basis aimed at achievement of the 6 MCHB outcomes.
		T3d(ii). Collaborate with Parent to Parent HICs and other parent organizations to build parent awareness around involvement in system of care at all levels.
		T3d(iii). Develop (or borrow/steal) state care notebook template (many models available) to be available to parents via medical home or website. Seizure action plan can be incorporated into notebook.
		T3d(iv). Seek funding for distribution of notebooks to families.
		T3d(v). Disseminate notebook via the web.
		T3d(vi). Establish ongoing, accessible mechanism (e.g. website, online guide) to make providers, agencies and families aware of eligibility and benefits provided by public programs and private financing resources. Assure frequent updates and publicize via outreach efforts.
		T3d(vii). Publicize state 1-800 number as source of assistance to families of CYSHCN facing barriers (financial, immigration, psychosocial, other) to care.
		T3d(viii). Provide/promote/support medical home care coordination with capacity to seek out and address barriers to care.

Primary Driver #6: All youth with special healthcare needs receive the services necessary for transition to adult health care, work and independence.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Patients have transition plan	C1a. Early in relationship, make a plan with family for "graduation" to adult care.	T1a(i). Work with state chapter of AAP and medical society to identify adult providers with interest and/or expertise in serving as medical home.
		T1a(ii). Engage payers in discussion of financing issues related to transition (e.g. possibility of engagement with two primary care providers during transition period).
		T1a(iii). Convene and support ongoing stakeholder consortium/coalition in on local, regional and/or state basis aimed at achievement of the 6 MCHB outcomes.
		T1a(iv). Engage state education agency and LEAs in local and state coalitions/consortia.

Appendix B: Newborn Hearing Screening Change Package

Primary Driver #1: All CSHCN receive coordinated ongoing, comprehensive care in a medical home as exemplified by reliable systems of care.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Identify PCP.	C1a. Hospital screener obtains and documents PCP name and contact info from family.	T1a(i). Promote identification of PCP prior to delivery with prenatal provider agencies and professional organizations.
		T1a(ii). Require identification of PCP prior to delivery in state contracted prenatal care coordination providers.
		T1a(iii). Require reporting of screening results and name of identified PCP/MH in EHDI legislation.
		T1a(iv). Create an award system for hospitals that report the child's PCP/MH (NCHAM Goal Bank).
S2. Ensure PCP has results of hearing screen and diagnostic tests.	C2a. Hospital staff verifies identity of PCP and faxes/calls screen result. Verification includes confirming provider has accepted the patient into their practice, knows the screen result and accepts responsibility for follow-up.	T2a(i). Assure communication of newborn hearing screening results to identified PCP by State EHDI program (modeled after blood screening program).
		T2a(ii). Integrate screening results "look up system" for providers with other public health data systems such as immunization registry.
	C2b. Use standardized process, fax-back, phone call, etc. to communicate result of audiology testing. For confirmed hearing loss fax results & care plan to the PCP/MH in 2 days.	T2b(i). Convene consortium of stakeholders including families to create best practice guidelines; template agreements, office-based practice improvements/standardized tools and distribute.
		T2b(ii). Customize AAP "Guidelines for Medical Providers" with state resources and make available to providers and families.
		T2b(iii). Promote/support committee on CYSHCN of state AAP and AFP as vehicles for disseminating best practices/practice modifications.
		T2b(iv). Require reporting the results of audiology testing to family, PCP and State in EHDI legislation.
S3. Educate PCP about medical work-up and care planning for infants with hearing loss.	C3a. Provide "just in time" information to PCP/MH about follow up for infants who "did not pass" the newborn screen; use standardized evidence-based materials; provide outreach with phone call to practice offering guidance and support.	T3a(i). Assure "just in time" information to PCP/MH about follow up for infants who "did not pass" the newborn screen.
		T3a(iv). Integrate MH EHDI work with other CYSHCN/MCH MH related activities –create interface with MCH to impact other MH initiatives occurring in state (NCHAM Goal Bank).

Primary Driver #1 (continued): All CSHCN receive coordinated ongoing, comprehensive care in a medical home.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S4. Streamline communication between PCP-specialists and family.	C4a. PCP office confirms follow-up appointment for diagnostic audiology with parents at time of first newborn PCP/MH visit; stress its importance.	T4a(i). Assure appointment follow-up e.g. to audiologist, ENT as part of EHDI tracking system.
	C4b. Agree on minimum content of referral and response letters e.g., between audiologist and PCP and use templates.	T4b(i). Convene consortium of stakeholders including families and professional organizations to create and distribute best practice guidelines; template agreements, office-based practice improvements, standardized tools (care map/ care summary etc.).
	C4c. Build service agreements, co-management plans, between primary and specialty care (ENT/ORL, audiology, genetics, ophthalmology, EI); include core competencies, referral guidelines, communication and expectations for access to one another.	T4c(i). Develop and make available to practices service agreements, co-management and practice management tools.
		T4c(ii). Work with Medicaid and private payers to establish mechanism for coverage of collaborative visits.
		T4c(iii). Provide or support care coordination to facilitate shared visits as needed.
		T4c(iv). Work with Hands and Voices, Family to Family Health Information Centers to get buy-in of family leaders and familiarize families with co-management concept.
	C4d. Families of DHH children sign universal consent form allowing sharing of information (HIPAA-FERPA) between PCP, audiology, family, EI and state EHDI program at time of referral to EI.	T4d(i). Develop shared consent form /MoU/Interagency agreements to streamline data sharing between EHDI, PCP and EI.
	C4e. Use standardized process, fax-back, phone call, etc. to communicate EI enrollment information and care plan to the PCP/MH within 2 days of IFSP.	T4e(i). Convene consortium of stakeholders including families and professional organizations to create and distribute best practice guidelines; template agreements, office-based practice improvements, standardized tools (care map/ care summary etc.)
	C4f. Parents have copies of case summary, care plans, medication lists in care notebook.	T4f(i). Develop in collaboration with families and providers standardized tools/templates like care maps/ care plans and care summary and make available to providers and parent organizations.
	C4g. Parents carry health information on flash-drives.	T4g(i). Promote access to personal electronic health information via web, flash drives, or other mechanisms as part of public health data infrastructure.

Primary Driver #1 (continued): All CSHCN receive coordinated ongoing, comprehensive care in a medical home.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S5. Registry of DHH children is used to streamline referral processes and ensure families receive all needed services.	C5a. Create and use a registry for infants with hearing loss; create a "worry list" monthly of those infants with no screening results, and all "did not pass" with no diagnostic results or not enrollment in EI.	T5a(i). Establishes and maintains statewide EHDI data collection and tracking system. Data system supports referrals to follow up services. Assures monitoring of follow up and referral to other services.
	C5b. Eliminate ambiguity; establish accountability for who is responsible for following infant; may vary by state.	T5b(i). Eliminate ambiguity; establish accountability for who is responsible for following infant; may vary by state. Roles and responsibilities delineated in best practice guidelines, administrative rules.
	C5c. Provide active "outreach" at first system failure e.g. nonattendance at audiology appointment.	T5c(i). Outreach to families and providers of infants on "worry list" as determined by statewide data collection and tracking system.

Primary Driver #2: All families of CSHCN have adequate private and/or public insurance to pay for the services they need.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Inform families of insurance options and facilitate enrolment.	C1a. Insurance liaison meets with families to determine child's coverage in prenatal period.	T1a(i). Assure (provide/support/train) network of care coordinators or other front-line personnel to carry out individualized benefits counseling.
		T1a(ii). Provide or identify point person to troubleshoot barriers to adequate coverage at the structural or systems level.
		T1a(iii). Provide training for customer service personnel at Medicaid and major private insurance companies to respond appropriately to calls from families of children with special health care needs.
	C1b. PCP office reviews insurance coverage with family at postnatal visit to PCP, and again after diagnosis of hearing loss.	T1b(i). Establish ongoing, accessible mechanism (e.g. website, online guide) to make providers, agencies and families aware of eligibility and benefits provided by public programs and private financing resources. Update this resource regularly by Title V staff. Publicize via outreach efforts.
		T1b(ii). Identify state programs that cover hearing aids, cochlear implants, and FM systems for children with hearing loss (NCHAM goal bank).
S2. Advocate for coverage of all hearing services.	C2a. Medical teams identify examples/families with insurance gaps, document and share findings with Title V to help maximize insurance benefits.	T2a(i). Synthesize the information gathered and partner with Hands and Voices, Family Voices and others to promote payment reform and hearing aid/cochlear implant coverage legislation, reimbursements for care coordination, coverage for needed health services.
		T2a(ii). Conduct regular scan of web and other sources to identify new and promising policy models nationally for funding of needed services.
		T2a(iv). Provide web links to and support either financially or through publicity, sites that provide up-to-date information on relevant policy initiatives.
	C2b. Clinicians work with Title V and insurers by reporting delays and obstacles to access. (Examples: authorizations needed for referrals, payment and scheduling appointments; delay to all specialty providers including ENT, genetics, audiology, hearing aid providers).	T2b(i). Establish mechanism where clinicians report obstacles and delays in access. Synthesize information and inform the consortium to advocate for system change.
	C2c. Providers have open contracts with all relevant insurers, and service agreements in place.	T2c(i). Utilize relationship with state Medicaid to promote supportive language in Medicaid managed care contracts (models in several states) and the consortium to advocate for open contracts.
S3. Supplement insurance cover with other financial supports.	C3a. Audiologist, PCP and EI providers link families with loaner aid banks, and other community-based resources for equipment/ services not provided through insurance.	T3a(i). Establish a state loaner hearing aid program.
		T3a(ii). Identify community resources that provide financial assistance for children with hearing loss; provide a summary of resources to practices.
		T3a(iii). Work with parents and providers to identify financial burdens e.g. hearing aids, cochlear implants relevant to raising a child who is DHH and find resources available to address those specific needs.

Primary Driver #3: All children are screened early and continuously for special needs.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Ensure all newborns are offered hearing screening within 1 mo. of birth.	C1a. Hospital staff and home birth midwives adopt protocols for offering screening at all newborns.	T1a(i). Establish EHDI protocols for screening, diagnosis and follow up in partnership with key organizations and agencies including homebirths as part of the work of the consortium. Include standardized scripts & improvement tools.
		T1a(ii). Monitor implementation of protocols & provide feedback via Score Card or other methods.
	C1b. Nurses and screeners use a standardized "script" to communicate with parents about the newborn hearing screening results.	T1b(i). Promote the use of PDSAs to develop communication of screening information and training to promote utilization of standardized scripts and other improvement tools.
	C1c. Hospitals complete rescreening before discharge from hospital for all infants who "did not pass" the initial screen.	T1c(i). Monitor screening rates and provide technical assistance on implementation of state EHDI protocols.
S2. Ensure all infants that do not pass screen receive diagnostic evaluation by age 3 months.	C2a. Audiologists create expedited appointment slots for newborns that "did not pass" the newborn screen; consider scheduling two appointments at one time in case a second one is needed, cancel if not used. Audiologists measure demand and supply for appointments to anticipate patterns and needs.	T2a/b(i). Monitor access to audiology services statewide, provide feedback, and promote the use of expedited appointment slots among audiology providers. T2a/b(ii). Improve capacity for audiologic services for children through provider training. T2a/b(iii). Create a network of mentors/experts to support increased capacity. T2a/b(iv). Establish audiology outreach sites supported by EHDI program. T2a/b(v). Utilize telehealth to assure statewide access.
	C2b. Prioritize newborn diagnostic examinations so infants are seen w/in the first month of life; reduce appointment backlog to <1 week.	
	C2c. Hospital staff ascertain two points of contact for families of infants who "did not pass" such as the phone number of a relative or friend.	T2c(i). Maintain up to date points of contact in EHDI data tracking system.
	C2d. Hospital staff schedule the follow-up appointment prior to discharge, within 3 days of the screen, stressing is importance with families.	T2d(i). Work with PCPs and audiology practices on new approaches to making appointments e.g. use of web-based appointment systems.

Primary Driver #3 (continued): All children are screened early and continuously for special needs.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S2. Ensure all infants that do not pass screen receive diagnostic evaluation by age 3 months.	C2e. Hospital staff, PCP/MH, and/ or audiology office give parents information to increase the likelihood of a successful diagnostic audiology visit, e.g., bring in infant tired to increase chance of sleeping for evaluation.	T2e(i). Create culturally competent information for families including tips on preparing for the diagnostic visit and disseminate including making available via web.
	C2f. Audiologists and PCPs standardize the approach to confirm the diagnosis of hearing loss; use template orders and referrals for diagnosis and evaluation.	T2f(i). Identify and maintain list of audiologists (and equipment) providing audiology services to infants, toddlers & children to confirm status.
	C2g. Audiologist calls family the night before the appointment to eliminate barriers and answer last minute questions e.g. parking, gas or transportation vouchers.	T2g(i). Promote/provide broad array of family supports statewide (transportation) so that providers and families are aware of resources.

Primary Driver #3 (continued): All children are screened early and continuously for special needs.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S3. Ensure all infants with hearing loss are enrolled in EI by age 6 months.	C3a. Audiologists/PCP refer family to EI within 48 hours of diagnosis of hearing loss- don't wait to determine degree of loss.	T3c(i). Standardize parameters needed for referral to EI e.g. any degree of hearing loss, do not need to establish severity.
	C3b. Standardize script to provide unbiased information for amplification/communication options.	T3cii. Establish the State EHDI protocol related to Part C (NCHAM Goal Bank).
S4. Ensure all infants with risk factors for hearing loss receive audiologic follow-up even if initial screen is passed.	C4a. Hospital screener obtains and documents information on risk factors for hearing loss and communicates to PCP/State EHDI program.	T4a(i). Create a template risk factor recording document and disseminate to hospitals, PCPs, audiologists.
	C4b. PCP reviews risks and makes necessary audiology follow-up appointments.	T4b(i). Track infants with risks to ensure audiologic follow-up occurs.
S5. Ensure all infants with hearing loss receive etiology investigations.	C5a. Standardize etiology categories; the choice of "unspecified" is the last option. Consider use of "under investigation," "to be determined," "unable to determine."	T5a(i). Create and disseminate a protocol for etiology determination for children with hearing loss.
		T5a(ii). Monitor results of etiology investigations and report regularly results at population level.
S6. Ensure all infants w/ hearing loss are screened for other neurodevelopmental conditions	C6a. PCPs and EI providers screen DHH children with standardized instruments for other ND conditions, e.g. ASQ, MCHAT for autism, PSC for mental health, etc.	T6a(i). Educate providers on screening for ND conditions and provide standardized tools.
	C6b. Refer all children with hearing loss for ophthalmology evaluation.	T6b(i). Create and disseminate a resource list of pediatric ophthalmologists.

Primary Driver #4: Services for CSHCN are organized in ways families can easily use.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. Families have information on all needed hearing services.	C1a. Create a list of resources for families of infants with hearing loss organized by region; include services and tools families can use such as care plans, roadmap, parent to parent supports and distribute to families.	T1a(i). Routinely update the Title V supported interactive resource database and toll-free hotline with EHDI specific information.
	C1b. Ensure parent organizations have access to all EHDI resources.	T1b(i). Publicize web sites and other sources of EHDI resources to parent organizations.
S3. All agencies and staff serving families are fully informed of and integrated with EHDI program.	C3a. Identify and engage community partners that can support follow-up of infants at-risk e.g. visiting nurses (VNA), social workers.	T3a(i). Integrate follow up with other MCH programs:Home visiting, WIC, Head Start etc. For example, at the time of enrollment in Early Head Start hearing screening results are reviewed, home visitors assess hearing screening follow up status.
	C3b. Provide regular reports on EHDI at hospital/ agency level to senior leadership e.g at hospital QI meetings and have them address or remove barriers to improvement.	T3b(i). Support electronic tracking system that informs relevant clinicians of system failures e.g. non arrival at appointment, non-enrolment with EI.

Primary Driver #5: Families of CSHCN partner in decision-making at all levels and are satisfied with services they receive, in active, well-informed patients and families.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. EHDI Programs provide culturally competent services.	C1a. Create educational documents for parents with appropriate reading levels and languages on screening, diagnosis and intervention and distribute to families via pamphlets, internet.	T1a(i). Convene parents and other partners to create educational materials – materials are reviewed for health literacy and cultural competence and translated to a variety of languages; distributed and updated by State.
	C1b. Utilize the RoadMap with families to outline expected care and referrals during the first year. Customize roadmap with state or local resources.	T1b(i). Create Road Map with families and makes available statewide in multiple languages (print and on-line).
		T1b(ii). Distribute care plan to partner agencies/organizations print and on-line.
	C1c. Offer and provide referral to Guide By Your Side, or other family support services, at time of confirmation of hearing loss.	T1c(i). Support referral to Guide By Your Side Program or other family support services at time of referral and diagnosis.
	C1d. Document parents' language preference.	T1d(i). Make available language preference on EHDI data/coordination system.
	C1e. Engage family in developing a written, collaborative and culturally appropriate plan of care.	T1e(i). Distribute care plan to partner agencies/organizations print and on-line –See C1cii.
S2. EHDI programs solicit parents feedback on services.	C2a. Measure parent experience of care with the newborn hearing screening process: quantitative (survey) and qualitative (focus groups). Use CAHMI Family-centered care measure.	T2a(i). Measure parent experience of care statewide and report findings.
		T2a(ii). Convene annual Parent Summit.
		T2a(iii). Support family newsletter/list serve.
S3. Parents are represented throughout EHDI program at state, county, practice levels.	C3a. Parent partners are invited to serve on EHDI Advisory boards at national, state, county, and practice levels.	T3a(i). Create state advisory structure that supports substantial and diverse representation of parents/youths.
		T3a(ii). Support statewide parent/youth involvement at the local and practice level (through training, technical assistance, financial).

Primary Driver #6: All youth with special healthcare needs receive the services necessary for transition to adult health care, work and independence.

Secondary Drivers	Clinical Change Ideas	Title V Change Ideas
S1. All DHH youth have a valid transition plan.	C1a. Create a resource list of providers including PCPs, audiologists, ENTS etc who are able to serve the young adult DHH community. Make this available to parents and providers via web.	T1a(i). Create a resource list of providers including PCPs, audiologists, ENTS etc who are able to serve the young adult DHH community. Make this available to parents and providers via web.
	C1b. Create and use a template for a transition plan for DHH adolescents to adult services.	T1b(i). Convene families and providers to create transition plan for DHH.
	C1c. Implement use of transition plan, with parents and providers contributing to plan.	T1c(i). Engage payers in discussion of financing issues related to transition (e.g. possibility of engagement with two primary care providers during transition period).
		T1c(ii). Promote implementation of transition plan through activities like Learning Collaborative and integration with other CYSHCN Transition program activities, e.g HRTW.

Collaborative Partners

Participating States
Epilepsy:
Florida, New Hampshire, Maine, Washington, New York,
California, Colorado, Nevada

Newborn Hearing:
Utah, Colorado, New York, Nevada, Massachusetts, Minnesota,
Washington, Hawaii, Illinois, Indiana, Iowa, Maine, North
Carolina, Virginia

Jumpstart:
Colorado, Connecticut, Illinois, Indiana, Kansas, Maryland,
Michigan, Mississippi, Missouri, Nebraska, Nevada, North Dakota,
Pennsylvania, Virginia, District Of Columbia, West Virginia,
Vermont