

**EVALUATION OF THE
MEDICAL HOME LEARNING COLLABORATIVE
FOR CHILDREN AND YOUTH WITH SPECIAL
HEALTH CARE NEEDS**

FINAL REPORT

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Submitted To:

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EXECUTIVE SUMMARY

In April 2005 through August 2005, John Snow, Inc. (JSI) conducted an evaluation of the Medical Home Learning Collaborative that was implemented by the Maternal and Child Health Bureau's Division of Services for Children with Special Health Care Needs. Learning Collaborative participants included state teams consisting of Title V office representatives, clinical practice teams (up to three per state), and parent partners. The evaluation's goal was to assess and report on participants' experiences in the Learning Collaborative, including the following: motivation for participation; barriers and facilitators to participation; key skills, knowledge, and perspectives gained; changes resulting from involvement in the collaborative; suggestions for improvement; and sustainability of medical home activities/model.

Practices participating in the collaborative were pediatric practices with rare exception. They included independent, network and academic medical center affiliated, and hospital-based practices in urban, suburban, and rural settings. Prior to attending the collaborative, most state and practice representatives were familiar with the concept of a medical home but had less understanding of how to operationalize this concept, although a few states and practices did indicate substantial previous medical home understanding and experience. Parent representatives had no previous knowledge of the medical home concept. Parents and practice staff had little knowledge of the Learning Collaborative approach before attending their first session. Time and cost were barriers to participation for both practices and parents.

Most of the state and practice staff interviewed indicated that care coordination reimbursement was a major concern about implementing and sustaining a medical home approach to care. States reported undertaking incremental steps to address this issue. Discussions with practice and state staff revealed various models of implementing care coordination other than a solely practice-based model. These variations on care coordination were thought to be more sustainable, though reimbursement remained a key concern. Practice staff and parents identified several specific practice changes that had occurred at the clinic level including: identification and flagging of charts of children and youth with special health care needs (CYSHCN); pre-appointment phone calls and meetings; care plan development; resource guides/referral network development; care coordination activities; and parent involvement activities.

With only a few exceptions, practices are continuing with their efforts to improve their medical home, and states are continuing to support efforts underway and to spread the concept. Many practice staff and state staff reported incorporating the continuous quality improvement processes learned at the collaborative with their medical home and other activities. Practice staff, state staff, and parents reported developing an appreciation of each others' roles, responsibilities, and challenges and reported ongoing, productive relationships. Most participants had specific suggestions for improvements that could be made to future Learning Collaborations that are listed in the report. Overall, the Learning Collaborative appeared to have been a very successful and well-received undertaking. There was nearly unanimous agreement that participants would engage in such a process again and that they would recommend it to others.

Based on JSI's interpretation of what we heard through our discussions with participants, suggestions for consideration are made for future collaboratives as follows: strategies for pre-collaborative preparation of participants; determination of whether a different strategy or further explanation is required about the care coordinator role; better "marketing" of the medical home term to parents; strategies for sustained parent involvement; strategies for addressing practice variations, consideration of including a session on working with Medicaid, and further consideration of the role of family practice sites.

I. BACKGROUND

John Snow, Inc. (JSI) is funded through the Maternal and Child Health Bureau (MCHB), Division of Services for Children with Special Health Care Needs (DSCSHN), to provide targeted intervention to states to assist them to achieve the national agenda for children and youth with special health care needs (CYSHCN) outlined in the President's New Freedom Initiative for Americans with Disabilities and to achieve Healthy People 2010 Objective 16.23. As part of this contract, JSI was asked by the DSCSHN in April 2005 to conduct an evaluation of the first Medical Home Learning Collaborative (LC) implemented in 2003. The goal of the evaluation was to assess and report on participants' experiences in the LC, including how the LC format influenced the way in which participants think about and act on quality improvement overall and how this was operationalized through the medical home concept.

Implementation of the medical home concept is one of MCHB's six core outcomes for children and youth with special health care needs to be achieved by 2010. MCHB partnered with the National Initiative for Children's Healthcare Quality (NICHQ) and the Center for Medical Home Improvement (CMHI) to develop a plan for instituting a Learning Collaborative as a way to develop clinical medical home capacity and promote the spread of the medical home concept.

The Institute for Healthcare Improvement (IHI) was created as a nonprofit organization in 1991 dedicated to quality improvement in healthcare. The *Breakthrough Series Collaborative Model* was developed by IHI as a means of operationalizing a continuous quality improvement approach at the clinic level (Kilo, 1998¹). The LC was a convergence of IHI's Breakthrough Series Approach and the medical home concept, as framed by Wagner's Chronic Care Model and Wasson's planned care model.

Eleven state Title V offices participated in the LC using their block grant monies. States were asked to select up to three clinical practices to participate in the LC, with each clinic practice identifying a lead physician, one care coordinator (CC) (or someone who might serve in this role), and a parent partner. Thirty-three practices total participated as follows: eight Title V offices had three practice partners, three Title V offices had two practice partners, and one Title V office had one practice. Three clinical practices from two different states participated in the LC without Title V involvement. Twenty-three Title V participants from 10 different states participated in an interview with JSI. A complete listing of the Title V offices and practices is provided in Appendix A.

The LC consisted of three face-to-face, two-day national meetings (*Learning Sessions*) as follows: April 2003 in Florida; June 2003 in Ohio; and November 2003 in Arizona. Between Learning Sessions were *Action Periods*, where participants worked toward the goals they had established for themselves for the LC. Participants were supported throughout the process by the LC faculty and a website offering information and resources as well as enabling data collection, communication, and sharing. For further information on the LC background and content of the Learning Sessions, readers are referred to the workbooks developed by NICHQ in partnership with CMHI. One workbook was developed as preparation for the LC, and separate workbooks were developed for each of the Learning Sessions.

¹ Kilo, CM. 1998. *Quality Management in Health Care*. 6(4), 1-13.

II. METHODS

JSI worked collaboratively with the DSCSHN/MCHB Medical Home Project Officer, Dr. Monique Fountain, to develop the scope of work and the evaluation questions. Continuous quality improvement as operationalized through the concept of the “Breakthrough Series” Learning Collaborative Model and Wagner’s Chronic Care Model as adapted for Medical Homes (NICHQ final report) served as the framework for developing the overall evaluation questions.

The final set of evaluation questions approved by Dr. Fountain was as follows:

- What was the motivation for engaging in the Medical Home for Children and Youth with Special Health Care Needs LC? What did practices and states hope to accomplish?
- What were the key contributions of the LC to practice organizations and states – key skills gained, key knowledge gained, key perspectives gained – with regard to quality improvement overall, serving CYSHCN generally, and medical home implementation specifically? What about the LC format were critical to these contributions?
- How did clinical practices and state Title V change as a result of involvement in the LC? What about the LC format were critical to these contributions?
- What are the shortcomings of the LC framework for operationalizing continuous quality improvement generally and medical homes specifically?
- What has endured a year after completing the process of the LC (e.g., changes in service delivery, approach to quality improvement)?

Separate discussion guides were developed for each of the key participants in the LC: practice sites, parents, and Title V staff. The guides flesh out the broad questions listed above. The questions were open-ended to allow individual thoughts and opinions to be recorded, but include specific prompts to ensure that all parts of the question were addressed. The guides were derived based on the evaluation framework. Discussions were conducted with some key faculty of the LC to further inform the development of the discussion guides. Dr. Fountain’s input and approval on all three guides was received before contacting participants. As per the iterative nature of qualitative research, the guides were revised as discussions progressed to capture reactions and feedback on new insights. The final set of discussion guides is included in Appendix B.

Dr. Fountain distributed, via email, an introductory letter explaining the purpose of the evaluation and introducing JSI as the contact point for the evaluation (Appendix C). Recipients of the letter were assured of the voluntary nature of participation. Initially, JSI had planned to contact staff in each of the 11 Title V offices involved, one clinic from each state, and the parent representative connected with the selected clinic. Clinics and parents not selected for interviews were going to be asked to join a focus group conducted via conference call. As JSI progressed through the scheduling process, it became clear that this approach would not work. Some clinic staff proved difficult to reach due to outdated contact information, the individual no longer being at the clinic, or did not respond to several contact attempts. Reaching parent representatives

proved even more difficult than clinic staff. Many parents had outdated contact information and many were no longer involved as closely in the clinical practices. Thus, the initial plan was inappropriate given the difficulty of contacting clinic sites and parent representatives. The alternative plan was for JSI to drop the idea of focus groups and instead contact as many practices and parent representatives as it could. A minimum of three attempts (combination of e-mail and telephone calls) were made to arrange a time for the phone call. Of those with valid contact information, 25 practice staff and seven parent partners, representing 17 practices completed interviews (see Appendix D for map of practice locations). Representatives in 10 Title V state offices also completed interviews.

Four JSI staff members comprised the evaluation team. The majority of discussions were conducted by two persons: one serving as a primary interviewer and one as the primary note taker. There were exceptions in that a few interviews were conducted by one person only in order to accommodate either interviewee or project team availability. The evaluation team debriefed on a weekly basis during the interview process. The purpose of the debrief was to identify patterns and themes emerging in responses, new ideas that arose, and unique circumstances that may qualify some responses. The debrief served as the qualitative analysis phase, where findings were put forth, discussed by the project team, and then tested in future interviews. Especially in the early stages of the interview process, special attention was paid during the debrief process to revising the discussion guides to enhance future interviews. Key findings reported below evolved through this iterative analysis process. A compilation of edited notes was developed for each group of participants (Title V staff, practices, and parents). Names have been deleted from these notes to protect the confidentiality of the respondent. These documents are included in the Appendix E.

Both qualitative and quantitative analyses are subject to interpretation based on the background and experiences of the analysts. JSI attempted to reduce these biases through checking and discussion of assumptions and conclusions made. With that said, the discussion section reflects the project team's understanding of the LC as related by those interviewed and as interpreted through the context of our professional backgrounds, training, and experiences. It should be noted that none of the project team actually attended a Learning Session; thus, all information is from secondary sources. Conclusions were drawn and suggestions made in the spirit of translating research into practice. JSI hopes that they will be useful to DSCSHN policy makers, LC faculty, and others concerned with improving service delivery and care for CYSHCN, all of whom have their own professional context for assessing their value and use.

III. FINDINGS

A. PRE-COLLABORATIVE

Selection of Teams

State Title V programs had several key motivations for participating in the Medical Home Learning Collaborative, including wanting to respond to Healthy People 2010 performance measures, increasing the number of CYSHCN being seen and supporting them, finding out what

other states were doing to get ideas for implementing the medical home, enhancing already established relationships with practices, and spreading the medical home concept throughout their states. States came to the Medical Home LC with a varied range of experience with the medical home concept. Some had medical homes as a focus of their efforts for a number of years. Other states had been the recent recipient of grants to promote medical homes and were hoping that the LC would kick start their grant activities. Still other states had very little knowledge and experience and wanted to better understand the concept and explore strategies for moving forward in this area.

Title V Offices were required to identify up to three clinical practices to participate in the LC. Selection of sites was based on interest and perceived commitment. Most states sought to have a diversity of practices involved in terms of urban/suburban/rural location, office-based/hospital-based/academic practices, and patient diversity in terms of publicly/privately insured, and race and ethnicity. The actual recruitment, however, depended much more on interest and willingness to support the time and effort required for the process. Some Title V interviewees noted that costs and time away from the clinic were larger barriers for small practices than larger hospital and/or academic affiliated practices. However, the administrative systems and approval processes in the larger practices were much harder to navigate than those in the smaller practices. A variety of strategies were used to recruit practices, including working through the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP) and other networks to identify interested practices, cold calling practices to sell them on the idea, and drawing on existing relationships between Title V and practices. Two of the larger states had a regional MCHB structure in place and drew on contacts in these regional offices to assist in the identification of clinics to participate.

The majority of states considered pediatric practices as the critical audience for spreading the medical home concept rather than family medicine practices. Most of the states had a close association with their state chapter of the AAP, which is a strong advocate of the medical home concept. It was through this partnership with AAP that, the states, in some cases, recruited sites to participate. While four states seemingly reached out to pediatric practices only, the other states tried to get family medicine practices involved but had difficulties, which interviewed state staff attributed to lower prioritization of medical home effort at family medicine practices, given the broader patient population served. Of note, two states said it was easier to get buy-in from family medicine practices. They noted that family medicine physicians are very familiar with the medical home concept and believe that “medical home is a renaming and repackaging of their training.” Interviewees thought there was an opportunity for pediatric practices to learn from family medicine practice colleagues.

Although the question was not asked directly, most states indicated that they supported the travel and expenses of practice staff to attend the national meetings. One state noted that practices still bore considerable opportunity costs while they were away from their offices, which the state was unable to support. During this interview, Title V staff mentioned that those costs would have been in the range of \$35,000 - \$40,000.

Practice characteristics of clinics interviewed (note that we do not have information on clinics that participated in the LC but were not interviewed) are shown below in Table 1.

Table 1
Characteristics of Practice Sites Interviewed

State	Practice Type ¹					FP/Ped ²	Urban/Rural	# of Providers (FTEs) ³	# / % of CSHCN ⁴
	PIP	PGP	HMO	HBP	AMC				
OH	XX					Ped	Rural	8.5	3%
NY		XX	XX			Ped	Rural	5	NA
OH	XX					FP	Rural	~ 3	< 100
MI		XX	XX	XX		Ped	Urban	NA	NA
FL				XX	XX	Ped	Urban	3	95
VA		XX				Ped	Urban	16	NA
NC	XX					Ped	Suburban	11	15%
FL	XX					Ped	Urban	1	377
OH	XX					Ped	Rural	7	3%
LA		XX	XX		XX	Ped	Urban	7	300
UT				XX	XX	Ped	Urban	11	15-20%
CO		XX		XX		Ped	Urban	13	3-5%
CO	XX					Ped	Urban	8	NA
WI		XX				Ped	Rural	5.5	10%
CT		XX				Ped	Suburban	7	<10%
PA				XX	XX	Ped	Urban	8	~ 25%
12	6	7	3	5	4			7.4	

¹ Practice Type Abbreviations
 PIP = Private Independent Practice
 PGP = Private Group Practice
 HMO = Clinic that is part of HMO Network
 HBP = Hospital-based clinic
 AMC = Clinic that is part of Academic Medical Center

² FP = Family Practice Clinic
 Ped = Pediatric Clinic

³ # of Full-Time Equivalents (MDs, APRNs) of clinical providers reported by practice site contact

⁴ Estimate of the number or proportion of CSHCN reported by practice (does not include ADD or asthma)

Practices, in turn, needed to identify a physician leader, a CC (or staff member who could potentially act in that role), and a parent partner. Those parents interviewed felt honored to be asked to participate in the LC. One had an advanced social work degree and liked to volunteer and felt she had the time because her child was at a point where he was “medically manageable.” Another parent interviewed had a background in advocacy for children. Most parents had been approached by their practice contacts and asked if they would be willing to participate. One parent interviewed was actually a state employee whose position it was to represent a parent point of view in Title V office activities and to work on the state level with parents.

Title V office representatives and practices certainly knew of the medical home concept prior to engaging in the LC, though many interviewees felt that they did not quite understand what it meant operationally at the clinic level. Very few had any knowledge of the LC concept and process outside of information received during the recruitment of states and practices. Although

the parent representative working at the state level felt she had an informed understanding of the LC process and the medical home concept, the other parents interviewed stated that they had no previous understanding of either before participating.

Practices and parents were asked how they would describe the LC process to someone who had not heard of it previously. A sampling of responses to this question is provided in Table 2.

Table 2
How Would You Describe the Medical Home Learning Collaborative Process to Someone Who Has Never Heard of it?

- An intense quality improvement process
- A process to identify new approaches and develop systems to overcome obstacles
- A project that gives you “permission” to take the time to analyze needs and explore how to improve what you are doing
- A curriculum for sustaining change in a practice setting
- A process that greases the wheels and encourages sites to improve what they are doing
- An effort to create a system that’s more efficient for the office and for the patients and their families by identifying needs and coordinating services
- Process and project that attempts to educate practices on how to improve their systems and the quality of care that they provide CYSHCN
- Process that teaches sites how to improve care through team work
- A way to envision how to deliver care within your practice more effectively
- A process that helped sites to refine what they did so that children and parents could feel at home and make the process as easy as possible
- An opportunity to learn about and develop an approach toward creating medical homes
- An intense introduction to the medical home concept
- A project that helps to figure out how to create a medical home supportive of patients
- A process that gets people to think about how MDs, nurses, and parent can work together to improve efficiency, quality, and care coordination
- Opportunity to share information with other sites about how to better serve CYSHCN
- Opportunity for families and medical community to bring their ideas together to develop family-centered systems of care
- How families and doctors can partner in the community to coordinate and develop comprehensive, consistent, quality service

Title V staff, practices, and parents were asked to recollect the goals their teams had put forth to achieve during the LC. A sample of responses to this question is provided in Table 3.

Table 3
Goals Established by Teams to Accomplish During
the Medical Home Learning Collaborative

As Reported by State Staff:

- Promote “correct spread” of concept; e.g., notion of coordinated, culturally competent, and family-centered care
- To involve families and more practices within the state
- Increase our expertise in knowing how to implement a medical home within a practice setting and information about how to develop a statewide initiative
- Exploratory – we wanted to learn what it was all about and how and what potential there was for improving services to CYSHCN
- Create a laboratory for exploring better office practices and creating models – models for other sites as to what is possible and how to go about it

As Reported by Practice Staff:

- Learn about the medical home
- Develop systems to identify CYSHCN so as to avoid scheduling errors (e.g., inappropriate staff)
- Refine care planning and care coordination
- Formalize clinic systems to reduce burden on the clinic and improve the quality of care
- To explore ways to increase patient/family satisfaction
- Get more parents involved
- Develop systems to facilitate better communication with our parents and specialty providers
- Wanted to create a blueprint for what to expect in our practice for CYSHCN
- To develop better relationship with Title V

As Reported by Parent Representatives:

- Get practices, parents, and Title V to understand what a Learning Collaborative is
- Figure out how a medical home can be implemented in everyday settings
- Expand the team that cares for CYSHCN
- Identify children with special health care needs
- Get the parents involved
- Provide resources for parents
- “Parent-to-parent” matching
- Learn how to collect data from other states
- Prove to insurance companies that we could save them money through this process and get them to pay for consultations

B. LESSONS LEARNED/ACTIVITIES UNDERTAKEN

This section is divided into the three response groups: states, practices, and parents.

States

Care Coordination Reimbursement

One issue that became apparent during the early phases of the interviews was the lack of funding for care coordinators that many saw as a barrier to sustainability of the medical home. JSI asked questions to the state Title V interviewees about funding available through their state for CYSHCN generally and the care coordination role specifically. In one state, if a practice is certified as a state-qualified CYSHCN provider, there is some minimal (\$3.00) care management fee provided through their Medicaid managed care option. In two other states, practices can receive some level of reimbursement through specific state programs (as opposed to general Medicaid), but this did not apply to all CYSHCN. For example, in one state, providers serving CYSHCN with high utilization could potentially receive some dollars for care management. Yet another state is involved in a partnership with Medicaid to implement a pilot program that will reimburse for specific Medicaid care management codes. This same project is working with a physician to develop an online curriculum for credentialing providers in the medical home concept. Credentialed providers will be allowed to collect the care management reimbursement.

Generally, though, the consensus was that cost and reimbursement continue to be a big barrier to implementation of the medical home concept. Most states were clearly working on the issue, most in collaboration with their state Medicaid programs. Relationships between Title V and Medicaid varied across the states. Some states had fairly strong relationships, others weaker to no relationship. This could be due to the organization of the state government. In some instances Medicaid is housed within the health departments, along with MCHB programs; in other states, Medicaid is in a separate department. Medicaid is seen as the “big fish” of state programs with much time and effort needed to change it in small ways. Various Medicaid Offices potentially have a different set of priorities that may not currently include the care management issue for CYSHCN. While some states were currently issuing or considering issuing grant monies to fund some care coordination positions, one state did not want to start the precedent of providing grants and having the issue removed from the larger reimbursement issue.

Approaches to Support and Spread

Two roles for the state put forth through the Medical Home Learning Collaborative are “support” and “spread.” Title V staff interviewed see themselves as a resource for information and as working to promote the spread of the medical home concept. Some Title V Offices have developed medical home websites and modules to support parents and practices and many states publish a medical home newsletter. Presentations and materials have been developed that are made available to various audiences. One state, a clear exception, said that they currently are doing very little with the medical home concept because their current priority was participating in the development of a Medicaid managed care initiative.

There was nearly unanimous agreement (among Title V and practice interviewees) that the LC enhanced relationships between the practices involved in the LC and the state Title V office and resulted in a much deeper understanding of the day-to-day realities of each others’ working lives. Several states continue to have regular meetings and/or conference calls with their practice sites.

Relationships with the clinics have endured and have been enhanced. Title V continues to serve as a resource to these sites regarding all components of a medical home, including care coordination and reimbursement issues. In turn, in several instances the roles and responsibilities of the practice members have grown to include serving as spokespeople/“champions” within their communities and/or at the state level for the medical home concept. This generally involves giving presentations to a variety of stakeholder audiences, including other providers, other state staff, and parents of CYSHCN. The notion of “peer to peer” or a physician talking to another physician was often noted as important for spreading the word about medical homes; such speakers may have more credibility and influence than state staff may have on their own. In a couple of instances, practice staff involved in the LC have been providing technical assistance to other practices. In those states developing and holding their own LCs or “LC-like” initiatives, practice staff involved in the national collaborative serve as “faculty” and presenters.

It was hard to determine whether state activities with regard to support and spread were as a result of states’ participation in the LC or whether they were an extension of activities started previous to the initiative. As noted earlier, several states already had substantial efforts underway with regard to the medical home concept. The distinction does not seem important, however. Clearly, ideas and strategies that were already in progress were strengthened or refined through participating in the LC, and new ideas and strategies were generated. Some state staff interviewed referred to the “CMHI model,” described as state staff traveling around to practices to provide direct, hands-on technical assistance. One Title V office indicated that this approach was nearly impossible for them to implement given the large size and diversity of the state. They instead are working on establishing regional centers that will provide such assistance, but currently do not have the funding to do so. However, they noted that two of their three practices involved in the national LC are serving as the medical home voice for other practices in their geographic area.

States took away from the table several ideas for enhancing the support and spread of the medical home concept in their state. Additionally, it seemed that many state staff took away the process of the LC itself as a tool for support and spread. Six of the states interviewed mentioned that they were thinking about or had already undertaken a learning collaborative approach in their own states. Two were replicating the LC at the state level. Another was going to do a LC replication at the community level. Two other states talked about an adaptation of the model, identified as “LC-like” and “peer-to-peer training.” In most cases the idea was still in the formulation stage. States thinking about such an approach were concerned about ways to reduce the cost of such an initiative, both from the planning and faculty perspective, as well as from the practice perspective (e.g., travel and time away from practices). The Plan-Do-Study-Act (PDSA) process, the notion of small changes, and peer-to-peer learning were frequently identified as specifics of the LC process that state staff will use for their own learning collaboratives or in their processes of providing support to sites.

Additionally, several state staff implied that they had gained specific knowledge around implementation and were better able to articulate the value of the medical home and its potential longer-term cost offset. They gave concrete examples of how to operationalize specific aspects of the medical home concept, including parent involvement techniques, care coordination, practice redesign in terms of patient flow, and development of care plans. Some states noted they

had instituted changes in language, such as using “medical home” instead of “primary care provider” and renaming a government CYSHCN unit “Medical Home.” While seemingly minor changes, those interviewed felt they were important symbolically and would help with the spread of the concept.

Several states implied that the LC was promoting one type of care coordination (e.g., practice-based CC). Those interviewed in these states expressed concern that one model of care coordination (e.g., one CC at each practice site) does not fit all states and/or practices, and they wished there had been a more flexible approach at the LC in this regard. Given the cost of such a model and the lack of reimbursement for care management services, they would have liked to have discussed other approaches to this critical piece of the medical home concept. For example, some of the larger states think that regional CCs, who serve several different practices, might be a sufficient and cost-effective approach. Another idea is for two or three practices in the same area to share the expense of a CC, perhaps rotating days in different offices. States want to experiment with different models.

Practices

Specific activities undertaken

Practice sites participated in the LC to enhance their medical home model and address operational and service delivery challenges at their practices with the overall goal of improving access to high-quality, responsive, and efficient care for their CYSHCN. The sites participated in a range of activities in order to meet this goal, and these activities fell into three major categories: care coordination, parent involvement/parent education, and continuous quality improvement.

One clear idea that came out of the discussions was that the sites needed to develop a medical home implementation plan that suited their interest and the circumstances at their sites. Ideas and methods could not be imposed on sites, rather sites needed to be able to adapt concepts, ideas, and strategies that are part of the medical home concept as they saw fit to their practices. This idea is evident in the broad range and mix of activities that JSI observed across the sites. The following is a summary of the activities that were conducted across the sites in this area.

Care Coordination and Care Planning

Practice sites explored how they could better plan for and coordinate the care that they provided their CYSHCN. They reviewed their scheduling processes, pre-appointment activities, intake procedures, workflow, staffing assignments, screening/identification procedures, and patient charting. They also developed resource guides, parent education materials, and refined their referral networks. Following are details on the specific activities that the sites JSI interviewed conducted related to care coordination:

- **Care Coordinator Role.** Most of the sites hired new staff members or appointed an existing staff member to be the CC. These staff members also typically helped to manage other activities that were part of the LC. The responsibilities of the CC varied greatly

across the sites, but, generally, the CC was responsible for working as a liaison between the site's clinical providers and the patient/family to help ensure that all of the necessary and appropriate care was provided in the most timely and efficient way. The CCs did pre-appointment planning, filled out prescriptions, made specialty care referrals, helped patients and families link with human service and educational resources, and provided other care management activities. The CC position in many cases was a full-time role, though especially in smaller practices, the CC had other nursing and/or administrative roles. A listing of functions of the CC identified through the interviews is in Table 4 below.

- **Screening and Identification Systems.** A number of sites instituted scheduling and intake procedures that allowed them to identify CYSHCN during scheduling and/or prior to their visit to the clinic. Flagging or identifying a child in this way allowed them to better plan and prepare for his/her appointment. Providers and clinical support staff could make preparations in advance (reviewing the chart, preparing tests, preparing prescription refills, collecting information, etc.) that would allow them to spend the time required to provide the highest quality care possible without causing scheduling problems. Flagging the child's chart or the child's appointment in the scheduling system also helped to ensure that the appointments immediately following a CYSHCN were not too closely scheduled. Those identified as requiring more time were flagged using methods such as chart sticker systems, MIS coding systems, blinking lights on computer scheduling screens, and/or color coding on paper schedules.
- **Pre-Appointment Contacts.** A number of sites initiated procedures that allowed nurses or CCs to 1) meet patients immediately prior to their clinic visits appointment as soon as they arrived in the waiting room or 2) have a telephone conversation within a few days prior to an appointment. Once again, this process allowed sites to learn in advance what a patient's issues or problems were likely to be during the visit and to prepare to address these issues, thus saving time and potentially improving the quality of the patient interaction. Some sites created appointment problem/goal lists that helped to identify the issues that were likely to come up at the appointment. Some sites obtained a list of the prescriptions that needed to be refilled or collected lists of likely referrals.
- **Care Plans, Problem Lists, and Other Forms.** A number of sites developed care planning tools as well as other forms that helped them to track important patient-related information. For example, some sites formalized a problem list and/or medication list that was placed on the first page of the patient's chart. Another site developed more comprehensive care plans that identified major problems, goals, objectives and set out specific plans regarding primary care, specialty care, occupational and physical therapy, drug therapy, and other services. Still other sites adopted the American Medical Association (AMA) emergency medical form or other types of emergency cards that helped the sites and the families to coordinate acute episodes or emergency services.
- **Referral Systems and Resource Guides.** A number of sites developed resource guides that enabled linking patients, families, and providers with the services they needed and helped to streamline the referral process. These guides were typically very

comprehensive and listed educational and human service resources as well as primary care and specialty care services. Some sites also took steps to develop more collaborative relationships with certain providers or provider organizations that were called on frequently. This helped to promote better service integration and improved communication.

- **Educational Resources and Seminars.** A number of sites held lectures, brown bag lunch meetings, and seminar series to educate parents and providers regarding aspects of care for CYSHCN. Some of these forums were condition specific (asthma, autism, cerebral palsy, etc.); others were more oriented towards treatments, services, or resources in the community. Practice sites also developed brochures, parent manuals, resource guides, and newsletters to help parents/providers to stay informed, share ideas, track resources, highlight opportunities, and enhance communication. Finally, one of the sites developed a resource room that was designed as a place that parents and providers could go to find information, search the web, and educate themselves.

Table 4
Functions of the Care Coordinator

- Identify and track CYSHCN
- Conduct pre-visit meetings/phone calls
- Gather and share information between patients, family members, and providers
- Create care plans
- Link patients and caregivers to community resources
- Ensure that patients and caregivers received all of the appropriate public/private benefits (insurance, respite care, SSI benefits, home health care services, personal care attendant hours, etc.)
- Conduct assessments and complete complexity ratings
- Manage patient charts and tracking forms
- Develop patient-/caregiver-/family-oriented educational materials
- Coordinate referrals
- Conduct patient advocacy and case management services
- Assist families to fill out prescriptions
- Assist with pharmacy related matters

Parent Involvement

Most of the sites that participated in the LC made great efforts to involve parents in their activities. The aim was to get input directly from patients and families, so that practices could develop more responsive operations, systems, and procedures. In addition, many sites organized efforts to educate and inform parents of CYSHCN regarding their child's condition or the therapies and treatments that were a part of his/her care. In both cases the goal was to develop a stronger provider-patient-family partnership that would lead to better communication, more informed care decisions, and more responsive, more coordinated, higher quality care. The following is a summary description of the specific types of interventions or activities that were conducted across the sites in this area.

- **Parent Advisory Groups.** Many sites developed Parent Advisory Groups that met periodically to discuss operations, policies, procedures, information systems, and services to explore ways that clinics could improve care for patients. The aim was to improve the quality of care, better coordinate care, and reduce wait/appointment times.
- **Operational Assessment.** Many sites implemented more short-term and focused activities to collect feedback and ideas from parents. Some sites held a series of focus groups, others held periodic parent meetings, and/or other sites conducted clinic "walk-throughs." All of these activities allowed sites to better understand the problems and challenges that some of their most complex patients encountered when seeking care so that they could develop new systems, refine their operations, and provide higher quality, more responsive services.
- **Parent Support Groups.** A number of the sites developed formal and informal parent support groups that provide an opportunity for parents to share ideas, talk about their experiences, and provide support to each other. A number of these groups evolved from the Parent Advisory Groups, whereas others were distinct activities.

It should be noted that nearly all of the sites struggled to find ways to involve and integrate parents and their ideas into the activities of the LC. Most sites were able to get parents to attend the LC national meetings, but it was more difficult to engage them in a long-term, consistent way at the practice sites. The parents who had the most to provide and the most to gain from being involved were also the parents who were least able to give their time and energy. Parents of CYSHCN live busy, often burdened lives, and it is difficult for them to participate consistently in these types of activities.

Table 5
Characteristics of Activities Undertaken by the Sites Interviewed

Site Code	State	Care Coordinator ¹	Screening/ Identification	Pre-appointment Contacts	Care Plans/ Problem Lists	Referral Systems	Educational Resources/ Seminars
a	OH	1		X	X		
b	NY	No	X				X
c	OH	1				X	X
d	MI	1	X		X	X	X
e	FL	1			X	X	
f	VA	2	X		X	X	X
g	NC	1	X	X		x	
h	FL	2	X		X		
i	OH	1	X				X
j	LA	1			X		
k	UT	1	X	X		X	
l	CO	2	X		X		
m	CO	No			X	X	
n	WI	No	X		X		X
o	CT	1			X	X	X
p	PA	1		X	X		X

¹ Most of the sites hired a new staff member to take on the care coordinator position but a number of sites assigned care coordinator responsibilities to one or more existing staff members. Sites with a new care coordinator are designated with a "1" and sites that assigned roles to existing staff are designated with a "2". Sites that did not have a care coordinator position are designated with a "no".

Code	State	Parent Involvement Activities		
		Advisory Groups ⁷	Operational Assessment ⁸	Support Groups ⁹
a	OH	x		
b	NY		x	x
c	OH			
d	MI	x	x	
e	FL	x		
f	VA			
g	NC	x		
h	FL	x	x	
i	OH	x	x	
j	LA			
k	UT		x	
l	CO		x	
m	CO		x	
n	WI		x	
o	CT		x	x
p	PA		x	

Continuous Quality Improvement Systems/Culture

Continuous quality improvement (CQI) was a major focus of the LC and all of the sites participated in CQI activities. Some of the sites conducted formal, focused CQI activities, following the PDSA format that were facilitated through regular team meetings. Other sites conducted much more sporadic and informal activities. Most of the sites created Medical Home Learning Collaborative Teams that were responsible for setting goals, developing plans, and implementing activities. In all cases there was a clear culture of self-evaluation and the intent was to identify challenges or problems in their operations, explore solutions, and develop new systems or procedures to address the issues identified.

Overall, JSI's impression was that most sites ultimately grasped the importance and the potential of the CQI/PDSA format, were able to apply it at their practice sites, and saw improvements. A couple of sites really took to the idea and had a great deal of success exploring new ideas and fine-tuning their operations, other sites were more bogged down in the process at first but learned to appreciate and use the concepts. Very few sites rejected the idea as too process-oriented and were not able to commit the time necessary to apply the concepts. Interviewees mentioned the importance of incremental change and taking small steps often.

Perspective of State Title V Role

Almost without exception, the practice sites JSI interviewed felt that having the state Title V team involved in the LC was positive and productive. Involving state Title V officials provided an opportunity to build stronger partnerships between the practice sites and the state health-related agencies. It also facilitated practical, productive networking opportunities and information sharing. Perhaps most significantly, the state Title V teams, in some cases, paid for the practice sites to participate in the LC meetings and in a few cases actually paid the CC's salary at the practice sites (generally through grant mechanisms or pilot projects). In these cases, the sites were extremely grateful and most commented that participation would not have been possible without this support. There were a few practice sites that were not as enthusiastic about their state team's involvement, but typically it was due to lack of resources at the state level. This hindered the state's ability to support sites and be involved in activities.

The practice sites were asked during the interview about what type of support they thought the states should provide. Most site responses could be fit into three categories; 1) funding and financing, 2) technical assistance, and 3) education and information sharing. More specifically:

- **Financing.** There was general consensus that the state should provide financial support to participate in the LC meetings. Most states did pay for travel; most sites said that they would not have been able to participate without this support. A number of people also thought it was the state's role either through Medicaid reimbursement or other financing strategies to fund the CC position.

Many of the practice sites also said that it was the state's role to help facilitate and advocate for new reimbursement policies that allowed providers and/or CCs to bill for care coordination activities.

- **Technical Assistance (TA).** A number of people said that they thought it was the state’s role to provide technical assistance to sites to help them to integrate the medical home concept with their practice operations. They thought that states should provide TA either through a group conference call, through on-site activities that helped sites to implement CQI processes, and/or implement various facets of the medical home.
- **Information Dissemination.** A number of sites noted that they thought it was the role of the state to disseminate information and make educational resources available on CQI and the medical home concept.

Parents

Reaching parents to conduct the follow up interviews was challenging. Some had moved, some had outdated contact information, and some were no longer as involved with the practice. This set of challenges in reaching parents for follow-up interviews is indicative of the challenges that practices face in engaging parents. JSI also heard from several practices and parents that were interviewed that many of the parents who were involved in the first meeting of the LC ended up dropping out or not attending the other two sessions of the LC. For example, one parent JSI interviewed had to drop out of the process after two months because of sickness in her family.

One parent interviewed worked at the state level. A second parent had a paid position at a practice. Both were responsible for working to represent the interests of parents in their positions. Both of these “parent” representatives held these positions prior to the LC process. The remaining parents interviewed participated on a volunteer basis.

With the exception of one parent, all other parents interviewed felt that the LC led to the practices realizing the importance of parent involvement and making sure that parents are invited to participate. All parents, except one, said that the process of the LC resulted in noticeable changes to clinical practices. A list of some clinic changes noted by parents interviewed is included in Table 6.

<p>Table 6 Changes in Clinic Practice Noted by Parents as a Result of Participation in the Learning Collaborative</p> <ul style="list-style-type: none"> • Care coordinator on staff – CC arranged all hospital care needed when parent partner’s daughter had a seizure and when she switched insurance companies. Implementation of a pre-appointment contact, follow-up process, and a chart identification process • Use of a “board maker” (communication aid for kids with limited language skills) • Establishing block appointment time for sick kids and another block for well kids • Allowing more appointment time for CYSHCN • Implementation of a care plan (one-page at-a-glance tool) for use with specialists and schools • Establishing a child-friendly area
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One parent, however, seemed frustrated with the lack of changes at her clinic. She felt that she and other clinic staff involved in the LC had worked hard, had several ideas for implementation, and were very committed to the concept of medical home. She felt, however, that there was very little buy-in at the director level of the practice and that her ideas were not being appreciated at that level. Providers at the clinic who attended the LC have since moved on to other practices, which she attributed to their dissatisfaction with their attempts to institute change at the clinic. She felt that any progress had “fallen apart” due to this lack of commitment. This parent mentioned that she and others involved in the LC are still trying to spread the idea throughout the state, and that this activity was the best thing to come out of the LC from her point of view.

Parents were asked about the activities that they had participated in. The parent employed by the state noted the following activities she had undertaken: helping develop a “care notebook,” a system for parents to organize care for their child; meeting regularly with parents to plan activities (e.g., sickle cell day, with child care available and with an expert speaker); providing input on materials and resources developed for parents; and being involved in the discussion with one practice around establishing a “transition practice,” where adult medicine providers and pediatricians would work side by side with the goal of easing the transition of special needs kids to adulthood.

Other parents identified the following activities that they had been involved in: assisting with grant writing; talking with other service organizations; organizing parent meetings; developing and implementing a time survey; compiling data for the time survey; assisting in the development of a care plan; holding parent meetings at home; assisting in setting up a pilot project to a system whereby the parent could consult with the physician without the child present. With the exception of the state employed parent, all other parents interviewed stated that they are no longer as involved with the clinic; although some indicated that they would be quite willing to still be engaged at some level.

C. PERSPECTIVE OF LEARNING COLLABORATIVE PROCESS AND SUSTAINABILITY OF MODEL

Perspective of process

The feedback that JSI received from the states, practice sites, and parents about the Medical Home Learning Collaborative experience was extremely positive. Most thought the LC national meetings were well organized and that the content of the sessions were informative and interesting. Many people cited the opportunity to talk with peers and share information as one of the most valuable aspects of the meetings. They felt that there was a great sense of collegiality and that people were not at all proprietary about what they had implemented. The meetings were a great opportunity to network and connect with people on areas of mutual interest.

Components of the LC that particularly appealed to the parents interviewed included meeting participants from other states and sharing of information, the wealth of information available through the LC, understanding state and practice perspective (and having them understand the

parent perspective), and feeling more empowered to speak with their physicians (“intimidation factor has decreased”). All who were asked said that they would participate again in such an activity, and they would recommend it to other parents. However, there were qualifiers for this recommendation. One parent said she would recommend it to others if they had the time and if child care was reimbursed. Another parent noted how essential it was to select a “good team that is organized and committed.” Another parent recognized the difficulty of involving parents, indicating that some cannot spare the time or have the resources to enable them to undertake the travel required.

The LC did seem to leave behind a culture of self-evaluation and the importance of taking small steps. Many interviewed were enamored by the formal PDSA format and were working with this model in the implementation of the medical home concept and in other areas. Though generally well received by states and practices particularly, a few interviewed did criticize the emphasis on continuous quality improvement and the PDSA format. Others saw the theoretical value but thought that the formal PDSA format was too time-consuming, labor-intensive, and not conducive to the project.

From feedback received, it was clear that the LC evolved over time and that participants’ understanding of their role, the continuous quality improvement notion, and the medical home concept also evolved over time. Parents indicated that they went into the LC with very little knowledge and understanding and that it was not clear what their role should be. Generally, however, parents were feeling much more comfortable by the third Learning Session. Some state staff felt that they had been set up as the “experts,” the ones to go to for support and guidance, but that they were initially uncertain of their role and felt that they were on the same learning curve as the practices they were intended to guide. One state person interviewed stated that she never did understand the process of PDSA until a year after the LC. She visited a site and “suddenly it clicked.” Some interviewed mentioned that it was clear that the process was somewhat rocky and that doing a LC on the medical home concept was different than doing a LC around a specific disease, as had been the previous experience of some of the faculty.

Some interviewed thought the process of the LC (i.e., the PDSA, then post on the web, then make changes) was too labor-intensive for practices. The practices do not have the time to do it at that level and would need to augment their staffs in order to follow through on the process. They also stated that the burden of reporting might have been too onerous. Some commented on Docsite, indicating that it was not suited to all the practice sites. Not all have Internet access and not all have the technical knowledge and skills to operate it. High parent turnover was one area of dissatisfaction noted by a couple of the parent interviewees. Not receiving pay or incentives (e.g., child care expenses) to attend, sitting for a long period of time listening to people, and ambiguity about what they should do in the meetings were other examples of dissatisfaction.

There were a lot of sessions on billing, coding, reimbursement, and care planning. Most participants seemed to enjoy these sessions and did not think they were too esoteric or theoretical. Generally, they thought they were interesting and valuable and, while they might have been dry at times, were useful and important. Many of these sessions were particularly well suited to the practice site participants as they had the most to gain from perfecting their coding, billing, and reimbursement mechanisms. There were a couple of people who thought that there

should have been more breakout sessions geared to specific subsets of the audience and fewer plenary sessions. The reasoning here was that the audience was so broad - practice sites/state officials/parents, urban/rural, private practices/hospital-based clinics/HMO clinics - that it was difficult to develop sessions that were appropriate for all subsets of the audience.

The most significant barriers to implementing the medical home concept and participating in the LC were time and money. Many of the clinical providers that participated in the LC said that it was much more time-consuming than expected to apply the CQI processes and explore new operations, procedures, and office systems. Most of the sites also commented that it was a financial burden to participate in the LC meetings not just due to expenses but also due to the opportunity costs and lost revenues. The same issues rang true for implementation of the medical home model. Many sites said that the medical home would be hard to sustain without proper reimbursement mechanisms allowing practices to bill for the additional services that they provided to their patients as part of the medical home model.

D. SUSTAINABILITY

One of the most significant challenges cited by those whom JSI interviewed was the issue of sustainability. Nearly everyone JSI interviewed was enthusiastic about the medical home model and felt strongly about the importance of creating a medical home for CYSHCN. Despite this enthusiasm, many of the people JSI talked to were concerned about whether it was feasible to implement a full-scale medical home model without tailored reimbursement mechanisms or funding streams that would allow practices to pay for the additional time required or operations that a comprehensive medical home demands.

Practices have implemented careful coding regimens that allow them to maximize their billing revenues, but many care coordination, communication, case management, and educational activities that are part of the medical home model are not reimbursable. Based on JSI's interviews, sustainability was a particular issue for independent, private practices who typically rely on reimbursement revenues. The HMO-affiliated clinics, hospital-based ambulatory centers, and the clinics affiliated with academic medical centers were less concerned (although it was still an issue for them), as they have other revenue streams which insulate them from some of the financial concerns.

Overall, the responses to the question as to whether the medical home model was sustainable fell into three categories. Some people were absolute in their contention that the medical home model was sustainable. These practice sites had identified a CC or had woven the CC's responsibilities into the roles of their existing clinic staff. Many in this group felt that the medical home activities were a part of everyday care and that most of the activities were cost-neutral if you had sound operations in place. Other sites were emphatic that a medical home was a great idea, but believed that it could only be sustained if the care coordination activities were reimbursed or if the CC position could be paid for through grants or special contracts. Finally, there were those who were more critical of the medical home potential and thought that the concept was good in theory, but until policies changed that allowed sites to be paid or reimbursed for their time and expense, it was not reasonable to expect practice sites to implement a medical home fully.

How to Improve the Medical Home Learning Collaborative

Tables 7, 8, and 9 detail the suggestions made on how to improve the LC.

Table 7

State Suggestions for How to Improve the Medical Home Learning Collaborative

- MCHB should explore and understand the cost and investment required for practices to become involved in the medical home concept so they know what they're getting into
- Provide separate discussion forums where larger, more urban states and smaller, more rural states can get together to discuss issues relevant to their settings
- Intended outcomes need to be specifically defined and intended participants need to be clearly identified so they can prepare before the LC
- Have a process for identifying practices before the LC as well as more time to pull in the practices before the LC
- Have a detailed and comprehensive orientation for states to become familiar with the concept and terminology, so they can help practice teams
- Make everybody's role and expectations clear ahead of time
- Provide child care for parents
- Medicaid, AAP, and AFP representatives need to be at the LC
- Provide reimbursement or an honorarium for parents and practitioners
- Have local technical assistance conferences that are less time-consuming
- Do a Train-the-Trainer Model so representatives can be a resource locally
- Allow LC participants from previous cycles to continue being part of the listserv
- After two years, have a follow-up session of the LC to share how barriers were overcome
- Bring previous LC participants and new LC participants together to share lessons learned
- Need to be flexible concerning CC model being promoted
- Focus more on other medical home components and not just on care coordination

Table 8

Practice Suggestions for How to Improve the Medical Home Learning Collaborative

- More information and background on the medical home concept would have been helpful. "It was overwhelming deciding where to start. Could have used 'Medical Home for Idiots'"
- Need more resources for technical assistance – TA is critical to actually implementing (versus only learning about) the medical home
- Should have been more prep for national meeting
- Financial help would be nice
- Pair like practices
- It does not necessarily address the needs of larger practices due to issues regarding bureaucracy and lack of autonomy
- It is too broad. It needs to be more of a functional plan – a cookie cutter kind of plan that can be put in place
- Maybe need more time to network with offices that are already doing this

Table 9
Parent Suggestions for How to Improve the Medical Home Learning Collaborative

- Would like to have met more frequently at national level
- Have “mini meetings” for new parents/practices so there could be more sharing. (“If you missed big one [national meeting], there’ll be another one”)
- Maybe more story-board time to get a better idea of what’s going on around the nation
- PDSA tool was confusing – “great tool but more time was needed to explain/educate/make everyone more comfortable with using it – if you do it, it will work”
- Possibly put more emphasis on parent-to-parent matching in the LC
- Need better shaping of parent role
- Would like to see how other states overcame barriers for involving parents two years later
- Family should be given incentives for participating – child care paid for, for example
- Include families from all socioeconomic classes although it will be a challenge for lower-income persons to participate
- Might be good to have a “go to” type of parent for other parents

IV. DISCUSSION/SUGGESTIONS FOR CONSIDERATION

Overall, the LC appeared to have been a very successful and well-received undertaking. This section summarizes and discusses some areas for potential improvement raised by those interviewed or through the project team’s interpretation of what we heard. As noted in the beginning of this report, the project team has no first-hand knowledge of the LC. Thus, the term “suggestions for consideration” rather than “recommendations” is used. Readers of this report who have first-hand knowledge of the planning and implementing of the collaborative LC will be better able to assess the usefulness and value of these suggestions.

- **Pre-collaborative phase:** If other collaboratives are instituted, we suggest more focus on the pre-collaborative stage. Parents and state staff interviewed, and practices to a lesser extent, often noted that they had felt unprepared for their participation in the collaborative. The *Preparation for Learning Session 1 Workbook* discusses some strategies for ensuring that the team is prepared to participate. It was not apparent from the interviews whether this level of preparation had occurred prior to the first national working session (although this question was not asked directly). Some faculty interviewed noted that they had new strategies to address these issues when developing future learning collaboratives. Other suggestions for improvement are to outline the roles and expectations of each practice team member in the *Preparation* workbook rather than collapsing all roles together under the “primary care practice” topic heading, and develop an informational package (or brochure) on the learning collaborative that the practices can distribute to parents before they agree to participate.
- **Care coordinator role:** What is clear from our discussion with practice sites and state officials is that there is more than one way to implement the care coordinator role of the medical home concept. While the Learning Collaborative has focused on practice-based, case management/care coordinator models, there are other models that are not practice-based

(e.g., state-supported regional care coordinators, care coordinators that are shared across a number of sites, and dividing up the various functions of care coordination among two or more clinic staff). Several interviewed felt that the LC was advocating for only the practice-based care coordinator model. Given that the care coordinator role is such a critical component of the medical home model, no doubt faculty and planners of the collaborative have considered this issue quite thoroughly. Regardless of whether the practice-based model is the preferred model, future collaborative organizers should consider addressing this point one way or the other (e.g., through further explanation or demonstration that a practice-based model is best or through further exploration of other models).

- **Marketing the “medical home” term:** The parents interviewed (except the parent who was employed by the state) had not previously heard of the medical home concept. This was despite the fact that these were truly motivated and interested individuals willing to participate in the LC. It was not surprising that the words “medical home” were not known, as they are somewhat of a jargon term for those in the field. Consideration, however, might be given to developing more widespread knowledge and usage of this term among the parent community. Even though the concept itself may not be clear, coining the term and having it accepted as common language heard among parents of CYSHCN may lead to increased demand from parents for medical home types of services from their providers. This demand, in turn, could become another way to create spread of the concept at the practice level.
- **Parent involvement:** Several of the practices and parents interviewed noted a variety of activities for involving parents at the practice level, including focus groups, surveys, input on scheduling, and input on creating “kid-friendly” waiting areas. A small number of practices interviewed had created a parent advisory group. What was clear from the interviews is how complex an issue it is to maintain parent involvement. Parents are usually volunteering their time, meaning that other commitments often take priority or arise at the last minute, affecting their capacity to take on the volunteer work. The nature of being a parent of a CYSHCN means that their lives are complex and demanding in ways that those who do not have such responsibilities may not understand. Although it seems the collaborative was successful in helping practices and parents develop ideas around parent participation, these activities seem like one-time activities (with the exception of the parent advisory groups) rather than a sustained parent involvement plan as a practice strategy. A suggestion for future collaboratives is to address this issue of maintaining parent involvement. Developing such strategies for ongoing parent involvement would need to take into account the temporary and intermittent commitment that parents can offer, how to involve more parents (including strategies for reaching out to parents and bringing new volunteer parents quickly up to speed), how to recognize and draw on the unique strengths that each parent brings to the practice, how to show appreciation for the work that parents contribute, and how to do this in a way that does not place undue burden on practice staff or resources.
- **Practice variation:** On the one hand, the medical home model is more conducive to large, hospital-based, HMO-based, or academic medical center-based clinics that have diversified funding and revenue streams and are, therefore, insulated from the time burdens and financial pressures that some sites feel. They may even be able to hire and pay for a staff member using overhead funds with less worry about reimbursement. On the other hand, larger

practices are at a disadvantage as they are less autonomous, and it is harder to implement new ideas efficiently within the bureaucratic structures that often exist. In these instances, smaller sites have an easier time because they are less bureaucratic, more autonomous organizations. Some practice staff suggested break-outs during the Learning Collaborative that separate group practices by size to better address issues of practice variation.

- **Medicaid:** Better reimbursement of services provided to CYSHCN, specifically care coordination activities, is important to the context of sustainability. Medicaid is a critical component of this context. Some states were further along than others in their relationships with their state Medicaid offices. Based on interviews conducted, Medicaid appeared not to be a very prominent issue. There were “nuts and bolts” sessions on how to maximize current reimbursement given the status quo. There did not appear to be topics related to working with state Medicaid offices toward change. One interviewee suggested that it would be helpful to invite Medicaid staff to the collaborative. Other suggestions for consideration include offering sessions on establishing relationships with Medicaid, the process of how change is accomplished in Medicaid, and how to advocate for Medicaid changes specific to CYSHCN.
- **Family medicine practices:** Pediatric practices are currently the emphasis for recruiting sites to participate in collaboratives and the focus of much of the work being done by the states in terms of support and spread. While most states had considered the issue of family medicine practices versus pediatric practices, perhaps this is also worthy of further consideration by the collaborative. Similarly, partnerships with AAP are firmly established with most Title V Offices, but there are fewer relationships between AFP and Title V. As noted by some interviewees, the concept of medical home may be much more familiar to family medical practice physicians given their training and background. JSI agrees that pediatric practices are probably where most of the work should be done. However, establishing better relationships with state chapters of AFP and developing strategies for better engaging family medicine practices may be worthwhile to consider.

V. CONCLUSION

The adaptation of the *Breakthrough Series* framework to the medical home concept seems to have been a success. There was nearly unanimous agreement among the interviewees that they would engage in such a process again and that they would recommend it to others. Practices developed a genuine appreciation for the benefits of parent involvement. Real changes occurred at many of the clinic sites, with parents and practice staff interviewed able to recite at least a few specific changes that had been made. Many practices remain actively engaged in working toward the medical home concept one full year after the Learning Collaborative. States appeared primarily to be using the Learning Collaborative approach (either various techniques and tools or the process itself) for assisting with their ongoing efforts at supporting sites and spreading the concept. States and practices seemed to have adapted the culture of continuous quality improvement through the notion of working on small, incremental changes. Overall feedback from those interviewed was very positive.

Appendix A

Medical Home Learning Collaborative Participants

**Medical Home Learning Collaborative
Practice and Title V Contact List**

Colorado	Contact
Title V Key Contact	James C.Ledbetter, MD
Title V Team Member #1	Kathy Watters, M.A.
Title V Team Member #3	Gina Robinson
Practice Team #1 Rocky Mountain Youth Clinic	Jeannie Burns, MD
Key Contact	Mary Zold-cc
Parent	Suzanne Woolfall
Practice Team #2 Southeast Denver Pediatrics	Michael Frank, MD
Care Coordinator	Pat Conner
Parent	Sally Maxey
Connecticut	Contact
Title V Team Member #1	Martha Okafor
Title V Team Member #2	Richard Melchreit – key contact
Title V Team Member #3	Dorothy Pacyna
Senior Leader	Norma Gyle
Practice Team #1 Pediatric Center	Dr. Paule Couture
Care Coordinator	Janet Hebert
Parent	Heidi Plummer
Practice Team #2 St. Mary’s Hospital Pediatrics	M. Alex Geertsma, MD
Care Coordinator	Pat Dwyer, RN
Parent	Mirna Elba Ortiz
Practice Team #3 Whitney Pediatrics	Donna Sandilla, RN
Care Coordinator	Stephanie Perkins, APRN
Parent	Catherine Diane Ramsey-Paige
Florida	Contact
Title V Team Member #1	David Wood, MD, MPH
Title V Team Member #2	Barbara Wexel, RN, MS
Title V Parent Partner	Desiree Durham-Deleon
Title V Team Member	Phyllis Sloyer
Title V Team Member	Sandra Everett
Senior Leader	David Wood
Practice Team #1 Univ. of FL Pediatric Primary Care Center at Andrew Robinson	Dr. Olin Mauldin
Medical Ass’t	Janice Young
Care Coordinator	Salonika Bolden – key contact
Parent	Tricia Herrick
Practice Team #2 Dr. David Weiss	Dr. David Weiss
Care Coordinator	Julie Lucio, RN
Parent	Roseanne White
Practice Team #3 Univ. of FL Pediatric Primary Care Center at San Jose	Dr. Sandra Morales
Key Contact	Janet Cagle, RN
Parent	Michelle Martinez

Louisiana	Contact
Title V Key Contact	Gary Q. Peck, MD
Title V Team Member #1	Linda Pippins
Title V Team Member #2	Eunice Perry
Title V Key Contact (2)	Phyllis Landry-Ratcliff
Practice Team #1 Children's Hospital Medical Practice Corporation	Keith Perrin, MD, FAAP
Care Coordinator	working on getting one 6/2
Parent	working on getting one 6/2
Practice Team #2 The Pediatric Clinic	Anthony Palazzo, MD
Care Coordinator	Phyllis Freeman
Parent	working on getting one 6/2
Michigan	Contact
Title V Key Contact Person	George Baker
Title V Team Member #2	Kathy Stiffler
Title V Team Member #3	Mary Marin
	Wendy Burdo-Hartman, MD
Senior Leader	George Baker
Key Contact Children's Choice	Bev Crider
Practice Team #1 Grand Rapids Pediatrics	Joannie VanDuinen, MD
Key Contact	Joan Thayer
Parent	Tambrey Stone
Practice Team #2 Ypsilanti Pediatrics	Layla Mohammed, MD
Care Coordinator	Pamela Hackney
Parent	Crystal Avram
Practice Team #3 Henry Ford Pediatrics - Detroit Campus	Tisa Johnson, MD
Care Coordinator	Garyzna (Giselle) Maciejewski
Parent	
New York	Contact
Title V Key Contact	Nancy Wade, MD, MPH
Title V Team Member #1	John Talarico, DO, MPH
Title V Team Member #2	Laurie Zavarella – Key contact
Title V Team Member #3	Christopher Kus, MD, MPH
Title V Team Member #4	Ruth Walden
Senior Leader	Nancy Wade, MD, MPH
Practice Team #1 Bassett Health Care	Christopher Kjolhede, MD
Care Coordinator	Cindy Fullington
Parent	Katheleen Wenck
Practice Team #2 Valley View Family Practice	Robert Ostrander, MD
Care Coordinator	Mary Ellen Oliver – key contact
Parent	Gretchen Daugherty
Practice Team #3 Brookdale Family Care Center @ Bristol	Sudhir Vashist, MD
Key Contact	Lynnette Hinds
Parent	Paulette Sappleton

North Carolina INDEPENDENT GROUPS – TITLE V NOT SPONSORING	
Practice Team #1 Chapel Hill Pediatrics and Adolescents, PA	Jennifer Lail, MD
Care Coordinator	Peggy Pulley
Parent	Lori Ireland
Practice Team #2 University of North Carolina, Pediatrics Clinic	Julie Story Byerley, MD, MPH
Care Coordinator	Chris Lockley, RN
Parent	Mary Rubenstein
Ohio	Contact
Title V-Key Contact	James Bryant, MD
Title V Team Member #2	Carol Kraus, RN
Senior Leader	J. Nick Baird, MD
Practice Team #1 Prime Care Pediatrics	Kim Reilly, MD
	Jerry Tiberio, MD
Care Coordinator	Sue Berger-key contact
Parent	Shelley Lynch
Parent	Alice Jones
	Jean Willson
Practice Team #2 Pandora Family Physicians	David Houston, MD
	Jeff Eiden, MD
Contact Person	Jill Kuhlman-CC
Parent	Diane Rieman
Oklahoma	Contact
Title V Key Contact	Louis Worley
Title V Team Member #2	Terry Johnsen
Senior Leader	Mary Stalnaker
Practice Team #1 Enid Heart Clinic & Pediatrics Inc.	Suman Malhotra, MD
Care Coordinator	Sheila Koehn – key contact
Parent	Cindi Felber
Practice Team #2 Dr. Janice Chleborad, MD	Janice Chleborad, MD
Care Coordinator	Christy Stewart, ARNP
Practice Team #3 Oklahoma University Pediatric Center	Donald Hamilton, MD
Social Worker	Amy Coatney
Care Coordinator	Stephanie Solomon
Pennsylvania	Contact
Key Contact	Anita Somplasky
Practice Team #1 Market Street Clinic at CHOP	Dr. Lisa Biggs
Care Coordinator	Rosemary Eikov
Parent	Sabra Townsend

Utah	Contact
Title V Key Contact	Vera Tait, MD
Title V Team Member #2	Barbara Ward
Title V Team Member #3	Holly Balken
Title V Team Member #4	Chris Chytraus
Practice Team #1 Dr. Terashima & Dr. Balog's Office	Robert Terashima, MD
Care Coordinator	Marilyn Chan, PNP
Parent	Amy Steadman
Practice Team #2 Intermountain Health Care / Budge Clinic	Dennis O'Dell, MD
Care Coordinator	Jessica Carpenter-key contact
Parent	Jessica Carpenter-parent advocate also
Practice Team #3 Pediatric Clinic at University of Utah	Chuck Norlin, MD
Care Coordinator	Amy Empey
Parent	Lynda Smith
Parent	Gina Pola-Money
Virginia	Contact
Title V Key Contact	Nancy Bullock, RN, MPH
Title V Team Member #2	Barbara Harding, RN, BAN
Title V Team Member #3	Cyndi Fisher, RN, MCN, CPNP
Senior Leader	David Suttle, MD
Practice Team #1 Richmond Pediatric Associates, Inc	Colleen A. Kraft, MD
Parent	Kiki Larkin
Practice Team #2 Inova Pediatric Center	Albert Brito, MD
Key Contact	Laurie Grossman-CC
Parent	Oriel Estrada
Practice Team #3 Children's Medical Group-Pediatric Associates	Carolyn Riegle, MD
Care Coordinator Care Connection for Children	Janet Martin, RN
Parent	working on one 6/3
Wisconsin	Contact
Title V Key Contact	Sharon Fleischfresser, MD, MPH
Title V Team Member #2	Kristina Stuart, BA, MA
Title V Team Member #3	Michelle Urban, MD
Title V Team Member #4	Holly Colby, RN, MS
Senior Leader	Kenneth Baldwin
Practice Team #1 Fond du Lac Regional Clinic	Howard Dhonau, MD
Key Contact	Theresa Leppla
Parent	Gina Redman
Practice Team #2 Marshfield Clinic	Marcia Wirt, MD
Key Contact	Dianne Fish-CC
Parent	Amy Bohl
Practice Team #3 Northpoint Pediatrics	Susan Bernstein, MD
Key Contact	Terri Adams
Parent	Pat Erving

Appendix B

Discussion Guides

State Interview Guide

Practice Interview Guide

Parent Interview Guide

STATE INTERVIEW GUIDE
EVALUATION OF THE LEARNING COLLABORATIVE ON THE
MEDICAL HOME FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Please describe where Title V and CSHCN fits in your state structure.

What was the motivation for engaging in the Medical Home for Children with Special Health Care Needs Learning Collaborative?

What did you set out to accomplish?

How did you select the clinical practices to participate from your state? (prompts: commitment, behind or ahead of the Medical Home curve, grant process, they approached you)

Was it a difficult or easy process to convince them to participate? Why?

Does your state provide any direct reimbursement for CSHCN? Are there any financing mechanisms for Medical Homes at the state level, through either Title V grants and/or other grants? Did this funding influence your decision to become involved in the collaborative? Why or why not?

Generally, the Learning Collaborative process, as developed by the Institute for Healthcare Improvement, focuses on clinical settings and disease-specific issues for continuous quality improvement. How did this process work coming from a state perspective and from a chronic care management process?

Did you choose your own medical home quality improvement tasks to work on, or did you work collaboratively with the clinic practices from your state?

If you worked separately on tasks, what goals did you set forth for your state?

A substantial amount of time was spent on nuts and bolts issues vs “conceptual” issues of the medical home (e.g., billing, coding, and reimbursement issues; care planning and care coordination, involving and working with parents). Was this helpful to you? Would you say the emphasis was more than was needed, less than was needed, or about right? Are there other nuts and bolts issues that you think it would have been helpful to address (prompt specifically for cultural competency and youth transition issues)?

What were the key skills gained, key knowledge gained, key perspectives gained from the Learning Collaborative process, with regard to:

Continuous quality improvement?

Title V and CSHCN specifically?

Medical home implementation specifically?

You mentioned previously what you set out to accomplish – was this achieved? If not, why?

As a result of the LC process, has your state Title V program (and/or CSHCN program) changed or do you do some things differently than you did previously? In what ways? What about the LC format was critical to this change process?

Two potential roles of Title V have been described as providing “support” to practices and helping with “spread” of the message. Have you adopted these roles? Could you describe what you’re doing with regard to “support”?

...with regard to “spread”?

From your perspective, what did the practices associated with your state take away from the LC process?

What are the shortcomings of the LC framework for operationalizing continuous quality improvement generally and medical homes specifically?

You’re now a year removed from the process, What has endured a year after completing the process of LC? Changes in service delivery? Relationships with sites? Approach to quality improvement?

Would you choose to engage in this type of process again? Why or why not? From your knowledge of state government and health services delivery, do you think the LC process is applicable, appropriate for other service delivery issues related to CSHCN? (prompt specifically for five other core outcomes for CSHCN as follows:

- 1) have adequate private and/or public insurance
- 2) Be screened early and continuously
- 3) Have services organized in ways that families can use them easily
- 4) Have their families participate in decision making at all levels and will be satisfied with the services they receive
- 5) Receive services necessary to make appropriate transitions to all aspects of adult life)

Are there any other Title V areas to which you think the LC process might be applicable?

Is there anything else you would like to add about your experience with the LC that we haven’t addressed through our discussion?

PRACTICE INTERVIEW GUIDE
EVALUATION OF THE LEARNING COLLABORATIVE ON THE
MEDICAL HOME FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Interview is voluntary and results will be kept confidential. Report that we produce for MCHB will not attribute statements to individuals.

Please describe your clinic in terms of location, number of providers/types of providers (probe for pediatricians and family practice), and patient demographics. Are you a community health center, part of a larger network, hospital based?

Before you made the decision to participate in the Learning Collaborative, how much did you know about the approach?

How did you make the decision to participate? Did the state approach you to participate or did you approach the state? How did you go about forming your team (e.g., physician leader, parent, care coordinator)?

How would you describe the Learning Collaborative process to someone who has never heard of it?

What were your goals that you hoped to achieve through the LC process?

What processes or procedures have you implemented (or planning on implementing) for a medical home?

Is there anything that you had planned to do that didn't get done? Why?

You mentioned a care coordinator position, who staffs this position? What are the responsibilities of this position?

As the "physician champion," were there any strategies that you used to disseminate knowledge gained/lessons learned to other physicians/providers at your site? What is the level of buy-in to the concept of medical home? Did this buy in exist before the LC or has it developed over time? (prompt around family practice vs. pediatricians: do FP docs see CSHCN? Is their buy-in/understanding of medical homes similar to that of pediatricians?)

Describe any specific changes you have implemented in your clinic setting as a result of participating in the process. (prompt: how did you do this before you engaged in the collaborative?) What about the LC format was critical to this change process?

Has there been any change in the way in which you access other resources/organizations that serve CSHCN within your community ("family care networks")? (e.g., more knowledge of, more communication/collaboration, more referrals to and from)

A substantial amount of time was spent on nuts and bolts issues vs “conceptual” issues of the medical home (e.g., billing, coding, and reimbursement issues; care planning and care coordination, involving and working with parents). Was this helpful to you? Would you say the emphasis was more than was needed, less than was needed, or about right? Are there other nuts and bolts issues that you think it would have been helpful to address (prompt specifically for cultural competency and youth transition issues)?

Generally, the Learning Collaborative process, as developed by the Institute for Healthcare Improvement, focuses on clinical settings for continuous quality improvement. This process was somewhat different than most in that it included Title V/CSHCN state staff as part of the team. What were some of the pros and cons of having state involvement?

What type of support do you think the State Title V should be able to provide for you at the practice level? Have you been able to get this type of support? Do you have an on-going relationship with the State? Please describe.

Similarly, having parents involved is somewhat different from the norm in LC processes. What were the pros and cons of having a parent on the team? Do you have an on-going relationship with the involved parents/other parents? Please describe.

If we surveyed parents of CSHCN about their experience with your practice, what do you think they would say?

What are the shortcomings of the LC framework as a means of encouraging medical homes?

Is the Medical Home sustainable? Why or why not?

Would you consider participating in a Learning Collaborative on another topic area? Do you have any ideas of clinical topics that would lend themselves to this process?

Is there anything else you would like to add about your experience with the LC that we haven't addressed through our discussion?

PARENT INTERVIEW GUIDE
EVALUATION OF THE LEARNING COLLABORATIVE ON THE
MEDICAL HOME FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Before you made the decision to participate in the Learning Collaborative, how much did you know about the LC approach?...How much did you know about medical homes for CSHCN?

How did you make the decision to participate? Who approached you about participating?

How would you describe the Learning Collaborative process to someone who has never heard of it?

What were the goals that your team hoped to achieve through the LC process?

To what extent and in what ways did you feel you were a partner in the process? To what extent and in what ways were you able to contribute to the team?

What did you like about the LC process?

What didn't you like about the LC process?

Describe any changes in clinical services that you have noted since your involvement in the LC process.

Describe any activities that you are involved in currently related to medical homes or CSHCN (prompts: advocacy, working with schools/education system, committee/coalition work)? Do you think you would be doing this if you hadn't been involved in the LC?

Are you still involved with the clinical site on medical home issues or other issues of serving CSHCN? If so, in what capacity?

You're now a year removed from the process. What has endured a year after completing the process of LC?

Would you choose to engage in this type of process again? Would you recommend to other parents that they should be involved in such a process? Why or why not?

Is there anything else you would like to add about your experience with the LC that we haven't addressed through our discussion?

Appendix C

Introductory Letter

April 25, 2005

Dear Collaborative Member:

The Maternal and Child Health Bureau (MCHB) is doing a follow up evaluation of members' experience in the 2003 Medical Home Learning Collaborative. Now that you have a year's worth of hind sight on the experience, we would like to ask you a few questions about what you thought about the process, any changes that have occurred as a result of participation, the extent to which momentum for change has sustained over the past year, and any changes you would suggest for future Learning Collaboratives.

We have engaged John Snow, Inc. (JSI) to conduct this evaluation for us. They will be e-mailing state Title V staff, practice teams, and parent representatives who participated in the collaborative during the first half of May to arrange times to conduct interviews with you over the phone. Interviews will be conducted from May through July. The interviews should take no longer than 45 minutes of your time. JSI will try to interview all Title V staff and at least one practice and one parent in each state. For practices and parents not reached individually, two toll-free conference call times will be established: one for practices and one for parents. These conference calls will be conducted as focus groups, with a moderator to guide the discussion and a recorder. The length of the conference calls will be one hour. We anticipate that the conference calls will be scheduled for late June.

After the interviews are completed, JSI will develop a report of their findings that will be submitted to MCHB. We would greatly appreciate and encourage your participation in this evaluation; however, your involvement is voluntary. If, for any reason, you choose not to participate, please respond to JSI's e-mail indicating such, and JSI will remove you from the list of interviewees.

Please call me if you have any questions or concerns regarding the evaluation (301) 443-1848. We look forward to learning from you and using your feedback in our future efforts.

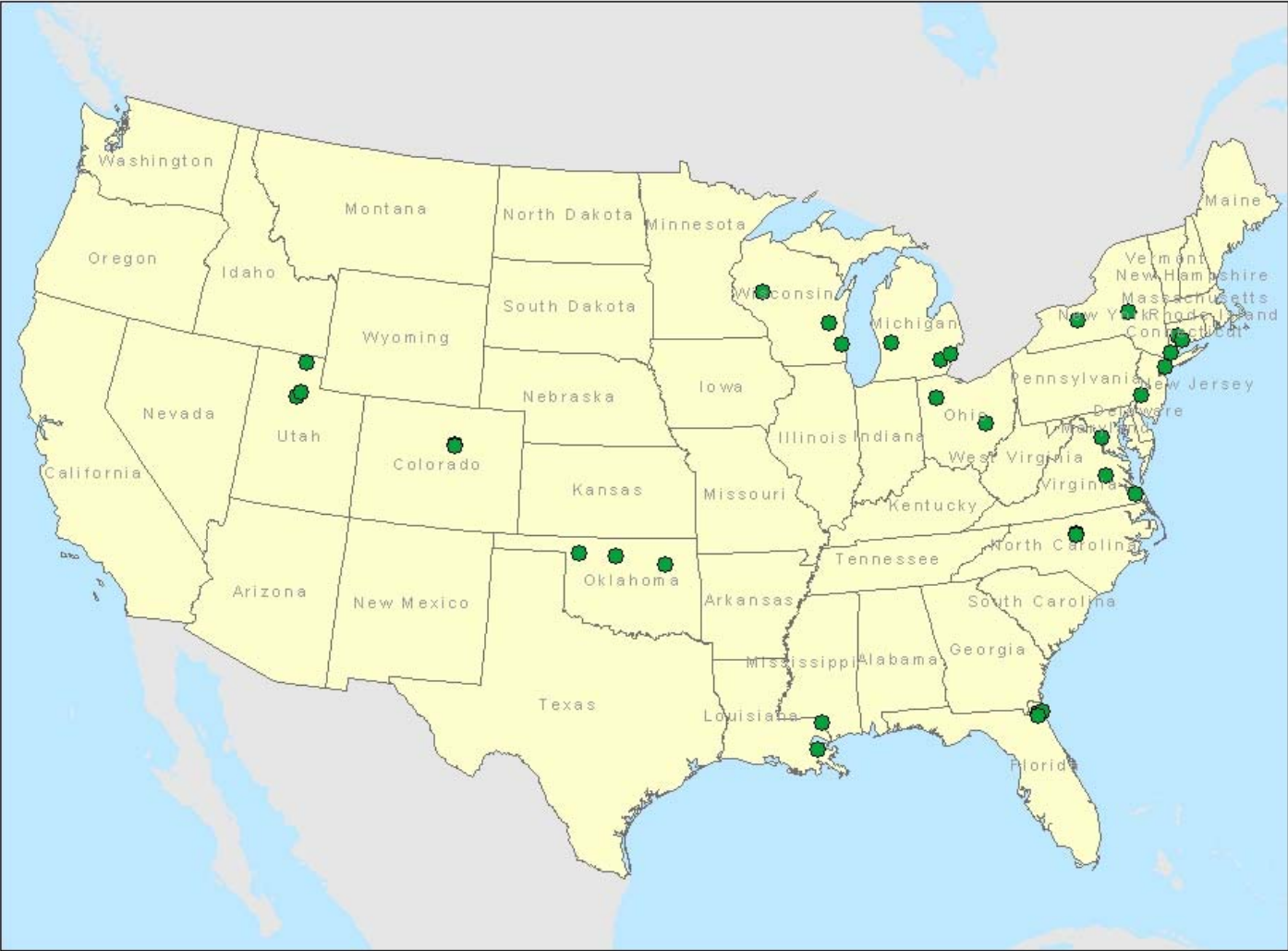
Yours Truly,

Monique Fountain

Appendix D

Map of Practice Locations

Location of Practice Sites



Appendix E

Summary Notes

State Interviews

Practice Interviews

Parent Interviews

STATE INTERVIEWS
EVALUATION OF THE LEARNING COLLABORATIVE ON THE
MEDICAL HOME FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Summary Responses

Please note: All individually, practice and state-identifying information has been removed from the interview responses. Also, where interviewees answered questions previously, certain questions may have been skipped. For consistency, letters assigned to represent each state correspond to letters used in the summary responses of the parent and practice interviews.

1. Please describe where Title V and CSHCN fits in your state structure.

State A

- Within the Department of Public Health (DPH).

State B

- On the state team, one person is a MD consultant to the project, another used to do early and periodic screening, diagnostic and treatment (ESPD) outreach and has Medicaid experience, third is part of Medical Home (MH) Team and Head of Family Voices and the fourth is Director of the Title V program.
- The State follows and tries to implement as best they can the Carl Cooley Model. It is on the American Academy of Pediatrics (AAP) MH Initiative Web Site.
- State involved with the MH Index, Parent Liaison, Care Coordination.

State C

- Under Children's Medical Service. This is in the Department of Health (DOH).

State D

- Presently in the Dept. of Community Health which includes DPH and Medicaid.
- CSHCN program presently based in DPH but two or three years ago it was placed in Medicaid.
- Title V and Medicaid efforts mixed. Director of MH Project is part of Medicaid.

State E

- Title V is within Division of Family Health, DOH.
- Medicaid is also within DOH.
- CSHCN is within the Bureau of Child and Adolescent Health.

State F

- In our state we, the Bureau for Children with Handicaps, are under the DOH and in the Division of Family.

State G

- During the MH Learning Collaborative (LC), our health department and department of human services had their hands full around progressive kinds of initiatives. We are at the Child Center in the College of Medicine at the Univ. So we have this initiative some pieces of which are supported by the Title V program. We took the leadership role in promoting MH initiatives in the state, but we are actually staff at the Univ.

State H

- Part of DPH, Division of Community and Family Health Services.

State I

- One state team member is director of the CSHCN program with Title V. Another is a contractor for provision of services under the Title V program. The other two are the state's Title V team.
- We were charged with bringing forth the 2010 goals and objectives. We follow a case management model to help families navigate all the systems of support. In my center there are four nurses, two case managers, an insurance eligibility specialist and an educator.

State J

- Division of Health and Family Services branches into the Division of Financing and the Division of Public Health. Under the Division of Public Health is the Bureau of Community Promotion, and under that is CSHCN and under that is the MCH CSHCN unit.

2. What was the motivation for engaging in the Medical Home for Children with Special Health Care Needs Learning Collaborative?

State A

- I was hired at DPH (from Medicaid) to assess how we were doing at reaching CSHCN. Found that the numbers were there but we did not have the infrastructure and community-based outreach to bring them in for services.

State B

- MCHB approached us as part of a national solicitation.
- State has very mature Title V MH Initiative – LC is a small part. We were already heavily involved in MH concepts and trying to promote efforts throughout the state. It fit in very well with what we were doing; it was natural.

State C

- The state has been promoting the MH concept for CSHCN since 1984 – very invested in all six indicators, but thinks that MH is the most critical of six indicators.

State D

- State had pretty much ignored MH thrust because the energy was focused on developing a managed care/insurance program designed specifically for CSHCN. MH was not a major goal of the managed care effort. It was important for CSHCN program within DPH to reorient itself to MH.

State E

- To gain an understanding of MH from other states.

State F

- We had been very interested in the MH concept. Our program had started to reimburse physicians for certain activities.
- We wanted to have a more intensive relationship with practices in the state and we liked the structure of the LC.
- Thought it was ideal for bringing in family participation.

State G

- When the MH LC opportunity came around we thought that might be an opportunity to kick start in the state, so we partnered with the state departments to apply for this. We responded to this thing that was like a RFP. It went through NHQ.

State H

- Already working on the MH for six years prior with a MCHB grant.
- Had five teams – pediatric, family practice. Had advisory group.

State I

- We have a state plan for meeting the Healthy People 2010 goals and MH is one of the goals of our state plan so when the LC became available we were happy to be chosen. We have a CSHCN program for children in six places and child development clinics in eleven places throughout state and Health People 2010.
- This allowed us to engage the community in a practice change initiative.

State J

- Need to respond to the National Performance Measures.
- We were mentored by another state a year before.
- Another state put together a 50 member advisory committee that included parents, medical and dental.
- We appreciated the MH concept and wanted to learn how to translate that into a PC setting.

What did you set out to accomplish?

State A

- It was exploratory. We wanted to learn what it was all about and how and what potential there was for improving services to CSHCN.

State B

- Get sites involved and get them to think about small, manageable changes.
- Get parents more involved.
- Create a laboratory for exploring better office practices, create models tailored to specific site circumstance that work and produce real, positive, change, and then use these sites as models. Not models of best practices but models for other sites as to what is possible and how to go about it.

States C

- Goals were to promote spread and “correct spread” – MH is not just “usual place of care” but has other attributes; e.g., notion of coordinated care, cultural competent, family centered – these are three critical ones.

State D

- Wanted to address the lack of cooperation between DPH and the state chapter of AAP.
- Felt that good ideas in MH needed to be integrated in to broader CSHCN effort.

State E

- The state received and implementation grant for MH and was struggling on this grant with how to engage providers. Needed to hear from other states and network.
- Visited two other states to talk about their work in this area. One was focusing more on implementation of MH and the other was focusing on dissemination of the process. These visits were very helpful and we decided that a blend of the two approaches would probably work best for our State.

State F

- To involve families, to involve more practices within the state.
- We had not involved FPs so we wanted to get a large FP involved and to get the practices involved in the whole concept of MH.
- All the pediatric practices know the concept and support it but being on board for the whole family involvement is not as good as it needs to be across the state.

State G

- Wanted to establish a state response for the Healthy People 2010 initiative and the MCHB outcome measures.
- We wanted to increase our expertise in knowing how to implement a MH within a medical practice, but also we wanted information about how to develop a statewide initiative.

State H

- Be a part of the process on a national level.
- Bring in three more practices.

State I

- The goals were to get a better understanding of MH and find out nationally what other states were doing.
- Also to pick up some tools to implement a change initiative in the state as well.
- Assuring that all CSHCN had a practice that was focused on their needs – that was the primary level of importance. There is a concern that pediatric clinics are limiting access to their clinics because of financial issues. So when they are talking productivity and reimbursement, there is a difference between those who take 45 minutes to see patients instead of seven, service is limited.

State J

- Give practices a practical means to implement a MH.

3. How did you select the clinical practices to participate from your state? (prompts: commitment, behind or ahead of the Medical Home curve, grant process, they approached you) Was it a difficult or easy process to convince them to participate? Why?

State A

- Tried to get pediatricians to buy into concept and recruited those who were willing to participate.
- Cost factor was the biggest barrier for them to get involved. They are not reimbursed for their time and effort either at the LC or when they get home to implement.
- One suburban, one urban, one hospital based. Tried to recruit PPO, but did not work because no administrative buy-in.

State B

- Already working with one practice and then expanded efforts to work with two more sites.
- One of the sites was clearly versed in the MH concept and had been working with the state Title V team. The other two were somewhat familiar but by no means fully versed.
- Not easy to get sites involved. Went to practices that we knew of and thought would be willing and eager to participate.
- Tried to find sites that would be able to invest the time into the project. Found one site where the lead was retiring and wanted to scale back his clinical time. This site did not follow though because the lead person was retiring and had no control over the practice who actually was not very interested.

State C

- One state person (a physician) is involved in MH at the national level and responsible for promoting MH in the area. This physician selected three sites: 1) pure private, 2) one university affiliated; 3) one in a public school.

State D

- Difficult to get sites involved. Worked with AAP chapter. Identified three interested parties and had to replace one of them with a fourth.
- Sites thought it would be too much work, time consuming and did not have the resources.
- Mostly identified sites that were closely aligned with AAP or State DPH.

State E

- Discussed with the CATCH grant coordinator, AFP, and others.
- Wanted the sites to be somewhat representative of the variation across the state.
- Decided on one urban tertiary care pediatric practice, one rural FP clinic, and one nearly rural but suburban pediatric practice that had many satellite clinics.
- An official letter of invite went out to all three and they all jumped quickly on board.

State F

- We had criteria – wanted mixture of rural and urban sites, wanted physicians who already knew about MH and were dedicated to learning more, we wanted field nurse consultants to be teamed up with practices.
- We also tried and one of our disappointments was that we wanted to get an academic practice involved but the Children’s Hospital practice we were not able to sustain throughout the LC. That is still one of our goals to get Children’s Hospital more closely involved but there are political situations and the demands already on those practices for paperwork. They agreed to participate under a little bit of duress but they were not as eager as our other two-three practices that continued on through. Got buy-in from the boss, she pressured the practices to get involved but they had not bought in. In retrospect, we should have chosen community-based practice of Children’s Hospital because they are more community-oriented than the inpatient clinics. Children’s Hospital is important because its where these kids get their specialty care.
- 12 Field Nurses assigned throughout our state divided among different regions. Their goal is to work with physicians, hospitals, etc. to ensure that CSHCN have access to the program and if eligible for their program are receiving benefits and also so that the groups we are working with know the other programs that the children can be referred to (i.e. WIC, Early Start). And they also work to ensure standards of care are being followed by the providers – they work with the physicians orienting them to the program and then do some linkage with the physicians. Our field nurse consultants are a resource to the clinic-based care coordinators and in the LC they assisted the practices in bringing together the learning teams. We did a lot of training with these nurses to teach them how to do group facilitation, prior to the LC. four-5.5 hour training. They helped put agendas together for meetings, facilitated, etc. As we moved through the LC the nurses took a back roll and the practices and families took over the project.
- We have a very high buy-in for the MH concept – it is a very integral part of our staff meetings. We tried to select nurses that had skill sets that could help facilitate and help practices along the way. They did a lot of after-hours work – being there when practices and families could meet. When we did physician and family assessments of the practices they came to us. This was more of a partnership. The nurses did a great job of facilitating these groups.

State G

- Starting out since we are in the pediatric section of the College of Medicine we had access to some pediatric PCPs. Then we went through the state’s AAP and from there we recruited likely practices and tried to sell them on the idea (almost cold-calling). It was not easy because the proposal came out in winter and pediatricians were too busy to talk to anyone (all the kids have colds) and they did not have time to talk about change initiatives. Additionally our state is very different from others in pediatric practices. Many of our PC practices in the state are single physician practices so they have a very difficult time pulling away from their practices to attend the LC. Might be rural nature of our state; we do not have enough pediatricians to go around here.
- Identified physicians interested in systems change work. We looked for these people because we thought we would have the most success with them.
- The Title V program paid for travel for them to stay in LC sessions out of state also the state chapter of the Academy of Pediatricians contributed to that and the University supported my participation.

State H

- 16 teams applied to participate with the first grant and we only picked five.
- Selected three more based on interest and commitment.

- Worked closely with AAP in selection.

State I

- Got the commitment of the six centers of excellence and each went to their own community to find a practice.
- It was challenging to find the one in the center of the state.
- It was difficult to engage the administration from our academic site at that time, so then I went outside into the community to seek support. We approached a practice that had a fair number of CSHCN but they were not interested. One practice was extremely invested. I was unsure if this was of value to them or not because they were already invested but they thought it would be a greater enhancement to what they were already doing.
- We also had them sign a letter of agreement. But one of the practices reneged and we had to find a second practice after the practice dropped out in the first LC session.

State J

- For the LC we put out an “all points bulletin” and sent it to the state’s AAP and AFP. We then called interested/motivated practices and tried to get a cross section of practice types. We were unable to recruit a FP, but we did get one rural practice, one that sent a lot of patients to Children’s Hospital and one who served a more urban, Medicaid population. This last practice already had a case coordinator.
- It was not difficult to recruit practices because the fact that the LC was national made it credible. Two practices even called after the LC began and said they were interested in participating. Three practices were not hard to recruit but the spreading part is trickier.

Do you think there is a difference between pediatric practices and family provider practices in their interest and/or commitment to medical homes? Do you work with both sets of practices? Do you think it is important to work with both sets of practices?

State A

- We did not have any FPs.

State E

- We felt it was very important to involve both FP and pediatric practices. FP practices are very familiar with the concept of MH through their training: “MH is a renaming of their training.”
- Pediatric practices learned so much from the FPs.

State H

- Harder to find a family provider with the time or interest.
- Was one family provider on Navajo reservation with initial grant
- We selected by demographics – urban/suburban/rural.

State J

- The state did a replication of the LC and was able to recruit one FP team. We felt that the FP team had an easier time with the concept of MH and issues related to transition because they were already half way there. The president of the state’s AFP participated in the LC replication. The state believes it is critical to work with FPs.

4. Does your state provide any direct reimbursement for CSHCN? Are there any financing mechanisms for Medical Homes at the state level, through either Title V grants and/or other grants? Did this funding influence your decision to become involved in the collaborative? Why or why not? (if they’re engaged in discussing this, prompt for CPT code reimbursement mechanisms vs grant or other mechanisms)

State A

- Paid for travel for the LC.
- Started a state LC at the same time and gave honorariums by re-channeling grant money so they can continue to use what they learned. Launched an independent evaluation of project.

State B

- The state provides no direct reimbursement for CSHCN.
- There are no financing mechanisms for MH at the state level and the Title V group does not provide any grants.
- I think funding allowed them to pay for the time of the person from Family Voices, which they saw as a positive component.
- Title V is a resource for information, works to promote the concepts, works to share information across states and does a lot of awareness work but there is no money or compensation given to sites that participate.

State C

- The state determines “qualified” providers of CSHCN – these practices can then receive Medicaid-enhanced reimbursement for seeing CSHCN and some minimal funding for case management, but reimbursement is low. Medicaid managed care option under PCCM model – only \$3.00 management fee.
- Support PC contracted programs –care coordination in separate administrative unit, but they do that for their assigned practices (regional approach to care coordination).
- Referred to circuit rider model – one care coordinator who relates to many PCP.
- Another approach is to pay an enhanced management fee. The state is not going in this direction – Medicaid is “big fish”; state Title V does not want to start bad precedent of providing grants and having it removed from larger reimbursement issue.
- Reimbursement ideas or progress in this area not related to LC – they have always been engaged in these discussions.
- State paid travel for practices to attend LC.

State D

- Travel was paid for to go to the conferences for the site. Paid for three people from each of the practices and four state team members. Someone from Family Voices went to meetings and was an important contributor and paid for own involvement.
- No direct reimbursement. No acknowledgement of MH concept in Medicaid reimbursement.
- Creative partnerships between various Medicaid and Community health partners who had a mandate to incorporate MH concepts.

State E

- Through the Physically Handicapped Child Program, based on county, can get reimbursed for services.

State F

- We do reimburse for care management but there is not reimbursement for anything else from MH at this time.
- The state budget includes a plan for a pilot project that will pay for case management codes in the state – much of this came out of the LC and our efforts in partnership with the Medicaid bureau. We are looking at ways to get reimbursement. We have been working with a physician in the state academy of pediatrics who is developing an online education curriculum to credential providers in the MH and eventually we will enable them to collect the case management funds. Next year we are doing a pilot within our bureau working with hopefully three practices in the state where we hopefully will pay for that service corps later in the practice. We are going to do it as a pilot and see how it works out. We will probably have the care coordinators bill us the case management codes, keep track of that and then look at outcomes. The big thing is that this is in our budget bill that Medicaid is going to do a pilot and look at this – this will open a door that even other payors in our state will recognize the value of the care management activities in the MH.
- We are looking for other funding sources too – wrote for a grant that we were not funded, but we are still looking.

State G

- Some services supported by Title V, some formulas are paid for.
- If you get SSI and you are under 18 you can get money from special programs.
- Lack of care coordination funding is clearly a barrier. The sites had to be innovative about who in their practices could be categorized as a care coordinator. Constantly asking question how are we going to pay for this.

State H

- Initial grant from MCHB provided \$7000 to practices to develop team, paid for time of MH facilitator.
- Could not cover time away for pediatricians – would have been \$35-40,000.
- Contribute to a MH website.
- Funded support (through block grant) to practices to develop resources, have team meetings, create newsletter.

State I

- A Title V program paid for parent airfare and hotel – that is all they were willing to or could afford to pay. Whatever payment was between the local program and the practice – no payment from the central office. We knew going into the LC that there was no financial support from the federal government.

State J

- The state provides some funds to local health departments, but not practices, to provide service coordination. They fund five regional centers that get a sum of money, 25% of which goes to local health departments. The regional centers are responsible for referrals, have parents on staff, provide technical assistance (TA) and training and coordinate with the First Step website. In the next grant cycle the state is looking to do local grants with MH as the umbrella concept. The regional centers will administer these local grants.
- CSHCN are a target in the state and Medicaid does provide targeted case management for high utilization CSHCN. However Medicaid does not fund anything that makes MH possible. From a Medicaid perspective a physician is already being paid to be a case manager when they are reimbursed for an office visit. Regarding the issue of transition they have collaborated with Milwaukee doctors to pilot a program through Medicaid.

5. Generally, the Learning Collaborative process, as developed by the Institute for Healthcare Improvement, focuses on clinical settings and disease-specific issues for continuous quality improvement. How did this process work coming from a state perspective and from a chronic care management process?

State A

- We only see it working in a private practice.
- It is very high level and overwhelming.
- It will not work in a hospital setting without getting CEO on board; and the Medicaid-based practice burnt out.
- Understood the concept of PDSA and small steps, but did not like the administrative burden of reporting.
- Have to have pediatrician champion to get other pediatricians on board.

State B

- CQI and PDSA format sounds good and we support it but it is hard to put into practice.
- Sites always want to think too big and do not value the potential of small changes and the idea of thinking incrementally. Sites that were involved and could think small had success.

State C

- Very labor intensive for pediatricians – PDSA cycle, then web post, then make changes – too labor intensive. Strongly believe in CQI, but practices have no time to do it at this level of intensity – practices would need staff augmentation to do this.
- Some of the instructional modules were very good; e.g., coding and billing module, cultural competence, Carl Cooley's index to assess where you are on the continuum of MH. Would like to take critical elements that can be replicated without so much labor intensity required. Perhaps something stand alone (like modules) but with some feedback/support.

State D

- PDSA process a pain. Annoying.
- Too process oriented. When you get down to the science of it though it is too much jargon. Families/parents were particularly put off. Alienated practices too.
- An important message that taking small steps is the way to get things done.

State E

- A regional approach to the diverse state has worked well previously. They think that this may be the way to go in terms of the MH. The state is too big to do CMHI model of having state folks go practice to practice to provide support and technical assistance. They would like eventually to have regional centers established that provide assistance to the practices contained in their geographic area as well as operating as the liaison between practices and the state. Lack of funding is major barrier to establishing such a system. However, two of the three practices (rural FP clinic and the suburban clinic) involved in the LC have begun to act as the MH voice for other practices around their areas.
- As mentioned previously, the state has a MH grant it is working on. The grant has two PIs, one who has since left. The new bureau director, who is a pediatrician, replaced the PI who left and joined the LC. This person is very committed to the concept of promoting MH.
- When they selected their Title V team to participate in the LC, they decided to mirror what the clinics were being asked to do; e.g., one physician; one family specialist, and one allied health professional.

State G

- I thought it was ok, if my perspective is right we were the first collaborative that focused on a concept rather than a particular condition. I think there were a couple rough spots and some of the sessions showed this transition – learning as you went along.

State H

- It was critical to learn how to go about making and evaluating changes.
- Like the LC approach – PDSA, baby steps.
- Documentation is becoming more critical for pediatric practices.
- Based on first meeting, it is much more difficult to have a LC based on a “concept” instead of a specific disease.
- MH more difficult to evaluate where you are than with a specific disease.
- Have to teach concept of how to make changes instead of actually making the changes.
- It is a process. You are never there. You need to continue to improve.

State I

- I think at first I really hated it and part of it was that it was different terminology than I was used to in a change process. However, since the training we have moved forward with the change in the state and I have to be honest, I was visiting a clinic the other day and PDSAs finally clicked and I started to get it.

State J

- This was new lingo for the practices (not as much for the state). A lot of people were more familiar with these concepts from an asthma perspective. Seemed like a good approach.

Did you choose your own medical home quality improvement tasks to work on, or did you work collaboratively with the clinic practices from your state? If you worked separately on tasks, what goals did you set forth for your state?

State A

- Be in line with the federal mandate.
- Increase the number of kids being seen and support them.
- Achieve some sort of family involvement.
- More collegial, peer to peer learning, so set up bi-monthly LC meeting for state.

State B

- Absolutely worked collaboratively with sites due to the variation across sites as to need but also due to the variation of the sites motivation for being involved.

State G

- The LC asked us to do a little of both but they focused on the Title V team doing something different from the practice teams. We looked at how we could translate this into some state initiative and began to put together some plans to figure out how to translate this for our state and the practices focused clearly on implanting it within their practices.

State H

- Already had an ID process, registry and care plan. Helped to solidify our processes and what we were already doing.
- Getting system integration grant to do LC within the state.
- Already had a lot in place – reinforced that what they were doing was correct.

State I

- Allowing them to address their individual practice needs, helping them do the site survey in their office. I do not think that I felt I needed to provide best practices or anything like that – they needed to individualize it to meet their needs.
- By the third training we had it together and knew what it was we were trying to accomplish. Our care coordinator probably took too much of a lead with the practice because if we were not there setting up meetings etc. things would not have happened. That was a lesson learned; the practice needs to buy-in and going through one physician alone does not work – need to have whole practice buy-in so should go to whole practice team.

State J

- We worked with the practices and did not do QI internally, though we did develop some new operations.
- Used the MH index. It was clear to the state and the practice teams alike that it was critical (1) to identify, (2) that there should be some sort of care planning and (3) linking to support services.
- The regional centers were critical in linking to support services. One practice was already connected to a regional center but the other two were not.

- After the Learning Session II the state had a retreat with state practices to try to give them a “101” on how state resources are structured. The practices said this was the most valuable part of the LC. How state programs worked started to make sense. Take home lesson was that Title V needed to do more outreach from the regional centers.

6. A substantial amount of time was spent on nuts and bolts issues vs “conceptual” issues of the medical home (e.g., billing, coding, and reimbursement issues; care planning and care coordination, involving and working with parents). Was this helpful to you? Would you say the emphasis was more than was needed, less than was needed, or about right? Are there other nuts and bolts issues that you think it would have been helpful to address (prompt specifically for cultural competency and youth transition issues)?

State A

- The magnitude of information was overwhelming.

State B

- It was an important part of the training and the sites and Title V people were very interested; definitely helpful.
- Seemed that the parents were inappropriately put through the nuts and bolts issues, particularly during the plenary sessions. Mostly this was covered in the breakouts but occasional covered in the plenary which seemed inappropriate.

State C

- Not sure. Need to ask other state participant if there are other nuts and bolts issues that need to be covered.

State D

- Valuable and useful generally.
- Not able to understand what it was really going to cost and tried to get practices to study how much this might cost, but could not get it done. MCHB should explore and understand the costs and investments that need to be made to implement the MH concept so that policies could be developed and sites can understand what they are getting into.

State E

- These issues are very state-specific. Perhaps an alternative approach would have been to bring the smaller states together to discuss and brainstorm and some of the larger states together.

State G

- This was good – conceptually we had it but knowing how to was the problem. This was helpful.
- State folks were already aware of MH concept; practices not as much, either a little bit or not at all.

State H

- It was helpful to the practices. Needed to know what could appropriately be done.
- Would have been nice to address other issues, such as cultural competency, but meetings were packed full; something else would have to be cut.
- Could have done less discussion, more info.

State I

- I think that the physicians and the practices really ate up the coding info. That is extremely important to them and we are continuing to address this in the spread initiative here. I think that was especially helpful. It is critical for buy-in because the physicians want to know if they are going to participate what is in it for them. Maybe more time could have spent on these coding issues.
- Examples where people have changed coding and it has worked are great for physician buy-in.
- Registry was not well received – identifying patients is important for the practice, but a lot of emphasis was placed on using DOC side and this was not well received because it was not realistic for a lot of the practices.
- I learned a tremendous amount – it positively impacted the work we do. As much as I did not like the PDSA and it is somewhat time consuming I think practices could benefit from taking that on.

State J

- People liked the coding part the best.
- The PDSA form was a struggle – the mantra to do things in small pieces proved true. Doing things in small pieces is hard for physicians who want to change the world.
- Cultural competency and youth transition issues should be addressed more. Not many minorities participated in the LC and the need for translations is an important research issue. At one of the University’s centers they are already doing some work with transitions. Medicaid is just beginning to see the importance of transitions.
- Having parents be part of the team was very important but very hard to have them involved.

7. What were the key skills gained, key knowledge gained, key perspectives gained from the Learning Collaborative process, with regard to:

Continuous quality improvement?

State B

- There are many ways that sites can make an impact and affect change; different domains and a large framework to work from. Some sites want to do this, not all sites are the same. Efforts need to be tailored. Different sites have different needs, resources and goals; could be weak in one domain as defined by the MH Index.

State F

- The whole evaluation process of how to look at a project – how do you evaluate your project and how do you use PDSAs (we call them Q Steps). Helped the practices go thru the whole process. That was hugely beneficial.
- LC helped us with structure and gave us a more structured way to move forward; PDSA, conference calls, the regular conference calls with practices.

State G

- Yes took away CQI and we are considering very strongly using the PDSA approach that we got through the LC in one of those models that we talked about and probably will promote it with individual physicians when we get out there with our TA project.

State H

- Reinforced a lot. It was more intense. Needed to be very supportive of practices. We asked a lot from them and they were already doing a lot. Data had to be in.
- Good to interact with people

Title V and CSHCN specifically?

State A

- Was not directly stated, but implied that we need to fund facilitation; we should not tell practices what they need to do but need to help practices make changes.

State B

- Had much more grandiose and substantial goals at the outset but learned to scale back expectations and think about incremental change i.e. we assumed practices were further along electronically than they were.
- Value of Care Plans.
- Value of Parent walk-through.
- Involvement of Family Voices staff in process was very valuable and helpful.

State D

- Help to build a relationship between the AAP, DPH, and practice sites.
- Helped to explore how they wanted to move forward.
- Helped them to develop a strategic plan.
- Important learning experience.

State H

- Nothing new, good to interact with and learn from other states.

State J

- When we think about spread, how do we sell this as a quality improvement issue? As a safety issue? We need to spin this for administrators because their buy-in is critical. Need a proof approach – this is a downside. Need to prove that it is cost effective.

Medical home implementation specifically?

State A

- In order to screen and identify, clinicians have to revamp their own skills and systems.
- Physicians need to identify and work with parents and coordinate services.

State B

- Importance of taking small steps and things about manageable, incremental change.
- How effective and possible it is to bring parents into change process.
- Value of Patient and Practice Index.
- Get sites to think about simple systems and Clinic Rules/Policy changes (eating in waiting room, streamlining intake procedures, thinking about family/parent burden, implementing ID/sticker systems).

State C

- Biggest/best outcome was that this group of three practices now fully understands what MH actually meant.
- One pediatrician in private practice is sold on this and he became “champion” and sometimes gives promotional presentations about MH to other physicians. We are thinking of doing statewide collaborative – if we do, this pediatrician would be on “faculty”.

State D

- Help to solidify the concepts of the MH. Pretty well understood now in the Medicaid Division and Dept. of Community Health.
- Variation between sites; learned about the concepts and also learned a sobering truth that it takes a lot of effort.

State E

- We felt we were ahead of the learning curve (“surprisingly”) when we arrived at the LC. Some of the teams were not even familiar with the concept of MH whereas we had been working on it for some time

State G

- Good examples of health care plans, examples of how to implement different components/aspects of the MH within a practice, and really fleshed out my understanding of this initiative at the national level and how we might be able to respond at the state level.

State H

- We took away from the meeting the LC process rather than MH substance.
- Role of case managers are education, dissemination of resources. There is some limited funding available for case management; one organization, for example provides some partial funding.
- There is a new grant in the state that will fund “ask the expert”. Thus, even though there may not be funding for case management, the role is essential at “some level”. For example, it may only be required that you “teach” where to get resources rather than actually get resources. Thus, although reimbursement is important to the discussion, there are some things that can be done in the interim.
- Perhaps a mixture of state support and clinic support would be appropriate for case management.

You mentioned previously what you set out to accomplish – was this achieved? If not, why?

State B

- Yes, it was challenging and I think we got fewer sites involved than we thought we would, but I think we were able to get a couple sites to implement real sustainable changes.
- They did get parents more involved, and
- Have created some examples that are helping to promote the MH concept.
- The LC fits nicely into their overall MH objectives and has helped us to prove to other sites in the state that it works. It is hard to go out to practices and say this works and is important without having examples to show that it does and that it is worth the effort.

State D

- Absolutely. Huge success in some ways but did not really motivate many sites to get involved more of a learning experience that helped Title V people to develop broader plan.

State G

- We negotiated with our state Medicaid agency to look at some funds potentially paying for a project to survey PCs in state about what they know about MH and if they have parts of implemented already and if they would like to get more info about the MH and we are engaged in that right now and what we intend to do with that is adjust the MH LC to fit our state and what they say. I have a strong feeling it will not look like a collaborative. It is hard for PCs to get away from their practices. I think we have to go to them and provide it more along the lines of a TA model, so we are going to try to confirm or get more info on that assumption through this survey and if we are right on this assumption we will follow through with that. We are just getting the survey printed and out within the next couple weeks. We have 2360 doctors to mail to and we have targeted a much smaller number to push for responses. (Targeting any docs that say they have seen children.)

State H

- The three practices that were involved in the initial grant were probably much further ahead than the other five
- They are more immersed; more invested.

8. As a result of the LC process, has your state Title V program (and/or CSHCN program) changed or do you do some things differently than you did previously? In what ways? What about the LC format was critical to this change process?

State A

- LC gave us a way to look at a concept. Gave us a model to redesign our system.
- Presented to Medicaid; they are looking at issues and a reimbursement system.

State B

- Have not made any drastic changes due to the LC. Were well versed in MH concepts and ideas prior to LC and knew of Carl Cooley's model and the AAP initiative.
- Believed in PDSA and CQI ideas. The LC gave us the resources and the impetus to get other sites involved and develop some real MH examples.
- A couple of sites are advancing and serve as a model to other practices; had a retreat that one other practice attended.

State C

- Care coordination role can be done in many different ways, but LC promoted only one.

State D

- Yes but maybe not as a result entirely of the LC.
- LC helped to underscore importance but the focus has been on other areas.

State E

- Yes, to some extent. We assessed the state of MH throughout the state and traveled around the state presenting on the concept to families and professionals.
- Developed an informational brochure.
- Renamed a unit for CSHCN within the Bureau of Child and Adolescent Health area to "Medical Home." This is symbolically very important.

State G

- Model for MH came out of the LC and then we inserted it into a different funding stream and now we are providing TA to clinic for children.
- Also working on two pilot projects at Children's Hospital – MH for kids in foster care and a MH for children with developmental disabilities. Focusing on exposing residents to MH concept and experience with it.

State H

- Trying to get the MH name out
- Through systems integration grant will add newborn screening as part of MH.
- We will change language from PCP to MH.
- Have outcome measures with regards to MH.
- We will use a "LC-like" process for our nine systems integration grantees. We will travel across the state doing TA. We are going to do our own statewide LC on MH and hope to have 10 new practices participate.

State I

- We incorporated the transition into our program and we brought back better ways to inform families of better MH, what to look for.
- We got ideas on forming care coordination and emergency care plans.

State J

- Someone from UMASS came and talked and presented information about what it costs to provide case management and what the efficiencies are for someone else to do it. Then folks came from AAP and talked about coding. The Johnson Foundation does this thing called Wing Spread – a think tank session – how to reimburse care coordination. This was presented this to the group and the presenter was going to try to organize something but we have not heard anything from him since then.
- We did do a replication of the LC with 10 practices participating.

9. Two potential roles of Title V have been described as providing "support" to practices and helping with "spread" of the message. Have you adopted these roles? Could you describe what you're doing with regard to "support"?

State A

- Realigned contracts with two regional centers; took funds to identify and align specialty services with 10 – 12 MHs.

- Sponsored the statewide LC – peer to peer training; addressing issues such as reimbursement; care coordination; transition; parent engagement.
- Talking with Medicaid, insurance department about reimbursement issues.

State B

- Definitely achieved both goals: support and dissemination of ideas.
- Increased awareness and created some substance that they can talk about and present on the road to other sites
- The LC provided ideas and taught practices a process for exploring what might help but mostly the initiative was state-driven.

State C

- State is thinking about incorporating MH language in its contracts.

State D

- Did not actively provide support to sites at least in the long run.
- Parent support by State’s Parent Involvement Council, Family Voices, AAP leadership.
- Title V Program was more around developing a Managed Care structure and developing systems of care then trying to assist individual practices.

State E

- See answer to question 8 above.

State G

- Working on two pilot projects at Children’s Hospital – MH for kids in foster care and a MH for children with developmental disabilities. Focusing on exposing residents to MH concept and experience with it.

State F

- With support of the practices we do pay for the service coordination codes (CPT codes) and we are looking to see how we can better support the service corps leader code within the practice.
- We also support the website which practices can use for families w/CSHCN and physician training with MH and we are trying to get that online so it is more available than just grand rounds. We are working with a physician at Children’s Hospital on this resource website that will be going statewide with in a year – it is also linked with national resources and it is linked with an organization that takes equipment that families are not using, refurbishes it and give it out to families with CSHCN. We did borrow this idea from other states. It has links to “how do I set up a SN trust? How do I link to an attorney?” It is also a directory for professionals. The state is in a partnership that is supporting this website.
- We have done a lot with the Bureau of Managed Health Care. The MH is one of the 10 screening questions they ask when new enrollees come on as a result of the LC.
- We have a pilot in nine counties where we have tied the MH with a nurse being the service coordinator for children with complicated medical needs and that is going along very well.

State H

- Serve as resource.
- Send info, including newsletter, to practices via AAP newsletter; family practice sites also included.
- Numerous presentations/lectures.
- Grants.
- Conference calls to the eight participating practices.
- Continuing to develop website as resource for parents and practices.
- Module on web is a mentor care coordinator to ask questions.

State I

- We paid travel expenses for teams and gave stipends and travel expenses to families who participated in the LC – we planned ahead and would have difficulty doing this without such planning.

...with regard to “spread”?

State A

- Held the statewide MH Academy; more than 100 physicians attended.
- Publish a MH newsletter.
- Extended to 10 sites via the statewide LC.

State B

- We have developed presentations and materials that are available to various large and small audiences and distributed in various ways that work to raise awareness of MH concepts.

- We have regular stakeholder meetings to raise awareness, share information, recruit new sites, and push forward various activities.
- Disseminating the benefits of parent involvement, practice redesign-patient flow, and care coordination.

State C

- State's first step is to ground our medical directors and pediatricians in MH concept throughout state (22 medical directors). Look to them as point people to implement and create spread – not all MDs are currently convinced that this is the right thing – right now most are concerned with Medicaid reimbursement
- Accomplish above with several presentations at MD meetings – participating physician from state has been doing these primarily. We have also identified MD who has CSHCN who is a very eloquent spokesperson and we will draw on this person too. A physician from one of involved practices also has done, and will continue to do, promotional presentations
- Want to get Medical Directors to select practices to participate in statewide LC. State is currently trying to set aside MCHB block grant funds to do collaborative either end of this year or early next year.
- We think the County Medical Societies need to take some ownership over this – the local Medical Directors interact with them – the state does not.

State D

- Talked with sites and made presentations at existing/scheduled meetings.

State E

- Talked about spread possibly through a regional model as highlighted previously.
- They did not feel comfortable talking about “support” because there is an RFA that is currently out, and they did not want any breaches of integrity to the process.

State F

- We developed brochures both for families and practices to explain the MH, the project.
- We have done a lot with outreach – teamed up with March of Dimes and had 12 educational sessions around the state. Also teamed up with the Bureau of Managed Care to have sessions about transitions – done eight of those around the state.
- We are trying to get the concept into the education community. I presented at early childhood education conferences – we are trying to bring the MH concept in and trying to get medical issues addressed in the education environment.
- There is a workgroup starting in September that we will be on. Not directly out of the LC we did get a champions grant from Utah and we are collaborating with a physician to see how we can work on a national website of resources.
- We try to tie MH in with as many activities as we can. If we are talking about immunization, we have tied the MH into our CHCs where we have educated them on the concepts. So we have really, I think we are close to where MH is intertwined with many of the things that we do within the DOH. We think of MH as being a key to accomplishing our goals.

State G

- The spread initiative is how we are framing it here in the state with our Title V agency and our Medicaid agency and how we are talking to the community. It is a spread initiative.

State H

- Added faith based groups and dental representatives to MH advisory group.
- Talked with businesses.
- University working with nine practices through systems integration grant.
- Working with another state to add five – 10 more practices.
- Holding LC on ADHD Early Intervention.

State I

- Need to have the whole practice team understand and they should have had their own team meetings to talk about the MH. The participating physician took things back and presented them at a staff meeting but things were not implemented well because the ideas were all external.
- We have continued to have monthly meetings to see where people need help and this is where we have begun to see the beginning of the disintegration of the group. Our concern was that if we could not engage and retain all three groups that had attended the LC what could we do to continue the spread of this initiative?

- We used a HRSA grant and one of the pediatric teams to support physicians in the community and to try to embrace MH. We have a contract with them to initiate MH participation throughout state. We are starting the process of having them write up their PDSA's and care plans. We are trying to replicate the LC in the community. It is slow and it is going to take a lot of work and the people working on this are doing a great job but my concern is how will things continue to move forward when our funding ends in June? Will all the care center directors continue to support this? Can we have continued support? I think we are just starting to gather some momentum and so I am already looking ahead and saying how are we going to sustain this?

State J

- For the state's replication it was much harder to recruit 10 practices. The state has a staff of three and this is a very labor intensive process. We contracted with the regional centers to provide support and to facilitate.

10. From your perspective, what did the practices associated with your state take away from the LC process?

State A

- Enlightenment on what it takes to implement a MH in a pediatric practice.

State B

- Importance of taking small steps and valuing small sustainable changes.
- Better understanding of Medicaid, specifically billing issues, and better connected to state officials and resources in this area.
- Better understanding of parent/family role, the challenges they face, and how to get them involved in a productive way. I think many practices are happy to have the patients "out in the dining room" but do not necessarily want them "back in the kitchen". Taught them value and process for including parents/families.

State C

- What they took away from their experience with the LC is that not one size (of care coordination) fits all (though one concept of MH does) – want to experiment with a couple of different models. This is not something that the LC promoted – this is something gleaned from the practices' involvement in the LC process.

State D

- One site developed a full fledge program and got a lot out of it.
- One practice had a horrible time and "basically did nothing" frustrating experience.

State E

- We felt, to some extent, that the practices had entered into the LC very enthusiastically. They came out somewhat disheartened, given that the care coordination seemed to be the primary thrust of the LC and there is no money to do this in the state. Compared to some of the resources available to their peers in other states, they felt their opportunities were not so broad.
- Despite above, they heard from the practices that they enjoyed the collegiality, they looked forward to the sessions, and they looked forward to discussing and brainstorming with peers from other states.

State F

- The practices are still meeting every one to two months, usually every month and the parents are still coming along.
- One of the practices got another MH grant and they have moved along and they now have developed a parent advisory group for their practice that also meets on a regular basis.

State G

- One of the practices in particular learned about the parent partner or family partner concept and began to see parents differently and as a resource for improvement.
- One of the details that the practices took away was the importance of identifying children with complex health care needs more than just remembering them all – that its important to identify them and have a system of managing that information.

State H

- More commitment.
- Looking at quality improvement through the concept of a MH.
- Continue to look at ways to improve.
- Reinforced whatever good work they were doing and gave them a new way of looking at it.

State I

- Identification of the patients. They developed a primary point of contact for each patient.

State J

- We think we walked in not knowing how much support the practices need and we were subsequently unable to provide that support and nurturing.

11. What are the shortcomings of the LC framework for operationalizing continuous quality improvement generally and medical homes specifically?

State A

- No tools to apply MH within the established system.
- The intended outcomes need to be specifically defined; the intended participants need to be clearly specified so preparation can be made before.
- Have more time before the LC and a process for identifying practices.
- We were looked to as experts.
- Help practitioners help CSHCN.

State B

- Very time consuming, costly, and challenging to provide TA to sites on a site-by-site basis in ways that actual fosters change.
- CQI and PDSA format is critically important and needs to be understood by sites but some sites and Title V groups got bogged down in the process of trying to teach and learn about it. It became a “four letter word” to some. Need to figure out an effective way to get people to think small and to operationalize a manageable process. Incremental Change.
- Dock Side Data System was a complete failure. Most states and sites craved a system so at first it seemed to be a good idea but the system was not suited to sites that were not technologically savvy and most of our sites were not able to implement it. They did not have internet access and the knowledge to operate system. The system was taken from another project/environment and was not appropriately tailored to LC or MH Program; seemed like an afterthought.
- Sites and parents met along site State Title V participants, which was a problem. There was the perception among the sites that the states were part of the overall process and were pushing or “ahead of the MH LC curve” but in fact many of the states were starting at ground zero just like many of the sites. This at times was awkward and created a bad dynamic.
- First LC meeting was not well organized, particularly from a parent involvement perspective but the second meeting was much better or more effective.

State C

- Too labor intensive – pediatricians have to take time away from practice to attend face-to-face meetings – requires three-four weekends.

State D

- Need to get AAP involved or all efforts are lost, so the LC should help to get them involved.

State E

- Focus on care coordination as cost to other six important components of the MH. A big disappointment was the overriding emphasis on care coordinator role. While we believe this is very important, we felt that the organizers had an agenda for promoting the care coordinator role in order that those who were at the LC would go back to their states and really fight for funding for this function. We would have liked to have seen more emphasis on the other six components of MH (e.g., cultural competency, family centered, etc.). We felt that whenever we tried to raise such issues, the organizers quickly returned the focus back to care coordination. One example, we came to one collaborative meeting very excited to discuss a regional approach, which they saw as a potential good solution for how to manage large states. Although at first the organizers were also enthusiastic and encouraged them to discuss idea, it again quickly reverted to the care coordinator. While we do believe in the importance of the care coordinator position, this did not seem like something that was even remotely possible in the near future for the state. Thus, we prefer to turn our efforts to other components of the MH that are more doable and where we can have more immediate successes.
- States were asked to bring “decision makers” to the LC. The size of our state did not allow for this type of quick decision-making. Although they may have had decision makers at the meeting, there are 15 or more other decision makers who did not attend the meeting who needed to be brought on board and buy-in to these new ideas. Low likelihood. Idea of big states versus small states was raised again as possibly something any future LC need to take into account.

- One of the practice teams selected their care coordinator and physician from two different clinics. This did not make any sense and did not work well. Eventually the team dropped out because of this. Next time, the state will not give as much discretion about who is selected to participate.

State F

- I liked the framework but it does require dedication and real commitment of time to make it work. I think it is hard in Title V's busy day and the practice's busy day to get that commitment and take the time. Where they did it they saw how effective it was and they saw results and the practices have continued the monthly meetings, the planning that they started in the LC. So if you can get through that initial difficulty of getting them to commit. I think Title V is a huge part of this – as long as they stay supportive, still have a strong partnership with the practices. A lot of it is just the relationships and working with them – not a huge financial support, more of a collaborative working relationship support.
- It is hard for parents to take the time to do it, to get babysitters and transportation. A lot of our support has been on the parent side. We did financially support them to go to the LC and actually we are still supporting the parents who are coming to the meetings at the practices.

State G

- It would have been much easier for me if I had a more detailed and comprehensive orientation early on to the Title V role. I felt like I was trying to catch up through part of it. Maybe even breaking the Title V team out early on and being clear about what their role is. Understanding ahead of time the scope of work that would be expected between the learning sessions.
- The parent partners seemed to feel the same way about their role; not understanding their role and why they were there right away. Some of the parents went home and said “why was I there” because they did not know. Make sure that the parents were up to speed at the beginning knowing why they were there. Not true for all parents there but it was true for some of them.

State H

- Too expensive.
- Asking practitioners to leave 12 days of work.

State I

- It may be a good thing to do but if there is no financial gain it will never reach its full potential.
- Medicaid reimbursement does not compensate physicians for the time and effort for CSHCN. Even finding MH is a challenge because physicians have Medicaid caps about how many they will see.
- Sustainability is a challenge.

State J

- Time/resource intensive.
- Issues related to spread – slow road.
- PDSA is a business model – hard, need more TA on this and it was pretty inflexible around this piece.

12. You're now a year removed from the process, What has endured a year after completing the process of LC? Changes in service delivery? Relationships with sites? Approach to quality improvement?

State B

- Regular regional meetings.
- Parental involvement.
- Approach to strategic team structure.

State C

- Practices have not given it up, which is important. We are supporting them with some resources.

State D

- Relationship between the AAP, DPH, and practice sites.

State E

- Relationships with clinics have endured and have been enhanced.
- Roles and responsibilities have grown for the practice members. They now serve as faculty for state trainings.
- They have achieved a great deal of spread; concept of MH has been spread throughout the state.
- PDSA is useful and bears repeating.

State G

- Relationships with sites have changed. One of the sites did not buy-in. I do not know whether or not they have any lasting MH component because at the end they just said this is too much work and I have to move on.

- Another practice kept some of the aspects in place and they are still connected with us.
- Another practice has also experienced a surge in workload. They are sold on the idea, but they can not manage the workload. Part of what is happening is that the practice is growing, do not know if this is directly attributable to the LC because they probably already were doing a lot of this otherwise they would not have participated. Now it is growing to the point that they have a hard time keeping up and things are falling by the wayside.

State H

- Family advocate advisory board.
- Continue to hold monthly conference calls.
- Continue to examine “spread”.

State I

- One practice that I did a first site visit with a few weeks ago seems to be doing bits and pieces of the MH – they have limited resources in this poor area of the state but they want to identify all the kids in their clinic and they want to look at their practice patterns for ADHD/asthma kids, they want to track referrals – simplistic things they can accomplish. In terms of the broader picture I am not sure for the future.

State J

- Have listserv for practices – send out coding information.
- Got integration grants.
- Relationships built endured (i.e. Medicaid with Title V and regional centers), more accessible, better able to maintain relationships across divisions. MCHB should make sure Medicaid colleagues are included in the MH.
- We are expanding into the adult population with SHCN.
- Trying to get MH language in contracts.

13. Do you still maintain contact with other State Title V offices that were involved in the collaborative? In which ways are these interactions helpful to you?

State A

- No.

State C

- Indirectly – we are one of leadership states with Bureau – in contact with other states that are too.
- Network was helpful for practices, but not really for states – because states are all doing things differently – all different places along continuum of MH. We think we are fairly far along this continuum

State E

- Relationships have endured and have been enhanced.
- Great opportunity for dialogue between docs and state folks.
- LC whetted the appetite – critical is keeping momentum going.

State F

- Within our region – we have worked a lot with two other states; particularly used one as a model. Some states we have strong relationships with. Other states we work with but do not have as much closeness with.
- One state was working with the insurance industry – I would like to see what they are doing and model that here.

State G

- LC gave me access to and introduced me to others in other states and national leaders. We have developed communication with some of them I.e. people in Colorado and we are touch with lots of those individuals.

State H

- Working collaboratively with state not participating in LC.

State J

- We have received TA from other states (i.e. Arizona) that were not part of the LC.
- Not directly through the LC.

14. Do you have any association with the American Academy of Pediatricians?...the American Academy of Family Practice? What is the nature of the association?

State A

- Yes, but there is no coordination between the national and state chapters. They need to work together.

State C

- AAP and state Title V are “joined at the hip” – one of our state people is AAP’s point person – “They are us and we are them”.
- Less of linkage with AFP although AAP links with AFP

State D

- Yes.

State E

- Yes, mentioned previously.

State F

- We are working with the Academy of Pediatrics and the Academy of Family Practice to support the MH. We have a joint committee – the traumatic brain injury community.

State H

- Worked closely with AAP in selecting practices to participate.

State J

- One state person sits on board of AAP. Relationship with AFP is not as strong.

15. Have you worked with your State Medicaid Department on issues related to the medical home? If yes, please describe.

State A

- Talking with Medicaid, insurance department about reimbursement issues.

State C

- Want to start a pilot program paying \$20/head for care coordination services, but not even under discussion at state (“would open Pandora’s box”) – reimburse one, have to reimburse all.

State E

- Yes, because they are also within the DOH, but slow process to effect change.
- Have discussed, and it is important to keep discussing eligibility issues with Medicaid, but it has not gone anywhere. Waiting to see what changes happen.

State G

- Yes, see answer to question 7 above.

State H

- Part of the Dept. for seven years.
- Partners for initial grant that provided funding for care coordinator.
- On executive committee.
- Working with insurance companies.
- Not a lot of funding, but they are at the table and engaged in discussions.
- Do not provide money for care coordinator but continue working with Medicaid on that issue.

State J

- Looking at language inclusivity.
- Looking at way to do managed care – to identify CSHCN and children at-risk

16. Would you choose to engage in this type of process again? Why or why not?

State A

- Yes, it is a good process; good ideas.
- Administration and coalition developers and other stakeholders should have been involved; should have taken Medicaid or AAP with us.

State C

- Yes, but with qualifications. Good features but too labor intensive.

State D

- Yes, but there needs to be more preparation before you get involved. Needs to more tailored to the varied participants. Suggested the application of a train the trainer type model. Academy representative that would be involved with the state train the state team and then go out to be the resource for the practice sites.

State E

- One would participate again. Other no longer works in area.

State F

- I hope that you can tell from our state that it was a very positive experience. We are eager to be involved in any more activities that come out of the LC. It gave us a framework and support from other states.

State G

- I think so now that I have gone through the process. The person we worked for has been on faculty in another collaborative.

State H

- Would do again if had funding. It takes a lot of money.

State I

- Yes I would do this, enjoyed the whole LC model and the methods they used for learning, the structure/ framework was good and in between sessions their encouragement for us to communicate with each other and other states. It was a great model.

State J

- Yes would engage again, but key would be resources (e.g. how do you pay for a care coordinator).
- Where are our adult providers?

17. From your knowledge of state government and health services delivery, do you think the LC process is applicable, appropriate for other service delivery issues related to CSHCN? (prompt specifically for five other core outcomes for CSHCN as follows:

- 1) have adequate private and/or public insurance
- 2) Be screened early and continuously
- 3) Have services organized in ways that families can use them easily
- 4) Have their families participate in decision making at all levels and will be satisfied with the services they receive
- 5) Receive services necessary to make appropriate transitions to all aspects of adult life)

State A

- Care coordination for CSHCN in our state.

State C– see #16

State D

- If there was reimbursement MH could happen. TA and support is not going to encourage sites to be involved on its own. LC would only work if there was reimbursement and if it was a more local TA conference that was less time consuming.

State H

- Not right to have family advocate without pay.

State J

- Our replication's Learning Session III focused entirely on 5) - need family physician participation

18. Are there any other Title V areas to which you think the LC process might be applicable?

State D

- Not sure

State E

- Thinks the LC process can be adapted to other areas. Suggested transition to and adult health care.

State G

- Sure I think for any one of those issues you could design a collaborative around any one of those, i.e. early and continuous screening.

State I

- Yes.

State J

- Our state is using a model similar to the LC for nutrition, quality improvement and perinatal care.

19. Is there anything else you would like to add about your experience with the LC that we haven't addressed through our discussion?

State A

- Biggest dilemma is financially supporting; funding or honorarium to take part in LC.
- How practice sites use the parent partner is problematic; had trouble defining role and giving authority.

- More flexible in private practice; hospital-based hindered productivity.

State C

- Some version of LC is good, but need more streamlined version.
- Pre-training “This is what you are going to experience” – state person was blown away at first session and practices were too. Someone from Title V tried to support practices as best they could.
- We felt to some extent that we were put in the position of “setting up” the practices.
- Should not have been allowed to go without AAP participation there – they would have then known how to promote on behalf of their membership.

State D

- Utah web site is a good resource. Increases assistance for decision support. Every state should not have to develop their own resource.
- MCHB should allow those involved in LC in previous grants to continue to part of the ListServ.

State E

- Bring back practices two years later to discuss progress and how barriers have been overcome.
- Could also bring two collaboratives together to share lessons learned.
- Need to be flexible concerning the care coordinator position.
- Parents are critical to the process.
- There were some problems in engaging parents – primarily, not paying them for their time; although they incurred no additional costs by participating, there was the lost revenue from their usual jobs.
- Despite difficulties of engaging parents, we feel it is essential. We do not want future collaboratives to take the easy way out and just say that it is too difficult to involve parents. Imperative that they are involved and in a substantial way. You do not want parents involved just “so they can tell their story.”

State G

- I think generally it was a good idea. It did give us credibility with others in the state so that we could take another step here and get other things done.
- We expect to use contents from the LC curriculum and tools like the care plan as models that we will make available in our state project. We may hear from them that they would love to come to three learning sessions that last for three days and one of the things that we forgot to tell you is that we have put together a couple 1.5 hr community trainings – one for mental health care service providers and used this materials that talks about what physicians are doing around the MH project, then we did a pediatric CME event. Community training for early interventions, schools, health depts., non-medical folks that serve kids – other community-based service providers, excluding health care providers.

State H

- Good people, leaders, players.
- Good experience; would not want to be left out.
- “2 thumbs up”
- This was their [faculty’s] first attempt – things will get smoother as they move forward.

State I

- Has helped the community to learn more about Title V and programs as a network and about the federal sources of funding
- Positive outcome from this. One PC practice struggled during the process. They did attend and did participate in between. There is a parent who is still very active in the statewide initiative. She was present.
- LC was great but in terms of realistic reimplementation for other programs. I do not know if people can afford to travel like we did. In order to continue this kind of process exploring alternative online participation that would be less costly.

State J

- As part of the integration grant, we are trying to look at how transitions are set up at Children’s Hospital and the Univ. What tools do people need to have to do a transition? One year ago we met with managed care organizations to see if anyone was interested in piloting a transition project but they were not.
- We think justification is important. New measures need to be created to reflect cost-savings because the traditional measures do not work for this.

PRACTICE INTERVIEWS
EVALUATION OF THE LEARNING COLLABORATIVE ON THE
MEDICAL HOME FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Summary Responses

Please note: All individually, practice and state-identifying information has been removed from the interview responses. Also, where interviewees answered questions previously, certain questions may have been skipped. For consistency, letters assigned to represent each state correspond to letters used in the summary responses of the parent and state interviews. If followed by a number (e.g. C1) this indicates that there were multiple practices interviewed in the state.

2a. Before you made the decision to participate in the Learning Collaborative, how much did you know about the LC approach?

Familiar

- Very familiar. (H, J, M)
- Chair of state AAP chapter and knew Title V officials; well versed in LC ideas. (M)
- Boss was very knowledgeable and asked them to participate. (C2, L)

Somewhat

- Somewhat aware but not well versed in jargon and specifics. Had heard of PDSA but did not know what the acronym meant exactly. (G1)
- Did not know much but thought it was a good idea. (D, E2)
- Heard of LC approach but did not know much. (C2, I, K, L)

Not at all

- Care manager knew nothing. (G1, J)
- Not aware of concept. (A1, A2, B, C1, E1, G2)

2b. Before you made the decision to participate in the Learning Collaborative, how much did you know about the MH Concept?

Familiar

- Boss was very knowledgeable and asked them to participate. (C2)
- Had been to a MH conference, was pretty familiar. (E2)
- Knew a lot about MH concept previous to going to LC and had many of the processes already implemented in practice. (I, J, K, L, M)
- Very well versed, taught on the topic at University. (H)

Somewhat

- Understood concept but not jargon/terms, basically a MH already. (A2, B, E1)
- Somewhat aware. (D, G1)
- Care manager knew care coordination, had heard of MH concept. (G1)
- Heard of MH approach but did not know much. (C2)

Not at all

- Did not know much but thought it was a good idea. (A1, A2, B, E2, G2)

2c. How did you make the decision to participate? Did the state approach you to participate or did you approach the state?

State

- Approached by state Title V. (A1, A2, B, E1, E2, H, J)
- State doing a MH pilot project with their practice already. When LC came around just switched involvement to LC efforts. (E2)
- Responded to a state RFP. (G1)
- Participated in state meeting and gradually got more and more involved. (G2)

University/AAP

- Approached by someone at University. (B, C1, L)

- In local AAP chapter. (I)

Forced upon Them

- Boss asked them to participate. Boss probably approached by state. (C2)
- Lead was a junior partner, who thought it was a good idea to build her career. (E2)
- Chosen by partners because I was the youngest partner. (E2)

Other

- Was totally swamped in my practice and thought it would help me to control my time. Negotiated that I would stay on board if they got me a care coordinator. (D)
- Cognizant of high costs for caring for CSHCN and was interested in exploring ways to reduce costs and increase reimbursement via managed care organizations and state insurance. (K)
- Received funds from the state's Blue Cross Blue Shield Foundation. (K)

2d. How did you go about forming your team (e.g., physician leader, parent, care coordinator)?

Providers

- Identified two physicians and a couple parent partners and worked from there. (E2)
- Worked to gradually recruit physicians in clinic; did not force them. Promoted idea and hoped it would spread. (H)
- Doctors in practice just volunteered. (E1)
- Only one physician in office, only RN became coordinator and identified parents. (C1)
- Chosen by partners because was the youngest partner. (E2)
- Lead was a junior partner, who thought it was a good idea to build career. (E2)
- No team just the doctor. (M)
- Identified a physician champion, care coordinator usually an RN, and the office manager in each of the three offices. (A1).
- Enlisted one of the nurse practitioners to help out. (A1)
- Physician had always been interested in concept. (A2)

Coordinators

- Care coordinator was nurse who simply expanded her role. (G1, H)
- Care Coordinator/Parent same person, not a nurse but knew how to coordinate care and what parents need from personal experience. (E1)
- Had a nurse who functioned as virtual care coordinator already. (A2, I, J)
- Hired an ER nurse to be care coordinator and worked to identify parents. (D)
- Identified one of the two RNs to become care coordinator. (E2)
- Identified a care coordinator only after LC was over. (M)
- Tough to keep care coordinator due to overwork. (M)
- Was already doing care coordination. (A2)

Parents

- Identified parents who they thought would be interested and capable. (A1, G1, H, I, J)
- Tough to get parents involved. (D, E2, M)
- Each physician agreed to identify two parents. (E2)

Other Comments

- Only wanted people who were really interested. 10 participants total some: some physicians and RNs. 50 total staff but only initially recruited 10. (L)

3. How would you describe the Learning Collaborative process to someone who has never heard of it?

Quality Improvement and Systems Change

- An intense quality improvement process. (C2, E2)
- Process to identify new approaches and develop systems to overcome obstacles. (D)
- A project that gives you “permission” to take the time to analyze needs and explore how to improve what you are doing. (G1)
- Opportunity to explore the needs and the challenges that families and clinics face when getting care so that you can try to develop ways to address these challenges. (G1, G2)
- A curriculum for sustaining change in a practice setting. (K)
- Process that greases the wheels and encourages sites to take a look at how to improve what they are doing. (K)

- An effort to create a system that is more efficient for the office and for the patients and their families by identifying needs and coordinating services. (A1)
- Process and project that attempts to educate practices in how to improve their systems and the quality of care that they provide CSHCN. (H)
- Process that teaches sites how to improve care through team work. (H)
- A way to envision how to deliver care within your practice more effectively. (J)
- Process that helped sites to refine what they did so that children and parents could feel at home and make the process as easy as possible. (J)

Learn about the Medical Home

- Opportunity to learn about and develop a uniform approach toward creating MH. (D)
- An intense introduction to the MH concept (E2)
- A project that helps to figure out how to create a MH that is more supportive of patients. (K)
- Learn about facilitating a more efficient and effective process for scheduling exams and helping with referrals. (A1)
- Pilot project to better identify CSHCN and better deliver care to them. (A2)
- Process that gets people to think about how physicians, nurses, and parents can work together to improve efficiency, quality, and care coordination. (H)
- Project that teaches sites how to implement a MH for CSHCN. (C1)
- Opportunity to learn about the MH and about implementing quality improvement. (E2)

Networking and Information Sharing

- Opportunity to share information with other sites about how to better serve CSHCN. (D)
- Speak with others doing the same thing and work with the state on ways to improve medical care. (A2)
- A networking process that provided information and a process to explore how sites could make changes to operations and office systems to improve care for special needs patients. (M)
- A networking opportunity to share information on how to better manage and care for CSHCN. (C1)

4. What were your goals that you hoped to achieve through the LC process?

- Learn about the MH. (E2, K)
- Develop systems to identify CSHCN so as to avoid scheduling errors (nurse practitioner might not be qualified to see a child with SHCN, physician needs to schedule longer appointments). (E2)
- Refine/create care planning and care coordination systems. (A2, C2, D, E1, E2, L)
- Incorporate patient/provider education. (E2)
- Create a new site called “Special Kids, Special Needs”. (E2)
- Formalize clinic systems to reduce burden on the clinic and improve the quality of care. (G1, H)
- To explore ways to increase patient/family satisfaction. (G1)
- Increase awareness in the clinic of patient/parent needs and challenges. (G1)
- Get parents more involved. (E2, G1)
- Try to make practice more kid-friendly. (E1)
- Develop systems to facilitate better communication with our parents and specialty providers. (D)
- Educate and keep parents informed and involved; created monthly educational seminars and a resource library. (A2, D)
- Wanted to create a blueprint for what to expect in our practice for CSHCN. (D)
- Wanted to be very active in disseminating this approach to care in our state and throughout other practices. Be active in the dissemination of MH to other practices. (D)
- Fortify some of our connections with community leaders. (D)
- Start to have more of a close relationship with them. (C2)
- To make practice improvements. (I)
- To develop better relationship with Title V. (I)
- Make a better place for patients and their families. (K)
- Learn how to develop registration and identify CSHCN. (K)
- Learn about care coordination, reimbursement and about other state and local resources. (K)
- Look at our processes, set up better ways to identify kids and improve the overall delivery of services to them. (A2)

- Educate staff. (A2)
- How to identify kids and review systems of care. (A2, D, E1, E2, M)
- Create some structure in the clinic around how we care for CSHCN. (A2)
- Develop more collaborative approach between MDs/nursing staff/parents. (H)
- Goals were mainly to identify what the physicians could do to improve the delivery of care for the CSHCN in our practice. (M)
- To become more of a MH. (E2)
- Learn how to better manage CSHCN. (C1)
- Wanted to provide more services. (J)
- Get all area providers to join process. (J)
- Validate what effect we were having. (J)

5. What processes or procedures have you implemented (or planning on implementing) for a medical home?

Care Planning

- Developed care planning tools. (E2)
- Developed care plans, on-line. (D)
- How to do care plans, make rosters (identification and flagging system). (C1)
- Developed computerized care plans for new patients. Wanted to develop Emergency Care Plan, but have not got there yet. (J)

Care Coordination

- Refined/formalized care coordination system. (E2)
- More structured and organized. Everyone from receptionist to nurse to physician is better with identifying and tracking CSHCN. Scheduling process has changed dependent on needs. There is consistency and continuity between clinics. (A2)
- Trying to get funding for a social worker to assist with care coordination. Formed a MH team to investigate and explore how to provide high quality, more efficient, better coordinated, more family-friendly care to CSHCN and their families. Developed a better understanding of the challenges that CSHCN and their families face when seeking care and dealing with their conditions. Developed a better understanding of the Care Coordinator role and how to coordinate care more effectively. (H)
- Care coordinator required to do some paperwork - pulling of charts, physical space usage/rooms, slowing down the operation.
- Hired fulltime care coordinator. (L)

CQI Systems/Culture

- Culture of self-evaluation. We now find ourselves asking “why?” and “what is not working?” or “is this working?” (E2)
- Learned that small things make a difference, can be done pretty easily and are cost neutral. Learned more about CQI and the PDSA format which was very valuable and effective (G1)
- State is conducting its own LC and has 17 practices involved. Our physician champion and two other physicians divide up the sites and provide on-site technical assistance with them. (I)
- Developed CQI approach that taught us the value of small steps, utilizing the PDSA cycle. (K)
- Learned a lot about making small changes and implementing PDSA cycles. (E2)
- Self-improvement process, extending to other areas of practice. (C1)

Parent Advisory/Parent Involvement/Parent Education

- Created a parent advisory group. Started off with 18 parents and has dwindled to a handful of regulars. (E2)
- Gained a better understanding of the needs of parents and how to change/improve clinic processes. (G1)
- Implemented focus groups with some of our families - big lesson from the LC was “ask the parents”. Parent partner meeting once a month and project coordinator meets individually with all the parent partners. This has helped to foster relationships with all of parent partners. (C2)
- Better skills in facilitating parent meetings and taking suggestions from them in regards to care plans. (A2)
- Learned a lot about getting input from parents. (E2)

Parent Education

- Hosted parent seminars in the evening around topics that parents wanted to know more about. We provided child care and fed the parents. Worked to empowered our parents to advocate for their children, whether it is in written form or face-to-face. Developed resource room – booklets, top 10 internet access sites, computers to

look up more information. Created provider newsletter and parent-to-parent suggestions book in this library. Created video library so they can watch the videos while waiting for us. Efficiency in education is a priority of ours. Talks at grant rounds, conferences around caring for kids with disabilities. Educational sessions at satellite sites. The level of buy-in from these sites is not so great. (D)

- Created documentation tools for asthma. (M)

Resource Guide/Referral Network

- Developed resource guide to make sure that providers were aware of what is available in the area. Create collaborative partnerships/linkages with other organizations. Want to identify resources to refer families (C2)

Other

- Have not done much. Created more comfortable, more kid-friendly waiting room. Have better idea of the MH. (E2)
- Learned how to manage clinic better, including coding and billing. (C1)
- Wanted to promote MH in to our satellite office – we never really got to that. (D)
- Planned new office around MH; i.e. used feedback from parent walk through. (L)

7. You mentioned a care coordinator position, who staffs this position? What are the responsibilities of this position?

Education

- Information gathering and resource sharing. (D)
- Communicating about DME needs. (I)

Care Planning

- Creating electronic care plans. (D).
- Developing care plans. Conducting one-year assessments for new patients. (C2)
- Care coordinator puts in the complexity rating (social, behavioral, technology dependent). Those identified get the pre-visit contact. Pre-filled forms for physicians with three concerns for visit, plus other documents related to care. Use bright paper for MH kids. (K)

Care Coordination/Case Management

- Have made pocket directories for physicians. Have a referral coordinator, separate from care coordinator. The care and referral coordinators have learned how to work together to coordinate care. (K)
- Helps families with referrals. Identifying resources in the community and general support. (I)
- Providing case management and social work activities (linking with resources, arranging referrals, social service issues, putting out fires. (C2)
- Care coordinator keeps track of resources. (D)

Patient Advocacy

- Conducting patient advocacy. Assisting families to fill out prescriptions. (C2)
- Assisting with pharmacy related matters. (I)

Other Comments

- You do not necessarily have to have a “care coordinator” – just make sure the functions are getting done in one way or another. (D)

8. Were there any strategies that you used to disseminate knowledge gained/lessons learned to other physicians/providers at your site?

What is the level of buy-in to the concept of medical home?

Did this buy in exist before the LC or has it developed over time?

(prompt around family practice vs. pediatricians: do FP docs see CSHCN? Is their buy-in/understanding of medical homes similar to that of pediatricians?)

- We found that providers are already busy/overwhelmed, best to approach them with what is in it for them. Held staff meetings and one-on-one conversations to promote new changes and next steps. Had providers fill out evaluations. One year out though, it is finally starting to click. I would tell others to be persistent. The level of buy-in has increased over time. This four year MCHB grant has allowed us to do things outside of our budget (i.e. have a care coordinator, website, and electronic registry). (E2)
- There was good buy-in and support among physicians and staff nurses regarding the concepts and changes they make. (G1)
- Grand rounds, conferences for AAP, and dissemination to other practices as mentioned previously. They say “you do it so well why cannot we keep sending them to you” and some of the pediatricians say they do not want to change how they practice medicine for the two-three CSHCN in their practice. (D)

- Out of 12 providers she has been working closely with, eight have bought in and four have not. Those who have not generally feel it is too much “uncompensated” work and that they are already providing high quality care. Physician champion identified another physician champion in addition to self. In such a large practice, it is important to have more than one champion. In the state-wide LC, they have all pediatric practices on board. They thought about adding FP practices, but that will have to come at some point in the future. They will be harder to convince. **(I)**
- The referral network has not changed for me, since I am the social worker, but there are probably more referrals made because the physicians are more aware. I do not see every kid, so if they think someone might need a referral they bring it to my attention. The communication is good with Early Childhood Connections, but not as good with Social Services. RNs and physicians more aware of referral networks and resources in the community **(A2)**
- Had office meetings every couple of months. Decided what criteria to use on computer list. Had buy-in from five or six staff. Still doing pretty well. **(A1)**
- Buy-in from physicians has been challenging. A couple are very involved but for the most part people are not that engaged. Better systems have been facilitated. Participating physicians are practicing the MH concept in their own way. Clinic Manager is a very important person to be involved. At this site, the clinic manager went to the first LC meeting and this really helped. **(H)**
- All three of the sites are still bought into it. **(M)**
- The physicians meet once/week. It is hard to get six different physicians to agree on the same process for anything, need to build in flexibility. Most of the physicians feel that it is a good idea but there is still a little resistance in how much time they think it takes. **(E2)**
- Office meetings, month office QA meetings with people from the University **(C1)**
- Some said it was a good idea, but had no time; some just said they had no time. Had some educational presentations for staff by parents, neurologists. Physicians did not attend. **(J)**

9. Describe any specific changes you have implemented in your clinic setting as a result of participating in the process. (prompt: how did you do this before you engaged in the collaborative?) What about the LC format was critical to this change process?

- Care Planning; we are printing emergency cards for families to carry with them. We hired a care coordinator for four days/week. Review of Schedule; every morning the care coordinator looks at patients coming in and identifies CSHCN if they are not already identified and then almost always meets with each family and patient. The care coordinator also does one week pre-contact visits so the PCP can review what has been going on (i.e. with sub-specialists) before the patient’s appointment. Education - Speaker comes in each month to talk about what community resources exist. Parent Involvement - Have developed a parent advisory committee. **(E2)**
- LC format and exercises were definitely responsible for the changes that were implemented gave them a system and the impetus to explore and also gave them some credibility and legitimacy in the clinic to pursue this and increase awareness. Sticker system on charts to identify CSHCN. Flashing button on electronic scheduling screen that identified CSHCN as complex cases. Used to warn schedulers not double book patients and to give physicians more room. Also allowed physicians to prepare for these cases and arrange their days accordingly. Located a wheel chair scale that has made a huge difference for some families. Doubled efforts to make sure that physicians got medication and problem list up-to-date on medical charts, particularly for CSHCN. Adopted AMA emergency medical form in clinic and with specialty providers. Developed a tri-fold brochure for parents to educate them on ways to improve care for their child and coordinate care more effectively. Created/Disseminated a Parent Handy Book. Developed Parent Support Group. Parent Focus Group planned but not yet implemented. **(G1)**
- Improved parent participation and feedback. I have good relationships with my families and informally receive feedback. The parents gave criticism and had great suggestions. **(D)**
- We know these families better – we know their circumstances better. **(C2)**
- The LC format was critical in that it allowed for the exchange of good ideas of how people organized around a problem. Not many changes because they were so far ahead of the curve previously. **(A1)**
- Designated care coordinator. Labeling our charts. Continue to have parent influence – still meet monthly with our team. Once/month invites a different service from the community to come in and give a presentation. Formed parent advisory group; care coordinator and physician leader sit in on this. Working on funding issues right now; what funding opportunities are available in our area to get kids plugged into Medicaid, on the

Waiver – trying to make an information sheet or guide for new parents to help navigate the system; its what they have found most frustrating through all of their experiences. (E2)

- Make sure we see CSHCN for yearly appointment. Develop full care plans. Office nurse is care coordinator, so parents no longer have to drive 45 minutes to Children’s Medical Services (CMS) for care coordinator separate from pediatrician. Develop emergency care plans. Parents more involved.
- We use our care plans with specialists. Communication has improved with providers. (J)

10. Has there been any change in the way in which you access other resources/organizations that serve CSHCN within your community (“family care networks”)? (e.g., more knowledge of, more communication/collaboration, more referrals to and from)

- Referral networks are improved. The practice is more aware of available services and vice versa. (E2)
- Organized brown bag lunches with area referral providers to help learn more about existing referral services. (E1)
- Always worked well with schools but have worked harder to improve relations and communication with specialty providers. (G1)
- LC helped to facilitate better, broader bonds with area referral agencies. Children’s Hospital, mental health clinic, public schools – good relationship with nurses who work in the schools and teachers/principles. Also last year we hosted two community partnership programs and thought about how to hook parents up with SSI and other organizations. The best bond I have is through the public schools and I do want to continue forming bonds with other organizations. (D)
- Binder with the resources that are available – but must work to keep it updated. Parent partner is affiliated with Institute for Family-Centered Care. Has assisted me and has been a valuable resource in directing families to where they can go/what avenues they have. (C2)
- Parents were calling specialist and are now getting some assistance, but wait times are increasing due to increased demand. Physicians are using care coordinator to assist with referrals. (K)
- The referral network has not changed for me, since I am the social worker. The communication is good with Early Childhood Connections, but not as good with Social Services. RNs and physicians more aware of referral networks and resources in the community. (A2)
- No change in accessing other resources. Referrals are more streamlined. We are better organized (A1)
- Much better communication between us and referral agencies because we are getting to know each other better. (E2)
- Office RN is now care coordinator and makes many referrals, though tries to have parents make their own appointments, unless impossible. Institute of Family Involvement representative has been handling issues with schools, so the care coordinator has not yet been involved with schools. (C1)
- We use our care plans with specialists. Communication has improved with providers (J)

11. Were the LC meeting helpful to you? Would you say that the emphasis of the curriculum (nuts and bolts issues) was more than was needed, less than was needed, or about right? Are there other nuts and bolts issues that you think it would have been helpful to address (prompt specifically for cultural competency and youth transition issues)?

Impressions of CQI/PDSA

- Emphasis on continuous quality improvement (PDSA) format was very helpful and useful. It was not a revelation for him but definitely helpful. (H)

Thoughts on Nuts and Bolts issues addressed in sessions

- The first time, I did not want to go and had to make myself. Then I started to realize that it is important for me to understand coding, etc. even if that is not specifically my job. The sessions with parents and with practices already doing care coordination and implementing MH were useful. (E2)
- Billing and getting paid for this type of stuff is essential but I always felt very discouraged afterwards as I felt like the information we got was not going to change anything with payers – so maybe too much time devoted to it for the results we got. (E2)
- Emphasis on nuts and bolts issues was appropriate and on target. Everyone was desperate to learn more about billing and how to get paid more regularly for the care they were providing (G1)
- I think the focus on nuts and bolts issues was just about right – I do not know if I learned anything differently because that was something I took on independently of the LC and I had gone to a lot of coding classes but it reinforced what I already knew. I think billing is an essential to address head on because for the most part private practices are going to say I cannot afford that. (D)

- Very important and worthwhile as coding and billing are sticking points of the MH concept. Insurers need to recognize they are saving money. (K)
- Billing/coding/reimbursement issues very important. (I)
- Nut and bolts session were helpful (C2)
- Billing and coding not helpful for physicians. Other stuff much more important. (H)
- Right amount of emphasis on nuts and bolts. (C1)
- Billing practices was helpful. (J)
- Coding was a big issue and it was helpful to review. The physicians were particularly interested in the coding. (A2)

Issues that should be addressed but were not

- Cultural competency might be useful for other practices, though not so much for us as our populations is fairly mono-cultural/mono-lingual. Youth transition issues would be a great topic to cover – it is on our practice’s list of goals. (E2)
- Could not think of nut and bolts issues that were left out. Cultural competency not an issue for their clinic. Transition is important but did not see it as a glaring omission. (G1)
- There was maybe one session on cultural competency. It would have been helpful to address this issue and youth transition. (A2)
- No language barriers here. Taught respect of CSHCN and families. Have refined our youth transition systems. Have a fax back survey for agencies willing to take patients. (K)
- Talking about youth transition issues is useless because there is no place to transition to, no system for this. (C1)
- Cultural competency issues, transition, and getting buy in of senior administration in larger organizations should have been fleshed out a little more. More on sustainability and how you can get practice sites to keep efforts going after the project. (J)

General Thoughts

- Thoroughly enjoyed that part of it. I found it interesting. “I thought that the learning sessions were very well done – good balance of issues that were addressed.” (E1)
- Best part of LC was information sharing at conferences, everyone was very willing to share information and participate, and no one was proprietary about what they were doing. (G1)
- It was very helpful to see what other practices were doing overcoming same obstacles as us. (D)
- Hearing from individual families useful. Ways of accessing resources helpful. (H)
- Sometimes things did get slow and drag and more time could have been spent on one-on- one with practices already doing the MH. Would be helpful to have something on interactions with states, but this would be hard to implement for a national collaborative. (C1)
- Title V supplemented with a presentation on youth transition. It was valuable hearing parent speakers. Would be good to have as part of the LC. (J)
- Implementation is a challenge and takes practice but it does work. (H)

12. Generally, the Learning Collaborative process, as developed by the Institute for Healthcare Improvement, focuses on clinical settings for continuous quality improvement. This process was somewhat different than most in that it included Title V/CSHCN state staff as part of the team. What were some of the pros and cons of having state involvement?

State Participation was excellent

- State participation was excellent. Historically, the level of communication with the state has not been productive so this was an improvement. (E2)
- It definitely has forged a wonderful relationship between our clinic and our state MH director. We have met a number of times to discuss issues and most recently we have been emailing back and forth to get together a group of physicians that are interested in working out transition issues for our population. (D)
- Thought it was great – one of the members of the team was from the state – the link to Niche Q – the field nurse. (E1)
- Cannot think of a single negative thing – they helped fund it – they were always a resource for us. (E1)
- No cons to state involvement; had a very positive rapport. (G1)
- Great Resource. They have a long standing relationship with the state Title V team and have had very good relations. This relationship will surely continue. (H)

- Nothing would have happened without the state. (H)
- Very strong pro – Title V agency funds my care coordinator role (since January '04). (C2)
- One of the more valuable parts of the LC as noted above. (I)
- No cons, good for networking, and great information resource. (A2)
- State participation was great – allowed doctors in the trenches to talk with the people who sign the checks and to see each other's perspectives. (C1)
- They were extremely supportive both financially and in providing the person with the state who met with us monthly and helped us work through issues and she took ideas back to state. (E2)
- Great. (J)

State Participation OK

- State did not do much due to lack of resources and the lack of time to focus on their project. Likewise, state staff did not seem to be able to devote the time they wanted to the project. (G1)

State Participation Not So Valuable

- The state kept pushing which was a pro and con. Felt a little intrusive, constantly checking to see if meeting goals. Certain evaluations took some time (A1)

Other Comments

- They gave us permission to make mistakes. Invited us to be part of a statewide Learning Cooperative. (G1)
- Did not have state involvement, would imagine it would shift thought process to the Medicaid population. (K)
- There needs to be more collaboration between public and private offices. Public health departments work on broader based systems stuff and the practices are dealing with the frontline daily needs of patients, and there is a disconnect between the two. There needs to be a transitional focus there that looks at that disconnect and it needs to come from public sector. (M)
- This contact with state was what led the practice to be able to set up a pilot project by which the state provides funding for a care coordinator. Previously the practice did not know and was not in contact with the state staff, this process created a connection. (C1)

13. What type of support do you think the State Title V should be able to provide for you at the practice level? Have you been able to get this type of support? Do you have an on-going relationship with the State? Please describe.

Provide Funding

- The state's financial role in providing education and sending us to places to learn was extremely helpful, particularly because the practice cannot always afford to do this. Some felt that the state had created an unfunded mandate which was unreasonable. Funding care coordinator is what would help most. (E2)
- Funding for care coordination role - Should provide 25% salary to get regional care coordinators. (D)
- Provide us with more social work help or clerical support. (C2)
- Could provide funding to hire care coordinator. (A2)
- Funding for care coordinator and TA re: implementing MH and CQI concepts. (C1)

Provide TA

- Provide TA to sites on PDSA and the MH. (G1)
- Funding for care coordinator and TA re: implementing MH and CQI concepts. (C1)
- Transition should be a state emphasis. (J)

Information Dissemination, Advocacy, and Promotion

- Information dissemination – available resources, how to get parents involved, family advocacy, etc. State should advocate for managed care organization/reimbursement policy changes. (D)
- Helping to share information between clinics involved. Hold all practice site meetings. (G1)
- Resource for Medicaid and billing issues and parent/family advocacy issues. (A2)
- Provided technical support, identified resources, organized monthly conference calls. (H)
- Title V does a lot through SSI and through other service agencies that they fund. These services should be better connected with primary care practices. (M)
- Title V is advocating among the state payers for better reimbursement. (E2)
- They are keeping the idea alive and expanding it to the whole state. Working with five regions, stimulating them to continue meeting and keep up the momentum. (J)

14. Similarly, having parents involved is somewhat different from the norm in LC processes. What were the pros and cons of having a parent on the team? Do you have an on-going relationship with the involved parents/other

parents? Please describe./ 15. If we surveyed parents of CSHCN about their experience with your practice, what do you think they would say?

- Parent involvement is necessary to this process because it makes you aware of the real, human side, not just the statistics. It is good to know what parents want for their children. Based on the recommendation from a LC physician we selected two parent partners. Unfortunately one of them had young children and was busy at home during the afternoons. She was here for one year, but it did not work out for her. We would like to find someone to replacement. Our second parent has been with us throughout and is indispensable. Currently we have one parent on our core team, we have the parent advisory group, and parents within our practice network with each other more informally. Additionally, the parents are working to explore healthcare and more general funding. Our parents are not yet interested in advocacy. That is a longer-term goal for our practice. (E2)
- Parents are invaluable. In the beginning a lot of the parents felt intimidated but gradually grew into their role. (E1)
- Very positive to have parents involved. Clearly one of the goals and interests of the clinic. Two to three parents participated and were part of the PDSA process. There was some frustration on both sides of the fence with trying to organize this aspect. Very time consuming for clinic basically doing this on own. Have created a Parent Support Group. Gave parents the expectation that there was going to be more to what was going on but not much has happened from their perspective. Raised expectations at the beginning and then could not find as much time as they wanted to do things with parents. They are hoping to hold a focus group. (G1)
- “We really had problems getting them involved in an active role”. (C2)
- Great to have their involvement. Our parents are very committed. They were able to attend all three sessions. We are working more on the individual level to get more family involvement. For instance, using our registry, our front desk staff calls the family the day before their appointment and reminds them to bring a list of concerns with them to the appointment. This is, in essence, their care plan. We contemplated the idea of developing a parent support group (support for one another), but decided against it because most parents are already involved in support networks outside of the practice setting. (I)
- Have a good and long-standing relationship with the parents. They are very insightful, Have good ideas for the forms. (A1)
- Parents had good ideas and had a positive impact. At first, both the parents and we were unsure and had a hard time getting together. Dropout rate high. (A2)
- Have heard rave reviews; linked to individual physicians. Had two parent forums; one was an info session from the superintendent (12 participants) and the other was a one-on-one listening session (three participants). There are parents that will be advocates and there are those that are too burdened. They need a lot of things, but often have limited access. Like pre-visit contact/survey; more streamlined. Some do not want to be identified as MH. Reached out to families and tried to get them involved but it was very difficult. Conducted a parent listening session and held a “focus group” on what worked and what does not work. Only three arrived out of 10, which was discouraging. Did a survey to try to figure out what was going on and how things could be improved. (K)
- State lead for Family Voices was part of the project; serves in advisory role. In addition has a parent of a CSHCN on the project but this part of the project has been difficult and they dropped out. To some extent they seem to have relied on feedback and support from Family Voices. Hoping with new coordinator, regular parent meetings will get off the ground. (H)
- There were several parents we identified and when we met with them they were enthusiastic but soon thereafter they were unable to make meetings. I was still in the mode of wanting to run the process and I never could transition myself to a mode of thinking about what the parents want. In many cases physicians think they are right and parents think they are right – I think it was fear that if I heard too much of what they wanted to do that I could not accomplish it would make me look bad. (M)
- Parent leaders have provided feedback on operations but it is hard to get parents to participate; single mothers, financial problems, stretched thin. (C1)
- That was excellent; we had a great time and our parent partner who stuck with us the entire time. She is still on our committee and has provided her time and great ideas we would not have thought of without having the parent perspective. I think our parent partner was very pleased with it – gotten a lot out of it as well as contributed a lot. Thinks that it has improved patient satisfaction. (E2)
- Invaluable to hear the parent’s perspective. Did a walk through with them and heard what it is like at each point of the visit. Not involved as much as they would have liked. (J)

16. What are the shortcomings of the LC framework as a means of encouraging medical homes?

Dependence on Grant Funding

- Dependent on our grant funding to keep sites involved in LC process and to retain care coordinator. Need to prove through ER rates, parent satisfaction, and physician time saved that this is a worthwhile investment. (E2)
- I think more information and background on the MH concept would have been helpful. “It was overwhelming trying to decide where to start. “Medical Home for Idiots” but that is just me I always need that simple little primer.” (D)
- No shortcomings. “Thought everything was very well organized, topics were relevant , excellent settings” (E1)
- Very positive experience. Is time consuming but as long as you keep things in perspective. No major shortcomings. They did not have a lot of resources to invest in new systems or the process itself. No staff time set aside. Doing it all on their own. No care coordinator. Need to think small, which they seem to have done well. They had to make sure that changes were cost neutral so could not do anything too grandiose. (G1)
- Need more resources for TA – TA is critical to actually implementing (versus only learning about) the MH. i.e., working individually with a clinic to assist them in devising their plan and offering support in following through on the plan. TA has been incorporated into statewide LC, where each site receives a number of days of TA. Should have had more preparation for national meeting (I)
- Financial help would be nice. Constant reassessment necessary but cumbersome. (A1)
- Pair practices with like practices. Education was onerous at first, but usually valuable. How do we pay for all this? (K)
- Time is the biggest issue and challenge. CQI takes a lot of time. You need personnel to manage it. Personnel in general is also a problem. Hard to get physicians motivated to be part of it and also care coordinators who are willing to work and stay for long periods as the care coordinator. There is a lot of training required and in the end the physician champion is responsible for doing the training. If the care coordinator leaves then it is hard and time consuming to replace him/her. Day to day, you have to keep thinking of a system, that may not be perfect, but will not ever be unless you keep thinking about it. (H)
- It does not necessarily address the needs of larger practices due to issues regarding bureaucracy and lack of autonomy. Care coordinator kept bringing up new barriers and we would try to fix one barrier and in fixing it we brought up other barriers. By time she left we had a lot of buy-in from the physicians in the office (but not the staff). It is too broad. It needs to be more of a functional plan; a cookie cutter kind of plan that can be put in place. (M)
- Maybe need more time to network with offices that are already doing this. (C1)
- Most providers do not have the time to see if it saves time or makes a difference. It is just one more thing they have to do. (J)

17. Is the Medical Home sustainable? Why or why not?

Yes - Absolutely

- It takes a lot of initiative and commitment from the staff but I definitely think it is sustainable. (D)
- Changes that they made are absolutely sustainable as they were cost neutral and not very burdensome.
- They have had a very positive effect and generally everyone seems bought into the process at their clinic
- Yes, absolutely. Concept is not new – We have been providing a MH and treating the whole family for a long time. (E1)
- Yes. Even care coordinator position is somewhat reimbursable if one uses the appropriate codes. (I)

Yes/Maybe - IF

- Care coordinator role funding is essential. (C2)
- Think about how to divide up care coordination activities/goals between existing staff. (D)
- Parent company (Regional managed care organization) has had very limited interest in trying to get their overall Health care System. Site involved in this effort and to expand things beyond their clinic. (G1)
- Need to overcome the barriers of time and money. Reimbursement is the big sticking point need to work with insurance companies to get them to change reimbursement policies and get them to value the power and impacts of the MH. (K)
- My time was not funded because my position already existed, but it did take additional time, not sure I could do it if it were not funded. (A2)
- Yes, if we had a care coordinator. Hard to do without one; everybody very busy. (A1)

- Yes as long as care coordination continues to be paid for. Currently having a care coordinator in the practice means that kids being seen at the office are not going to the Children's Medical Services for care coordination. This is budget neutral. **(C1)**
- I really do think it is ultimately but it requires such a change in philosophy of physicians and they are such the driving force it will be very slow coming but if we do not keep working towards it, it will never happen. **(M)**
- I think so; I think we are definitely sustaining it in our office with the caveat that we would not have been able to afford a care coordinator without the grant. The practice is very committed though so we would probably make it work. **(E2)**

Challenges

- Made more challenging due to lack of funds for a care coordinator. **(D)**
- Hard for private practice, time wise. Ideas and concepts valid but impractical in private practice. **(A1)**
- If we had funding we could do chart reviews to check for appropriate coding and care plans. Also we could use funding so physicians could take part in care plan update meetings. **(A2)**
- It is sustainable in a medical center (academic) setting but it seems like it would be a lot more challenging in a private practice setting. Obtaining compensation for services is the only way to sustain this program. **(H)**
- Need clinic backing. Needs to be written policy, systems in place, and it needs to be somebody's job. Need a paid care coordinator. **(J)**

Other Comments

- It is easier for FPs to do MH than it would be for a pediatrician. Our care coordinator was fulltime in our office anyway and care coordination was just one aspect of our time – we used those funds for extra hours. We did not have to hire someone as a fulltime care coordinator – our care coordinator coordinates care for our adults too – that is basically what she does. **(E1)**
- Insurers need to see and be pressured to incorporate calculus into rating setting. Need to get pharmaceuticals reimbursed. Prove to them that it is cost saving e.g. care coordination and reduced emergency department usage. **(K)**
- Suggested that sites get compensated outside of the FFS mechanism for care coordination. If it is based in FFS system then it does not empower nurses and clinicians that can not bill to be involved in care coordination. Clinics should be compensated on a per patient basis for caring for complex cases. This would lead to better care coordination, higher quality of care, and ultimately reduced costs. The managed care companies would benefit the most and therefore should pay. **(H)**

PARENT INTERVIEWS
EVALUATION OF THE LEARNING COLLABORATIVE ON THE
MEDICAL HOME FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Summary Responses

Please note: All individually, practice and state-identifying information has been removed from the interview responses. Also, where interviewees answered questions previously, certain questions may have been skipped. For consistency, letters assigned to represent each parent correspond to letters used in the summary responses of the state and practice interviews. If followed by a number (e.g. J2) this indicates that there were parents from multiple practices interviewed in the state.

1. Before you made the decision to participate in the Learning Collaborative, how much did you know about the LC approach?...How much did you know about medical homes for CSHCN?

- Did not know about LC approach or MH for CSHCN. (A)
- Nothing before my pediatrician approached me. (K)
- Was not familiar with concept. (I)
- On staff of Department of Health, Title V, in Parent Advocate position. Also parent of CSHCN. She serves as a resource to families in the Jacksonville area who have CSHCN from age birth to 21. She is “family voice” at DOH in all decisions related to CSHCN; she provides input on materials and resources that are developed that are directed to families. She has been paid for three years; did things informally previously. She sees mission as providing comprehensive care for these kids, based on family involvement, dignity, and respect. (C)
- A little bit about the LC. More about the MH. She sits on a state MCH advisory committee and a MH from another state came to a meeting and gave a presentation. (J)
- Nothing about either LC or MH. (J2)

How did you make the decision to participate? Who approached you about participating?

- Pediatrician’s office approached me; respect pediatrician and it sounded like a great idea. My child was medically manageable. Have MSW and volunteered before; seemed a way to get back into professional world.
- I was an isolated single parent and it seemed a good way to be less isolated. Thought I personally could benefit as well as help others. (A)
- Have a background in advocacy for young children. (K)
- Former social worker for Title V program for CSHCN so they asked me to participate. Doctors nominated me. Thought this would be a great opportunity to help parents like self. (I)
- Approached by several people within Title V, DPH to participate in the LC. (C)
- A family provider that was “always there for us” (has since moved) asked if I wanted to be involved and spoke to my pediatrician and got her buy-in. (J)
- My pediatrician approached me and gave me a brief explanation and I decided to do it. (J2)

2. How would you describe the Learning Collaborative process to someone who has never heard of it?

- Described MH, not LC. Not tangible, not a place. How families and doctors can partner in community to coordinate and develop comprehensive, consistent, quality service. Requires a paradigm shift. (A)
- Sharing ideas on how to improve care for CSHCN. (K)
- They would have to have a strong team, have to have a care coordinator, one designated PCP that would take on the responsibility, and they would have to have team members that had the time and energy to commit to this process. People did not know what they were getting themselves into. They did not realize there was a project involved. The clinic I went with is different from other practices – 70% Hispanic, a lot of turnover in front/receptionist areas – lost one of best nurses – high turnover. Everyone has no medical insurance, eight different languages spoken. Need to have team members that will stay, be committed and educate team before they sign the papers. (I)
- Opportunity for families and medical community to bring their ideas together to develop family-centered systems of care. (C)

- A group of 17 states appointed by MCH and their participating clinics interested in MH, coming together to learn to put a comprehensive program together for CSHCN and everyone who knows them and who are involved in their care and know their needs. (J)
- Complicated. A contained decision making process to decide where you want to go and what data you want to collect. (J2)

3. What were the goals that your team hoped to achieve through the LC process?

- Consistent parental involvement. Sign on more clinics and providers. Understand MH concept and talk about more knowledgably. Spread the word about MH. (A)
- Learn from other states how to collect data. Prove to insurance that we could save them money through this process and get them to pay for consultations. (K)
- To expand the team to get more members. But only lost members – at least 300 CSHCN with one part-time. Identify the children. Get the parents involved – provide resources for them. Parent-to-parent matching. (I)
- I participated in parent teams, practice teams, and joint meetings between practices and parents, I also wore Title V hat. A goal was to get practices and Title V and parents to all understand what a LC is. Another goal was to figure out how we can implement this in three practices in our area; how this can be done in everyday settings. (C)
- Put together a comprehensive three-four page care plan with our clinic and the Children’s Hospital people. (J)
- Identifying (flagging) of CSHCN and then devising a portable care plan. (J2)

4. To what extent and in what ways did you feel you were a partner in the process? To what extent and in what ways were you able to contribute to the team?

- Helped recruit parents. Partnered in development of time studies; walked through and sat with parents. Helped develop survey given to parents. Data compilation for survey. Brief presentation. Parent meetings at my house. Development of care plan. Tried to set up pilot where parent could consult with physician without child there – not sure what happened to idea; probably no way to bill for it. (A)
- Full partner; we were really a team. They were paid and I was not; maybe they felt they were overusing me. More advisory role for implementation. (K)
- Parents feel more empowered to talk with physicians, even personal level thus, deepening relationship. Looking at medical team as people. Intimidation factor has decreased. On few panels to talk about MH. (C)
- Each time we met with a coding person from the hospital, but feels her biggest contribution was the letter she wrote to families explaining the MH so they would understand the concept and encourage them to get a care plan together. (J)
- I basically developed the care plan and then sent it out to the team and other parents for suggestions. (J2)

5. What did you like about the LC process?

- New idea geared toward CSHCN. Helped to know pediatricians office better. Helped families and providers see where the other side was coming from. Relationship building. (A)
- Meeting people from across US. See how they interfaced with their state government. I was able to get the state involved; called the governor’s office and then they got involved. (K)
- Information they gave was wonderful. People who greeted us/organized it very friendly and helpful. Maybe more story-board time to get a better idea of what is going around the nation. (I)
- Meetings with other states and find out about what they are actually doing – what is working/ not – care notebooks are an example. Liked how booklets were set up with timeline. Liked support system – knowing that support exists, team open. (C)
- It was very inclusive of parents and represented families. There was a session to talk about our fears and concerns and another session that helped us prepare for presenting to other parents that she was going to use with a parent support group, but she never got the chance. (J)
- I learned a lot and I like being valued as a parent. (J2)

6. What didn’t you like about the LC process?

- Figuring out parents’ role in process initially. Some parents dropped off, lost interest. Need list of what to do. Need to shape their role. (A)
- Sitting for a long period of time listening to people. (K)

- PDSA tool was confusing – great tool but more time was needed to explain/educate make everyone more comfortable with using it – if you do it, it will work. Getting the parents together was very hard – a lot of them saying they did not know who the parents were in the beginning – high parent turnover – parents wanted more involvement in meetings. Doc site was a hard thing to obtain thru the hospital but we thought this would be a great system to use. Parents were not paid to go, not sure if any members of the team were paid to go. Trying to speak for other parents, hotel accommodations were terrible ; staff was nasty – a lot of really negative things. (I)
- Meeting more frequently on the national level. (C)
- Should have mini meetings for new parents/practices – more sharing to go on – more dates to choose from (if you missed the big one, there will be another). (C)
- Felt there was some behind the scenes discussion that parents were not privy to and that parents should be dealt with honestly, one-on-one. At some clinics parents were freely reimbursed their time and expenses, but her clinic said they wanted to use the money for a parent support group that never happened. She had to call the state and raise hell before she was reimbursed for childcare while at the LC. Thought her clinic should get grant money for support group. Also, parents need to know about the room deposit before they get there, especially, if they do not travel much and are far away from home. (J)
- There has been a lot of red tape with the administration of the clinic and the other pediatricians. Just her pediatrician is working on it. “The others think it is a great idea if we get it going.” (J2)

7. Describe any changes in clinical services that you have noted since your involvement in the LC process.

- Based on time study, made changes in scheduling, allowing more time for CSHCN and have “block” appointment times (i.e., blocks for sick kids and blocks for well kids). The care plan – one page at-a-glance for specialists, school. (A)
- Created pre-contact structure, follow-up, identifying (charts marked). Started using Board Maker (commercially available communication aid for kids with limited language skills) to understand what a child’s needs are. (K)
- Not with the clinic I attended with; we found that they were not interested. The director has always shot down all my ideas. I do not think she understood what I could do for that clinic with my computer skills and Spanish. She would not let it stay. Not sure why cannot make the doctors continue to do it – no buy-in from administration – buy-in is gone – they left. Met person who is well acquainted the organization Medical Home PLUS – trying to spread it throughout state. Best thing that came out of LC – needs to work and want it to work – statewide coalition. (I)
- Practices now make sure parents are invited to the table. They realize importance of parent involvement. Parents so excited to know they have a voice in the clinics where they are seen. Parents are actually “in” practice – e.g., parents going in and setting up kid friendly area. (C)
- Developed code for identifying CSHCN in data system. 10 parents developed their child’s care plan. Was very pleased with her child’s care plan. Did not realize how much information providers needed. She gave it to her child’s school, to her specialty providers and when she transitioned to adult care (daughter is 20 now) to her new provider. The MD and nurse coordinator helped with the transition. (J)
- Changes are limited to only a few CSHCN. Only a few have care plans. The administration is not allowing any time for the pediatrician to implement. (J2)

8. Describe any activities that you are involved in currently related to medical homes or CSHCN (prompts: advocacy, working with schools/education system, committee/coalition work)? Do you think you would be doing this if you hadn’t been involved in the LC?

- None; moved further away and am working full time. Would be happy to work from home if I had a list of parents to call or something like that. Have some time because now my son gets 35 hours a week of in-home nursing care. (A)
- She participated in a parents’ panel and provided input on CSHCN and it was really counterproductive but she said that if something was well organized and people thought she could be helpful that she would definitely do it again. (K)

- Worked on “care notebooks” – system for parents to organize the care for their child; e.g., names, addresses, and appointment times for all services. They got this idea from other states at the LC – the state (led by this parent) has completed this and they will soon be distributed statewide. Clinic group meets regularly to organize ideas – planning sickle cell day, with child care available and expert speaker. State provides some support for parents; e.g., providing a facility to meet – they do not provide transportation. One of the offices is physically looking at expanding waiting area to include a “sick” area (cut down on contagion). I am involved with this. Another idea being considered is establishing a “transition practice”, where adult medicine physicians would be placed with pediatricians to ease transition of CSHCN to adulthood. One practice thinking of setting up a beeper system, so parents can wait outside or inside their car until their appointment time (helps if a CSHCN gets hyperactive given stimulation of waiting room, for example). (C)
- Says not involved because: Daughter transitioned into adult care; but see #7 – gave care plan to adult provider. Also (mentioned later in conversation) made copies of MH documents and shares with anyone who is interested – other parents, friend who runs group home for the disabled. This friend is using MH documents at this group home. At other clinics, parents were paid for their time and saw other parents on a day-to-day basis, but she was not and did not. (Not sure of her point, but maybe on-going relationships not established?) (J)
- Still working with the team, but not really involved in any other activities. Would have absolutely been involved without the LC, though. (J2)

9. Are you still involved with the clinical site on medical home issues or other issues of serving CSHCN? If so, in what capacity?

- No. (A)
- Covered autism; have moved on to something else. Not as involved as I was, but would be if needed. (K)
- Not involved. See above #8. (J)
- Still the parent partner trying to get care plans in place and a trying to get a parent group together. There is so much red tape from the administration. They will not release names of parents. (J2)

10. You’re now a year removed from the process. What has endured a year after completing the process of LC?

- The systems have been maintained. Insurance thinking of reimbursement. (K)
- No it has not been maintained. The physician who was in charge left. The new director said he could not handle it. Then it was passed on to someone else who said she will start it in summer (when she started in spring) – she has not called and I ran into her today and I just know that its completely fallen apart and I put a lot of hours and effort into that project and I really wanted to see it take off. There is a lack of drive in the clinic as well. They have lost two of the best nurses they have ever had. The project fell apart after July last year – I lost funding, my mentor has written proposals to the director of a Title V program to implement parent-to-parent. There is no funding for me. I have been unemployed for four months for now and I cannot find work. Paid under a catch grant – did research, wrote the bibliographies for the grant, did consulting, talked to other organizations – organized it, bought the food. Did it for free for six months, then they hired me because they got the grant but then we lost the grant and did not get the second grant that we worked for – I cannot work for free. We did a lot of work as a team with a tight schedule. We worked our butts off – we did medical summaries. I did them all and put them all in their charts to be filled by the doctors. We created PowerPoint presentations – we had meetings with the staff. We were very passionate. (I)
- Not involved anymore, but called the RN coordinator because they have become friends and she said nothing was happening. There needs to be more buy-in from the administrators of the clinic and Children’s Hospital. (J)

11. Would you choose to engage in this type of process again? Would you recommend to other parents that they should be involved in such a process? Why or why not?

- Yes. I would recommend to others because you can get isolated and feel that the office does not care. Nice to be involved. It is difficult to involve other parents; some cannot spare the time; some do not even have transportation. (A)
- Yes, I would be involved. Would recommend to other parents if they had the time; and insurance would pay for childcare. (K)
- I would do this again. What will I bring back and how will I be able to implement the things that I learned. I do know that the hospital has a program with a physician who is really interested. I would love to share – I am definitely an advocate – I would love to learn more and help others. If I had to do this all over again, I would want a team that is committed and organized. I would want a good team. You need a good foundation. (I)

- Yes, and I would recommend it to other parents. (C)
- Yes, it was wonderful and I am glad I participated. Believes in the MH concept and thinks that if parents are not happy, they need to “keep beatin’, and beatin’ and beatin’ on the door ‘til someone answers”. Thinks it will be hard to meet 2010 and MCHB outcome measures with administrative barriers and it would be easier to lay down the law from above and have it trickle down, rather than trying to get this idea to trickle up. (J)
- Yes, would do it again and yes, would recommend it to others. Changes will not happen unless parents ask for it because parents are the ones who bring in the money. (J2)

12. Is there anything else you would like to add about your experience with the LC that we haven’t addressed through our discussion?

- It was a great experience. Would like to see how other states overcame barriers for involving parents. Family should be given some sort of incentives for participating – child care expenses, for example. Include families from all socioeconomic classes although a challenge for lower income persons because of financial barriers to participation. Might be good to have a “go to” type of parent for other parents. (A)
- If HRSA could spend a tenth on adults on what they spend on CSHCN and transition issues, that would be great. After become adults they are dropped from the system and life expectancy has increased a great deal. (K)
- Medical Home PLUS provides resources, statewide coalition among all these different organization for children, Parent-to-Parent, etc are all in it. They are putting a lot of emphasis on mental health for children because my child does not know how to deal with the fact that she has a disability – not just physical health but mental health as well. Put parent-to-parent matching in the LC?? (I)
- No. (C)
- Feels like her CSHCN is a gift and a calling from god to improve things for others with special needs. (J)
- Nope. (J2)

Parent Partner who was unable to participate but had following comments (C1):

- Had to drop out after two months because her father became very sick and almost died. However, she noted that the service she has received has dramatically improved because of the LC. She noted what we learned in an interview with the practice she goes to had told us about how they worked with Children’s Medical Service (CMS) to get a care coordinator on site. The care coordinator is now her point of contact. She is accessible, responds quickly, and is organized and knowledgeable. When her daughter had a seizure she called the care coordinator who organized all the hospital care. When they switched insurances the care coordinator organized everything involved with that including helping them to get secondary insurance to pay for what was not covered. She believes that this all would not have happened without the LC. She was only able to attend one LC session but from that she commented that she liked how they brought in other successful ideas and showcased them. It made what was seemingly an overwhelming and daunting task seem more achievable.