

Evaluation of the Statewide Implementation of the Medical Home Concept
for Children with Special Health Care Needs, Phases 1 and 2

2005 Final Report

Prepared for:

Iowa Medical Home Initiative

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Executive summary

Since 2003, the Iowa Center for Evaluation Research has worked with the Iowa Medical Home Initiative to perform a process evaluation on its initial attempt to establish medical homes throughout the state for children with special health care needs.

The Initiative used several entities to advise and implement the project: a Planning Group, a Core Advisory and Action Group, Facilitation Teams, Physician Advisors, Nurse Facilitators, and Family Partners. Health care clinics were recruited to participate in establishing medical homes in three phases. This evaluation covers Phases 1 and 2.

The process evaluation approach ICER used allowed for flexibility in planning and research design, and helped educate both evaluators and IMHI project staff. Evaluators used a mix of qualitative and quantitative methods and succeeded in measuring implementation steps not dependent on the medical home definition and those outcomes that occurred before the evaluation period ended.

Generally, the medical home concept may be stated as a continuity of family-centered, community-based, coordinated health care, and in IMHI's case, especially for children with special health care needs. Other organizations prefer a chronic illness focus. This is neither a complete nor accepted definition of a medical home model; indeed, lack of a clear definition influenced both Initiative and evaluator efforts. Establishing an accepted, understood definition would make a big difference in future project and evaluation successes.

The evaluation findings suggest that the Iowa Medical Home Initiative is very much a work in progress and that adjustments to current plans and strategies are needed if the project is to meet its goal of establishing medical homes throughout the state. In both Phases 1 and 2, the evaluators found that medical home adoption proceeded slower than IMHI anticipated. Phase 1 Clinics, although surprised at how much work was involved, believe they are on the verge of becoming medical homes. IMHI's efforts, tools, resources and encouragement were cited as prime reasons for successful progress. Barriers that either slowed achievement of medical home status or caused a clinic to drop out of the Initiative were demands on clinic staff time, the workload required and technology constraints.

Findings about Phase 2 found that Nurse Facilitators played a significant role in helping clinics begin to adopt a medical home model. Their experience with Phase 1 clinics was a source of expertise reassuring to Phase 2 Clinic staff. Having an enthusiastic physician on staff or a motivated Physician Advisor was also helpful. Some of the barriers to medical home implementation in this phase were time constraints on clinic staff; meeting attendance and content for the various planning and advisory groups; technological problems at the clinic level; and for all concerned in both phases, lack of a clear medical home definition.

Recommendations to the Initiative include:

- clinic/practice recruitment (develop ways to speed the process and reduce wasted time);
- facilitation (make better use of the theoretical tools the Diffusion of Innovations and the Plan, So, Study, Act cycle to, among other things, help identify internal leaders or champions);
- Family Partners (improve their sense of participation and value);
- planning process (increase strategic planning efforts and periodic reviews and revisit meeting formats and participant invitees);
- Core Advisory and Action Group (alter the composition and role of this advisory group to improve its efficacy); and
- for IMHI overall, several steps are outlined (work more efficiently, improve communication, invite more complete participant inclusion, and redirect policy focus).

This process evaluation concluded that the IMHI primary goal of establishing medical homes in Iowa for children with special health care needs was not met during the evaluation period. This conclusion is clouded by the lack of a medical home definition that would clearly delineate when a medical home has been established. IMHI made adjustments to their planning and implementation processes throughout the project period, but were surprised during Phase 2; additional adjustments are needed. Every aspect of Phase 2, from recruitment to facilitation to implementation was slower than expected after the Phase 1 experience. The dual-pronged policy approach taken by IMHI

appeared more to thin their effectiveness than to expand their reach. More data are needed to assess which policy approach – clinic or statewide level – is more effective at establishing medical homes in Iowa for children with special health care needs.

1. Introduction

This evaluation report outlines the work and results of a three-year process evaluation of the Iowa Medical Home Initiative (IMHI). The Initiative project was designed to promote and establish medical homes. It was informed by the Plan, Do, Study, Act (PDSA) cycle¹ of rapid change and the Diffusion of Innovations theory.² The Iowa Center for Evaluation Research's process evaluation involved close collaboration between the Evaluation Team and IMHI staff.

Generally, the medical home concept may be stated as a continuity of family-centered, community-based, coordinated health care, and in IMHI's case, for children with special health care needs. Other organizations prefer a chronic illness focus. This is neither a complete nor accepted definition of a medical home model; indeed, lack of a clear definition was influenced both Initiative and evaluator efforts. Establishing an accepted, understood definition would make a big difference in future project and evaluation successes.

1.1 Report format

This final report presents a background on the concept of medical home, a review of the IMHI project, process evaluation research questions, methods, findings, and recommendations. The information in this report provides a description of IMHI and data to inform future efforts.

The remainder of chapter 1 describes Iowa Center for Evaluation Research's (ICER) work over the three-year evaluation period. Chapters 2 and 3 supply a description of the IMHI and its history, along with a review of relevant literature. Chapter 4 describes the process evaluation, including research questions, methods, and findings. Chapters 5 and 6 summarize the report and include project recommendations for future IMHI work.

1.2 Major evaluation activities

ICER was selected as the evaluator for IMHI in August 2003. From the beginning, the Evaluation Team was a collaborative partner in the design and implementation of the evaluation. Because IMHI had outlined an innovative project to promote and establish medical homes, the Evaluation Team and the Planning Group established a close collaboration during which the Evaluation Team attended Planning Group meetings, Core Advisory and Action Group meetings, and other key planning-related activities. This collaboration reflected the complexity of the project and allowed the evaluation to react to changes in project design.

Attending these meetings provided the Evaluation Team with an inside perspective, as well as an opportunity to negotiate the shape of the evaluation with those who would benefit most from the evaluation results. As the Evaluation Team began to understand the project, research questions were developed. Initially, these questions were presented to the Planning Group and refined based on their input. Later, as the project changed and matured over time, and the needs of the Planning Group evolved, research questions were modified, added, and deleted. This project represented a unique way to engage clinics in

change, thus at the heart of the evaluation were questions about how change occurred and why. These process evaluation questions were best answered by qualitative research.

The table below (Exhibit 1-1) outlines the evaluation activities.

Exhibit 1-1. Summary of evaluation activities

	CHMI Family Survey	Web/paper Surveys	Interviews	Blogs	Facilitation Meeting Summary	Clinic Quarterly Summary	Meeting Observations and Notes	Meeting Minutes and Agendas	Focus Group
Planning Group		May 2005; June 2005	Fall 2003- Winter 2004	X			X	X	
CAAG		May 2005	Winter 2004- Summer 2004	X			X	X	June 2005
Nurse Facilitators		June 2005			X			X (for some meetings)	
Phase 1 Clinics	X (see Families)	June-July 2005			X	April 2004	X	X	
Phase 2 Clinics		June-July 2005			X(for some meetings)			X (for some meetings)	
Family Partners		June-July 2005			X	April 2004	X	X	
Families	April 2004- November 2004; April 2005								

1.3 Stakeholders

1.3.1 Planning Group

The Planning Group guided the project and had the opportunity to reflect, advise, and decide on decisions important to the project. The Planning Group consisted of the IMHI Physician Director; the Nurse Director; the Nurse Coordinator; three Physician Advisors, including a pediatrician and a family medicine physician; and the Evaluation Team. The group held monthly four hour meetings. This group broke into smaller groups to complete more time-intensive tasks such as event planning and grant writing.

1.3.2 Core Advisory and Action Group (CAAG)

The CAAG was developed as a group to advise IMHI, to provide new ideas, and to give assistance with breaking down barriers to the spread of the medical home concept. The members of the CAAG are representatives from the following agencies:

- Iowa Academy of Family Physicians (IAFP)
- Child Health Specialty Clinics (CHSC)
- Iowa Chapter of the American Academy of Pediatrics
- American Academy of Pediatrics (AAP)
- Family Voices of Iowa
- Department of Human Services (DHS)
- Early ACCESS, CHSC Parent Consultant Network
- Bureau of Local Public Health Services
- Prevention of Disabilities Policy Council
- University of Iowa College of Public Health

- Iowa Foundation for Medical Care/Medicaid Programs
- Wellmark
- Blue Cross and Blue Shield of IA
- Iowa Department of Human Services
- Iowa Department of Public Health (IDPH)
- ASK Resource Center
- University of Iowa Health Care (UIHC)
- Iowa Rural Health Association
- Calhoun County Department of Public Health
- Clinic A
- Clinic C

The group held meetings on a quarterly basis. Action Groups were added to the CAAG to increase the engagement of the group members (See Exhibits 1-2 and 1-3 below).

Action Groups worked as committees organized around areas the CAAG felt required more intensive attention and action.

Exhibit 1-2. Iowa Medical Home Initiative Organizational Chart: July 2003-August 2004

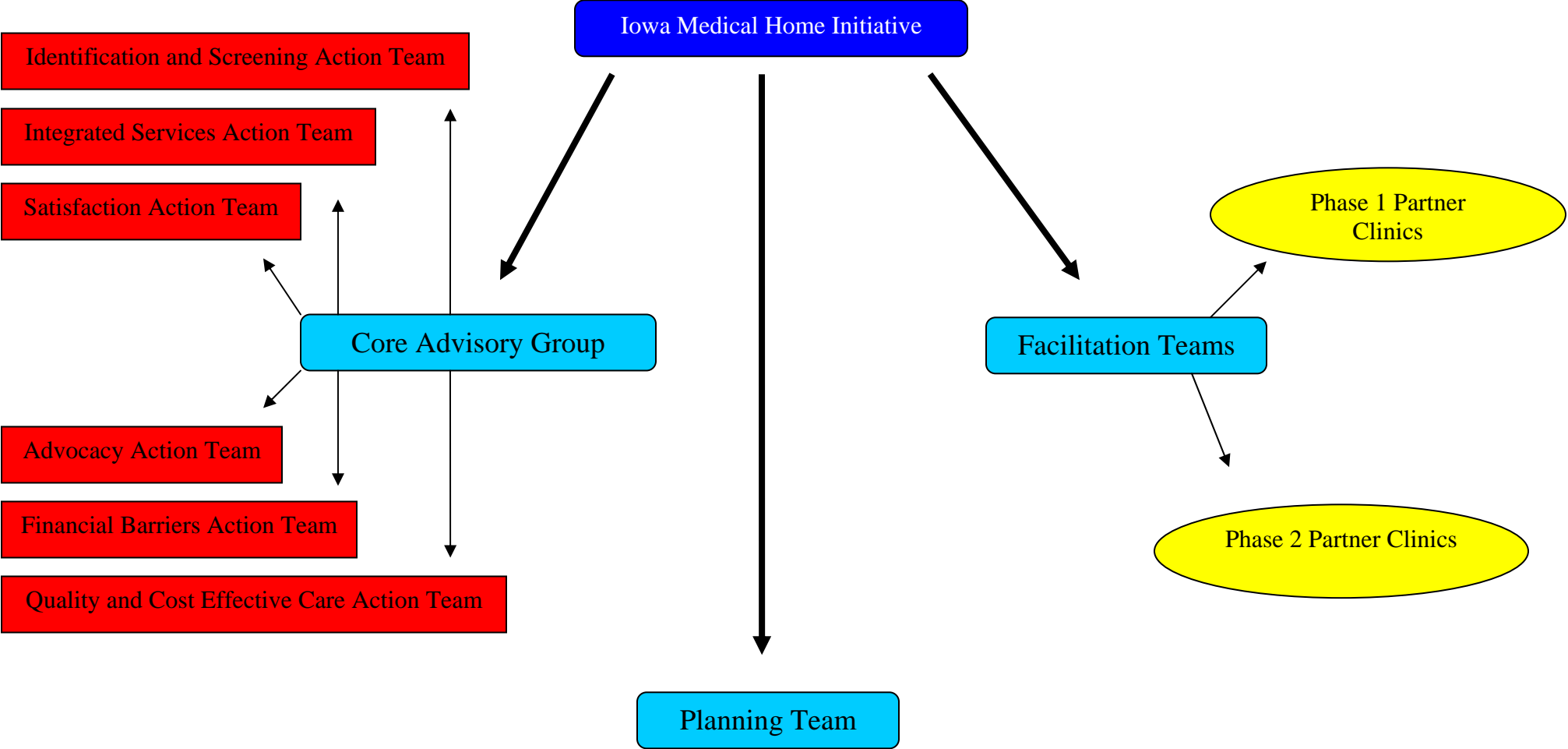
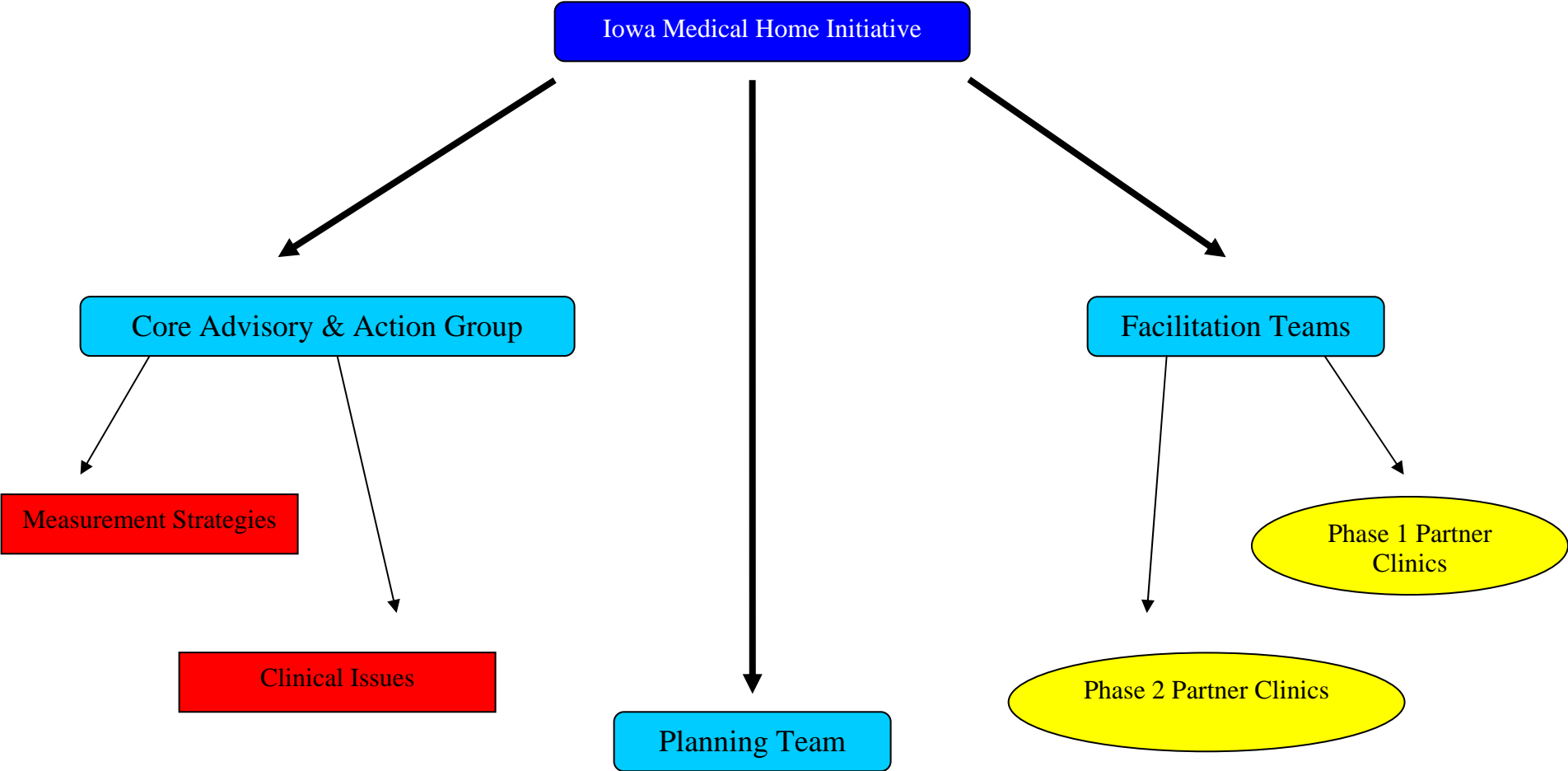


Exhibit 1-3. Iowa Medical Home Initiative Organizational Chart: September 2004-present day



1.3.3 Facilitation Teams and clinics

Facilitation Teams recruited clinics and helped them through the IMHI process of establishing a medical home. The Facilitation Teams consisted of one of the Nurse Facilitators (including the Nurse Director or Nurse Coordinator) and occasionally another member of the Planning Group.

Three clinics were successfully recruited in Phase 1. The criteria for selection were the clinics' level of interest in medical homes and their physicians' potential to influence other clinics' physicians in their decisions to adopt a medical home model. Early in 2003, clinics signed Memorandum of Agreement(s) with IMHI following a series of informational sessions with the IMHI Facilitation Team. Phase 1 Clinics had monthly meetings and intensive contact with the Facilitators until late 2004 when the clinics moved to meeting quarterly. Ten clinics participated in Phase 2. As early as December 2004 IMHI began work with some of the Phase 2 Clinics on a regular basis. Clinics in both phases initially completed the Medical Home Index (developed by the Center for Medical Home Improvement).³ From these assessments the clinics developed aim statements and goals. Interventions and strategies were selected to achieve the goals. Clinics either focused on improving a process in their clinic that would impact the care of all children with special health care needs (CSHCN), or on a particular diagnosis such as attention deficit disorder/attention deficit disorder with hyperactivity (ADD/ADHD). A systems-based, rapid cycle change process, Plan/Do/Study/Act (PDSA), was used as a mechanism for change.

2. Literature Review

2.1 Introduction

This review examines the concept of a medical home, the context in which it developed, current activities around the concept, the evolving definition and measurement issues, and the research about the advantages and barriers to the medical home concept.

The move to support medical homes is a large national effort directed at addressing issues related to the increasing number of CSHCN, the increasing medical costs and the inadequacies of our current health care system. The concept has a history that stretches back over a quarter of a century and is still evolving. Many institutions are working on various aspects of the medical home concept; some of their activities are described in this paper.

The definition of a medical home and measuring medical homeness are two of the more important issues facing those implementing this health care concept. Without a common and concise definition it is difficult for people to understand what a medical home is. Although there is more agreement now about what a medical home is than when the concept was first discussed in 1978, there is still ambiguity about how a medical home should be measured. Operationalizing the definition at the population, large group and practice level to be able to measure medical homeness has been difficult.

A medical home has been defined by the Maternal and Child Health Bureau (MCHB) and the AAP to provide “care that is accessible, family centered, continuous, comprehensive,

coordinated, compassionate, and culturally effective.”³ A more comprehensive look at the definition of a medical home is discussed in Section 2-3.

Because of the difficulty in defining a medical home and measuring it and the limited number of practices that have fully implemented the medical home concept, the research on advantages to a medical home have been limited. Most of the evidence supports the importance of continuity of care and points to the deficits of the current system. The main barriers to adopting and sustaining a medical home for a practice were outlined in the 1980s, including training of pediatricians, care coordination and reimbursement. These barriers have changed little in the past 20 years.

2.2 Medical home background

The increase in the number of children defined as having special health care needs and the rising costs of their care have made it clear to many that the current system of health care does not work for these children. The concept of a medical home developed out of this realization.

The population of children identified as CSHCN has grown due to “improved diagnosis and early identification; enhanced survival from premature birth, birth defects, and chronic illness; and better access to specialized care”.⁴In 2001 the estimated prevalence of CSHCN was 12.8%.⁵ The definition for CSHCN has also undergone changes, which have increased the number of children identified as having special health care needs. The Maternal and Child Health Bureau (MCHB) now advocates the following definition to

aid in classifying children as CSHCN: “Children, birth to 21 years, with or at risk for chronic physical, developmental, behavioral or emotional conditions and who require health and related services of a type and amount beyond that required by children generally.”⁶

The health care requirements and related issues such as growth, nutrition, safety, and injury prevention, for CSHCN and their families have been well documented.⁷ Under the current system of care, medical costs for CSHCN are large. For CSHCN who have commercial health insurance, the per member, per month (PMPM) costs are high. In one study the PMPM costs averaged \$328, compared to children in general (\$84). But the average costs for CSHCN do not provide an accurate picture of PMPM costs for an individual CSHCN. CSHCN with highly involved or severe needs had an average PMPM of \$2,867, while those CSHCN with only one condition had an average PMPM for \$159.⁸

There is also a debate in the literature about the indirect costs of caring for a CSHCN. It has been hypothesized that parents of CSHCN are more likely to be unemployed than parents of children without special health care needs. It has been argued that parents with CSHCN are burdened with their children’s care in such a way that they cannot seek employment outside of the home. Recent research indicates that a subset of parents of CSHCN who have health problems of their own are negatively impacted.⁹ On the other side of the debate, Loprest and Davidoff state, “Although we did find that parents of CSHCN in low-income families are less likely to be working, we did not find that they

were particularly burdened or disadvantages with respect to employment barriers, relative to parents of low-income children without special health care needs.”⁹ Their finding comes from the 1999 and 2000 National Health Interview Surveys, while data from the 1994 National Health Interview Survey on Disability indicated that having a child with poor health is associated with reduced employment of mothers and fathers.¹⁰ That definition of children with poor health status was broader than the one used by Loprest and Davidoff, who looked only at CSHCN. Another study by Thyen, Kuhlthau and Perrin, looking solely at mothers of children assisted by technology and employment status, found that 1/3 of the mothers quit their employment in order to take care of their child.¹¹

The current, disjointed system of health care in the United States does not adequately address the special health concerns of CSHCN⁷ because the current primary care services are designed to meet the needs of children without special health care needs.¹² CSHCN require services above that of the needs of children without special health care needs. The concept of a medical home, as currently defined by the American Academy of Pediatrics (AAP), offers a model for the delivery of health care and other services to CSHCN and their families. Further, as health care for CSHCN has moved from a focus on caring for the child’s particular health care need(s) to caring for the child in a more holistic way to finally recognizing that the entire family and their needs must also be addressed, the medical home concept is receiving more attention.¹³

2.2.1 *Chronology*

The concept of medical home began as an opinion that CSHCN required a place to have all their medical records centralized, and has since evolved at the grassroots level to a more comprehensive understanding of community level care.¹⁴ First addressed by the AAP in the 1970s,¹⁴ in the 1980s Calvin Sia, MD, FAAP, spearheaded the implementation of the medical home concept in Hawaii.¹⁵ This first attempt at promoting medical homes used a definition very similar to the current 2002 definition supported by the AAP.¹⁴ The approach in Hawaii targeted the elimination of major barriers to its implementation, such as training of pediatricians, care coordination, and reimbursement. Hawaii's success with implementing the medical home concept placed it at the forefront of efforts to spread use of this model. In 1988 the Hawaii Medical Journal published a journal article titled, "The medical home comes of age."¹⁶ Now almost a quarter of a century later, the medical home concept is still evolving.

Later, the AAP program Community Access to Child Health (CATCH) was formed in part to promote the medical home concept. CATCH was joined by the AAP-supported Training Project, which was modeled after training programs in Hawaii.¹⁴

In 1999, the National Center for Medical Home Initiatives for Children with Special Needs was founded. As a part of the Department of Health and Human Services (DHHS) Maternal and Child Health Bureau's (MCHB) commitment to CSHCN and their families, MCHB partnered with the AAP to support the creation of this new center, which focuses on policy changes, training of health care professionals, outcomes, and technical

assistance.¹⁴ In 2002, the AAP released a policy statement from the Medical Home Initiatives for Children with Special Needs Project Advisory Committee, which was intended to clarify the definition of a medical home.¹⁷ This definition is discussed in more detail later in the paper.

2.2.2 *Programs and outcomes*

MCHB's state Title V programs for CSHCN have focused on providing and promoting family-centered, community-based, coordinated care for children with special health care needs to facilitate the development of community-based systems of services for such children and their families since 1989.¹⁸ MCHB developed six core outcomes to measure the attainment of the *Healthy People 2010* goals relevant to CSHCN. The outcomes are:

1. Families of CSHCN will partner in decision making and will be satisfied with the services that they receive.
2. CSHCN will receive coordinated, ongoing, comprehensive care within a medical home.
3. Families of CSHCN will have adequate private and/or public insurance to pay for the services that they need.
4. Children will be screened early and continuously for special health care needs.
5. Community-based service systems will be organized so that families can use them easily.
6. Youths with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence.

The Iowa Medical Home Initiative is a part of this larger national effort to reach the goal of all CSHCN having a medical home by 2010. In 2001 Iowa was awarded a federal grant from MCHB to promote and create medical homes for CSHCN across the state of Iowa. Currently, most published medical home efforts in other states have focused on physician education and implementing medical homes in practices.

Continuing medical education training is thought to be a way to inform physicians about medical homes and to encourage the adoption of the medical home model.

Educating Physicians in their Communities Program (EPIC) used a train-the-trainer approach to inform pediatricians and other health care professionals about early intervention, collaboration and care coordination, and processes for reimbursement for the above-mentioned activities.¹⁹ To insure that CSHCN have a medical home, the AAP, Family Voices, MCHB, and others developed a training program for primary care physicians, pediatric office staff, child health advocates, allied health care professionals, and parents of CSHCN.²⁰ The program is called “Every Child Deserves a Medical Home.” It introduces the elements of a medical home, defined by AAP as family-professional partnerships, practices, policies and procedures; comprehensive, coordinated, collaborative care; transitioning; advocacy for policy; surveillance; and screening. The program is implemented by AAP’s organization, the National Center of Medical Home Initiatives for CSHCN.

Some of the issues raised by researchers as challenges or requirements to adopting a medical home model are related to educating pediatricians-in-training. In 2000 the AAP made recommendations for the training of future pediatricians in the Future of Pediatric Education II (FOPE II). AAP recommended, “Pediatricians of the future will need to be educated for this role and will need to establish community standards for the management of both routine and complex patients in the ‘medical home.’ This role is based on their education and experience delivering health care to children and on their knowledge of the latest evidence-based research. Because the ‘medical home’ concept is not limited simply to pediatric care, a ‘medical home’ for children should be the goals of all providers who care for children.”²¹

Other programs have concentrated on having public health staff or care coordinators, who are not employees of the practice present in pediatrician’s offices to facilitate care coordination and referrals.¹⁹ A project in Decatur, GA worked with the local board of health, the school district and local health care providers and hospitals to provide a place for each student to receive regular care.¹⁹ Both of these models fail to fully embrace the entire concept of a medical home according to the AAP definition (see below).

A program which was influential in the Iowa Medical Home Initiative’s development was the Pediatric Alliance for Coordinated Care (PACC). This project involved multiple practices taking part in an intervention that included continuing medical education (CME), training, networking, 8 hours per week of care coordination by a pediatric nurse

practitioner (PNP) and support for implementing systematic changes such as individualized health plans.²²

2.3 Defining a medical home

When the concept of a medical home was originally conceived in 1978, there were 4 parts: 1) geographic and financial accessibility, 2) continuity of care from the prenatal period through early childhood and adolescence, 3) coordination through identification of needs and linkage of the family to services needed by the child, and 4) community orientation of awareness of child health problems and resources within the community.²³ It was not until 1992 that the AAP formulated the first policy statement to outline an official definition for a medical home.²⁴ This definition encompassed accessible, continuous, comprehensive, family-centered, coordinated and compassionate care.

In 2002, the AAP released a policy statement from the Medical Home Initiatives for Children with Special Needs Project Advisory Committee, which was intended to clarify the definition of a medical home.¹⁷ The revised definition adds “culturally effective” and 37 elements to the list of characteristics of a medical home. The policy statement further clarifies each characteristic of a medical home:

- Accessibility refers to such issues as quality and type of care being provided in the child’s community and all forms of insurance being accepted.
- The family-centered component addresses the family’s central role in care giving and joint decision making.

- Continuity of care relates to the same physician providing care from infancy to transition and the physicians' ability to participate in care received by other providers. Comprehensive care involves access to care 24 hours a day, 365 days a year and the need for providers to identify and address other related needs.
- Services related to comprehensive care include family-centered care; information sharing and management; provision of primary care; availability of ambulatory care 24 hours a day, 365 days a year; care over a longer period of time and planned transitions; identification for consultation, referral and collaboration with specialists and subspecialists; inclusion of early intervention programs and local resources for child and family; care coordination services; maintaining accessible, comprehensive records; and provision of services for transition to adulthood.
- Coordinating the services and care the child and family receive and maintaining central records are part of the coordinated care component.
- Expressed concern and efforts to understand relate to compassionate care.
- Culturally effective care recognizes, values, respects and incorporates cultural background into the care and information provided to families.¹⁷

Despite this much more precise definition, there is still ambiguity around what a medical home is.^{25 26} For instance, care coordination, a piece central to the medical home concept, is often misinterpreted by pediatricians. Many pediatricians believe they currently do provide care coordination, but when they are asked about specific activities they respond that they do not provide care coordination as defined by AAP.²⁷ This type

of disconnect points to the value of a well-articulated definition that has wide-spread acceptance and can be measured.

Many physicians and researchers continue to believe a medical home and regular source of care are identical.²⁸ But a medical home is much more than a source of primary care or the opposite of having a relationship with a specialist. Because a medical home is, at the very least a source of primary care, the comparison is understandable, but fails to acknowledge the entire concept.

2.4 Challenges to measuring

Measuring medical homeness at the practice level and ascertaining the proportion of CSHCN who have a medical home has been the emphasis of much of the recent published work on medical homes. Despite precise definitions, there is still ambiguity around how to measure a medical home and what a medical home is.^{25 26} Without adequate and standardized methods for measuring this concept, it is not possible to determine what practices have achieved a medical home. Research on the outcomes related to the adoption of a medical home is even more problematic to determine when there is no accepted definition. Because of the lack of standardization and the previous ambiguity of the definition it is not always clear that the researchers are measuring the same construct.

2.4.1 Population Level Measurements

Finding data sources to measure access to a medical home at the population (child and family) level is a challenge. In order to assess medical home access at the population level in CSHCN, Bethel, Read and Brockwood looked at the National Survey of Children with Special Health Care Needs, the National Medical Expenditures Panel Survey, the Consumer Assessment of Health Plans Study Child Survey, and the Consumer Assessment of Health Plans Study Child Survey-Children with Chronic Conditions.²⁵ None of these surveys were designed to measure presence of or access to a medical home. Furthermore, using just the Consumer Assessment of Health Plans Study Child Survey-Children with Chronic Conditions, the researchers found a wide range of variability from 43.9% to 74%, depending on which scoring methods and questions were used.²⁵ This variability calls into question the way we are trying to measure medical home access or presence at the population level.

Further research by Strickland, et al., found that 52.6% of families of CSHCN state they have access to a medical home as defined by the following five criteria: 1) usual place for sick/well care; 2) a personal doctor or nurse; 3) no difficulty in obtaining needed referrals; 4) needed care coordination; and 5) family-centered care.⁵ However, when race and ethnicity were examined, Hispanics, non-Hispanic blacks, and non-Hispanic children of other racial and ethnic backgrounds were significantly more likely not to have a medical home.⁵ Ninety percent of CSHCN had a usual source of care, 78.1% of CSHCN families said they had no difficulty in receiving referrals, and 66.8% of parents reported their doctors provided all parts of family-centered care.⁵

In 2001, McPherson, Weissman, Strickland, van Dyck, Blumberg and Newacheck conducted a study to evaluate the proportion of CSHCN whose health care meets the six core outcomes outlined by MCHB (see below).¹³ According to their research, it is very likely that the United States will achieve these core outcomes by 2010. They found that the proportion of CSHCN whose health care meets the outcome definition is at or above 50% in 5 of the 6 outcomes. With another 5 years of effort before the 2010 deadline, it will not be difficult to raise the proportion of CSHCN whose health care is in accordance with the 6 outcomes to near 100 percent.¹³ The data sources for these outcomes were the National Survey of Children with Special Health Care Needs and National Health Interview Survey from NCHS, CDC. The six outcomes are related to the 2002 AAP definition, but they do not measure the entire medical home concept.

For example, the second outcome, “CSHCN will receive coordinated, ongoing, comprehensive care within a medical home,” was measured by 15 different questions about usual source of care, care coordination, and family centered care. One such question was “Effective care coordination was received when needed.” Families, who did not know about care coordination they could have used, would not have enough information to answer this question correctly. Another outcome, “Children will be screened early and continuously for special health care needs,” was measured asking whether the children had at least 1 preventive medical visit and 1 dental visit in the last year. Unfortunately, preventive medical visits and dental care do not equate to early and

continuous screening. Below are the 6 MCHB outcomes and in parentheses the percent of CSHCN, who have achieved these outcomes.

1. Families of CSHCN will partner in decision making and will be satisfied with the services that they receive (57.7%).
2. CSHCN will receive coordinated, ongoing, comprehensive care within a medical home (52.6%).
3. Families of CSHCN will have adequate private and/or public insurance to pay for the services that they need (59.6%).
4. Children will be screened early and continuously for special health care needs (51.6%).
5. Community-based service systems will be organized so that families can use them easily (74.3%).
6. Youths with special health care needs will receive the services necessary to make transitions to adult life, including adult health care, work, and independence (5.8%).

For their research on the impact a medical home had on immunization coverage rates, Ortega, Stewart, Dowshen and Katz used the 1992 AAP medical home definition.²⁹ They operationalized the definition by asking: 1) Is there a medical place the child goes to for regular health check-ups (well baby care)?; 2) Is there a medical place that child regularly goes to when child is sick?; 3) When the child needs a regular check-up or is sick, does the child unusually see the same doctor or nurse?; 4) Was the child ever

without a regular doctor or medical care person?; 5) Have you ever had trouble scheduling a health care visit for the child?.²⁹

A study was conducted in Alabama to assess whether the changes in the Medicaid program increased the number of children with access to a medical home.³⁰ The researchers' definition of a medical home was the "use of a single primary care physician combined with the receipt of at least one well child visit from that physician during the year." This definition only represents a small part of the continuity of care part of the AAP definition, presenting measurement and comparison difficulties. One of the unique facets of the Alabama study was the use of Medicaid claims data to determine access to a medical home, or, more precisely, the existence of a relationship between a child and a single health care provider. Only 11.8% of the Medicaid-enrolled children in Alabama met their definition of access to a medical home during the baseline year, and there was not a remarkable increase after the implementation of changes to Medicaid.

Measuring "medical homeness" or the extent to which a practice has embraced and implemented the concept of a medical home is a vital part to efforts researching and spreading the medical home concept.

2.4.2 Practice level measurements

The most extensive effort to measure medical homeness at the practice level using the 2002 AAP definition was undertaken by the Center for Medical Home Improvement (CMHI), a part of the Hood Center for Children and Families at the Children's Hospital

at Dartmouth Hitchcock Medical Center. CMHI developed a tool kit, “Building a Medical Home: Improvement Strategies in Primary Care for Children with Special Health Care Needs” in 2000.¹² This tool kit consists of the Medical Home Index, a validated tool for measuring medical homeness in medical practices developed by CMHI, and the Medical Home Family Index, designed to measure the family’s experience within the medical practice (developed by CMHI).

The Medical Home Index, designed to be a guide for self-assessment and continuous quality improvement process, has 6 domains in 25 themes. The domains are organizational capacity, chronic care management, care coordination, community outreach, data management and quality improvement. Themes within these domains are rated by the medical and office staff on a scale from 1 to 4. These levels represent 1) basic pediatric care, 2) responsive care, 3) proactive care, and 4) comprehensive care.

Staff members rate their practice as having partially or completely achieved each level. The authors of the index addressed issues of contrast validity and inter-rater reliability and internal consistency through a review of the literature and other tools, an extensive review of the tool by national experts and a two-phased process for field testing the tool with 43 pediatric practices across the country.

Other efforts to measure medical homeness at the practice level have been less extensive. Care coordination, a part of the medical home definition that has gained a lot of attention was examined by Gupta, O’Conner and Quezada-Gomez.²⁷ The researchers attempted to

measure care coordination activities among AAP members. The questionnaire had an extensive list of care coordination activities including scheduling of extra time for appointments, helping make referrals, and discussing potential family needs and services available. This survey helped to identify barriers to care coordination from the pediatricians' perspective. Although Gupta, O'Connor and Quezada-Gomez were not able to measure medical homeness, the information about care coordination is important. Care coordination is one of the critical elements that sets a medical home apart from current primary care. It is also important because care coordination is resource-consuming without a method for reimbursement.

2.5 Researching the advantages and benefits to a medical home

To make a broad-based systemic change in our current medical care system, there needs to be a large body of evidence proving that the medical home approach is effective. Unfortunately, such evidence is limited because of definition and measurement issues outlined above. Furthermore, too few clinics have fully embraced the medical home concept long enough for an adequate evaluation of health and financial outcomes.

Nonetheless, researchers have tried to tease out important components of a medical home and measure the outcomes. Continuity of care, one of many components of a medical home, has been an area of concentration of researchers. Continuity of care appears to be related to parents' perception of quality of care.³¹ A high degree of continuity is associated with a perception of greater quality of care. There is also evidence to suggest continuity of care may improve immunization coverage. The research suggests that if

continuity of care happens early in a child's life, at the first source of health care, a child's immunization coverage is positively impacted. Children who had continuity of care lasting at least 12 to 14 months were 17.5 times more likely to be up-to-date with immunizations at 18 months of age than children with continuity of care of less than 6 months.³²

In its 2002 policy statement on medical homes, the AAP recognized the opposite of having a medical home—that health care via emergency rooms and other episodic sources of care was more costly and less efficient than a medical home.¹⁷ The research to support this statement is not yet complete. However, using economic modeling McBurney, Simpson and Darden were able to illustrate how increasing continuity of care through a pediatric medical home could result in reduced emergency department charges.³³ Specifically, when continuity of care was increased by 10 percentage points, \$19,905 in emergency department charges per pediatric patient was saved.³³

Unfortunately, this economic-focused research alone does not make a powerful case for the adoption of the medical home concept. Continuity of care, as measured by these studies, i.e., receiving care from a single health care provider, may enforce the importance of having a single primary care provider, but it does not, on its own, support the medical home approach. A medical home is more than having a single source of care, more than having a primary care physician. There is evidence both from US and international studies that a source of primary care relates to better health, more efficient use of resources and greater equity in care for individuals and population-wide.²⁸ What

researchers have yet to clearly show is the added benefit of a medical home on top of a single primary care provider. Until this evidence is found, it is difficult to argue the advantages of a medical home when a regular source for primary care may suffice.

Using the National Survey of Children With Special Health Care Needs, Strickland, et al., looked at the following criteria to measure access to a medical home and outcomes: “1) a usual place for sick/well care; 2) a personal doctor or nurse; 3) no difficulty in obtaining needed referrals; 4) needed care coordination; and 5) family-centered care received.”⁵ These measures of a medical home are more encompassing than just continuity of care or a single source for primary care. CSHCN without a medical home as defined by these 5 criteria are twice as likely to have delayed or forgone care than those with a medical home as reported by their families.⁵ CSHCN without a medical home are three times as likely to have family support need unmet than CSHCN with a medical home.⁵

Although measuring outcomes at the practice level have been limited, due to the small number of practices that have fully adopted the medical home concept, an evaluation of a medical home intervention by PACC illustrated an increase in parent satisfaction and some evidence for possible improved health outcomes.²² Families in PACC-involved practices stated “There were improvements in getting appointments, referrals, telephone calls answered, prescriptions filled, transportation and respite care.”²² When Pediatric Nurse Practitioners were involved with families more often than average, these families reported understanding their children’s medical conditions better. More families

received individual health plans and families who used their individual health plans stated their experiences were improved. “The children in these practices were hospitalized fewer times and their parent[s] missed fewer days of work than before the institution of the program.”²²

Transitioning youth with special health care needs to adulthood and adult medical care requires purposeful planning. Medical homes have been proposed as a method for easing this transition. This model is suggested to provide the framework for collaboration between the youth with special health care needs (YSHCN), the family, the health care professionals and other community services,³⁴ but there is no published evidence to show how medical homes can accomplish transition better than the current system.

2.6 Barriers to the adoption of medical homes

Some of the main barriers to adopting the medical home concept have already been discussed: confusion around how to define the medical home and weaknesses in measuring. This section will touch on other barriers to the spread of the medical home concept including the current system of health care delivery, the structure of pediatric offices, the involvement of families and consumers, and issues around training and information and costs.

The current system of health care delivery prevents many of the changes required for a medical home because the current system is illness- oriented.¹⁶ Reimbursement-how it is driven and why-drives the current system. Many of the tasks pediatric offices are

expected to undertake are resource consuming without reimbursement. For example, current reimbursement for preventive care is very low^{16 12 27} and reimbursement for new activities is limited.¹² Some change in the funding mechanism is required or some type of additional funding is needed.²² Also because “time is money”, the limited resource of time is not adequate to cover care coordination activities.²⁷

Further, the current structure of pediatric offices does not facilitate the adoption of a medical home model. Many pediatric offices do not have the data system capability to identify CSHCN in order to make systemic changes to their care on a population level.¹² Quality improvement processes or other means of making changes are not necessarily methods familiar to office staff.¹² Offices have to take steps to implement processes to communicate with a wide range of people they have not had to communicate with before, such as educators, parents, and other service providers.³⁵

Pediatric offices will require a champion to spearhead these changes, but such a champion is not always present.²² Staffing issues are also a problem. Many pediatric offices are not staffed with the cultural and language expertise their communities might require²² and there simply may not be enough staff members to do many of the tasks required for a medical home approach, such as care coordination.²⁷

Families are the center of a medical home, but their lack of involvement in the past presents a challenging change for the health care system and the families. Consumer or parental involvement in the change process has also been limited.^{12, 22} Further, a change

in the current system requires all parties, including parents, to take on different roles. This role change has not clearly been articulated and understood¹² and changes in the office have not taken place to increase communication with parents.³⁵ Sia and Peter point out that families identified as “high-risk” may be difficult to work with, which does not encourage the change process.¹⁶

Training and information appear to be key in many changes and adopting the medical home concept is no different than other innovations. Continuing medical education opportunities on new morbidity is not sufficient for physicians providing health care to the current CSHCN population.¹⁶

Information about services available in the community and better referral networks are needed.^{27, 35} Partnerships between academic medical centers and practices must exist in order to address issues of training, consultation and hospitalization.²² Very few pediatric practices have access to such partnerships.

Concerns about money, the cost of providing a medical home to CSHCN, and particularly the costs of unreimbursable services provided to CSHCN and their families have been major concerns for health care professionals attempting to implement the medical home concept in their practices. The cost for unreimbursable care coordination is estimated at a range of \$22,809 to \$33, 048 per year for a pediatric practice.³⁶ This cost represents the salary of a care coordinator for a community-based, general suburban pediatric practice, with 4.0 full time equivalent (FTE) pediatric physicians, 2.7 FTE RNs,

1.0 FTE nurse practitioner, 2.0 FTE medical assistants, and 4.88 FTE clerical and office managerial staff. The practices have nearly 5800 patients. This dollar figure was calculated by tabulating every type of care coordinating activity that was nonbillable that any of the medical providers or staff performed or provided for their patients over a 95 day period. It was not surprising that 73% of the activity recorded was telephone contact, which, although very common is not reimbursable under most insurance plans. The PACC program in Boston estimated their costs for the medical home project at about \$400 per year for each child with severe special health care needs.²² The \$400 primarily covers 8 hours per week for a PNP's time.

As illustrated, several issues described in the literature are challenges to the implementation of the IMHI. Particularly, the lack of a functional definition of a medical home and the lack of evidence for better patient outcomes and cost effectiveness present difficulties to the Initiative.

3. IMHI project background and understanding

3.1 Project review

The IMHI is a part of a larger national effort to reach the goal of all CSHCN having a medical home by 2010. In 2001, Iowa was awarded a federal grant from MCHB to promote and create medical homes for CSHCN across the state of Iowa. In their

“Promise to the State,” IMHI articulated the following goals:

1. To establish medical homes for CSHCN;
2. To partner with families for all decision-making;
3. To address the issue of adequate insurance to pay for needed services;
4. To promote early and continuous screening for special health care needs;
5. To provide organized, community-based, easy-to-use services; and
6. To provide transition services to adulthood for youth with special health care needs.

The IMHI project consisted of 4 main components: (1) the Planning Group, (2) the CAAG, (3) the Facilitation Teams, and (4) clinics (see Exhibits 1-2 and 1-3 above). The role and activities of these project components are described in the sections below.

Iowa’s initiative differs from efforts going on in other states because the IMHI also works with family physicians, while other states have targeted only pediatric physicians. Most small communities in Iowa, a rural state with an older population, do not have enough children to support a pediatric office, so many of the children in Iowa are cared for by family physicians, not pediatricians.

3.2 Guiding concepts

The IMHI project used a quality improvement method to implement change and a theory about how new ideas are adopted to guide the project. The Plan, Do, Study, Act cycle (PDSA)¹ was the method the IMHI staff used to direct clinics in their change processes. Diffusion of Innovations² was used to explain how the medical home concept would spread within practices and throughout Iowa.

3.2.1 PDSA Cycle

The Plan, Do, Study, Act cycle refers to a process for quality improvement frequently used in the clinical practice setting.¹ The first step involves planning which change will be attempted. Second, that change is tested on a small scale or by doing a pilot test. Next, the test results are studied and finally, based on the test results, the change is modified and refined. The entire process continues over and over again until the change is completely implemented in its best form. This idea of small, rapid, continuous changes is believed to be ideal for busy medical practices where work cannot be halted in order to make needed changes. This quality improvement mechanism in an abbreviated form is taught to clinics participating in IMHI as a method of “trying out” changes that need to be made in order to create a medical home. The general concept also informs the culture of the larger IMHI effort. Small, innovative changes are made on a continuous basis in order to achieve the best results.

3.2.2 *Diffusion of Innovations (Also known within IMHI as spread theory)*

The theoretical framework within IMHI for the adoption of the medical home model is the Diffusion of Innovations.² This theory explains how new ideas and practices spread throughout a population. Rogers, the theory's author, proposes that people adopt new innovations at various rates based on how the innovation is perceived.² These perceived characteristics are: 1) relative advantage in relation to current or other ideas; 2) compatibility with current practices; 3) complexity of the innovation; 4) trialability or chance to experiment with the innovation; and 5) whether the innovation and its results can be observed by others.

When these characteristics are perceived favorably by the potential adopter, the innovation is likely to be adopted. The channel used to communicate about the innovation also plays a role. Interpersonal communication between similar individuals increases the likelihood of adoption.

The Diffusion of Innovations has served as the theoretical framework for several interventions and projects.³⁷⁻⁴⁰ Each of these research studies used the Diffusion of Innovations five constructs to guide the materials used in the evaluation of the projects. In these studies surveys or interviews were used to gauge participant perceptions toward implementing an "innovation" based on the five constructs, as well as potential influencers or barriers toward implementing the intervention.³⁸⁻⁴⁰ Results from these evaluations can be used to strengthen the IMHI program.

A number of factors may enhance or inhibit the adoption of an innovation. One misperception that stakeholders may have going into the implementation of a project is that the use of diffusion will provide for a swift change throughout the organization.⁴¹ This, however, is not always the case. Lia-Hoagberg and colleagues found that in an attempt to implement a new set of guidelines, a group of public health nurses repeatedly commented that a lack of time prevented them from using the new guidelines.³⁸ Their findings suggest that time, both in the adoption of an innovation and in training, should be viewed as an important factor. Complexity is another issue in change adoption rate cited frequently by those involved in the implementation process.^{37, 38} The more confusing a new innovation is, the less likely members are to accept it. Thus, it is important to establish clarity with the new process. Research suggests that incorporation the Diffusion of Innovations into a project may be helpful. Participants must feel that the new innovation will be efficacious. A possible way to assure participants is through the support, encouragement, and enthusiasm that peers and supervisors have for the new innovation.^{38, 39, 42, 43} Finally, presenting new information in a user-friendly way, accompanied by support, may be helpful in accepting the new innovation.³⁸

Rogers and Scott conclude that, “The most important single indicator of effectiveness (defined as the degree to which the implementation of an outreach strategy attains its stated goals) is the rate of adoption of an innovation...by an intended audience.” This indicator rate may be accomplished through summative (or outcome) evaluation, but these researchers stress the importance of formative evaluations to inform stakeholders about the effectiveness of a program and how the program can be strengthened.⁴³

Because the natural diffusion of change within a practice can require a great deal of time, especially in the health care field, specific approaches to reduce the time needed for diffusion should be used.⁴⁴ The facilitation process used in Phase 1 attempts to speed up the normal process of diffusion among early adopters by providing them with support and information to enable them to adopt the medical home concept in their practices at a faster rate. IMHI tries to make it easier for clinics to adopt the new processes that increase their medical homeness. The IMHI Facilitation Teams work to present the relative advantage of a medical home, as opposed to the current disjointed system of care. The facilitation process and PDSA cycle ensure that changes are compatible with current practices. Although the innovation of a medical home appears very complex, the Medical Home Index and the PDSA cycle break the complexity into smaller, manageable pieces. The facilitation process allows for clinics and staff to carry out trial runs of small parts of the medical home model, tweaking it and trying it again (trialability). Observability of the innovation is more difficult to achieve, as currently there are only a few medical home projects running nationally. However, Phase 2 Clinics are able to benefit from testimonials from Phase 1 clinic staff. Since interpersonal communication is key to the IMHI effort, facilitation is done via in-person meetings and conference calls.

4. Process evaluation

Process evaluation does not concentrate on end results or outcomes, but instead explores the inner workings of a program by giving program managers the opportunity to learn from their program. This knowledge is especially vital when a program is new or innovative. The relative newness of the concept of medical home and the approaches necessary for implementing the concept provide an ideal situation for a process evaluation. A process evaluation is strengthened by a collaborative relationship between the evaluators and the project, which allows the knowledge gained to be used to improve the program, aid in explaining the logic or change theory of the program, and provides information about replicating the program.

4.1 Methods

For this mixed-methods process evaluation, both qualitative and quantitative research methods were employed to provide the most vivid picture of Phase 1 and Phase 2. The qualitative methods helped to uncover themes not readily visible to the Evaluation Team or IMHI staff. To benefit most from the qualitative data and satisfy concerns about validity, multiple sources and multiple qualitative and quantitative methods were used. The various sources and methods allowed for triangulation of the data and provided the richest data on how the project worked and how people perceived the project.

4.2 Research questions

Exhibit 4-1 below summarizes the research questions, subquestions, data sources, and method of analysis used. The Evaluation Team developed these questions with the Planning Group.

Exhibit 4-1. Process evaluation research questions, data sources, and analytical methods

Research questions	Subquestions	Data source	Analysis
IMHI goals			
Has IMHI established medical homes for CSHCN?	Is there a definition or criteria for medical home achievement?	Planning Group observations and notes	Qualitative Analysis
	Are clinics continuing to work on the concept?	Planning Group agendas and minutes	Descriptive Statistics
		Facilitation Meeting Summaries	
		Clinic Surveys	
Has IMHI partnered with families for all decision making?	What was the role of Family Partners?	Facilitation Meeting Summaries	Qualitative Analysis
	How were families involved in the CAAG?	Family Partner Surveys	Descriptive Statistics
		CAAG meeting observations and notes	
	How were families involved with the Planning Group?	CAAG Survey	
		Planning Group notes and observations	
Are services community-based and easy to use?	How easy do families think services are to access?	Facilitation Meeting Summaries	Qualitative Analysis
		Facilitation Meeting notes and observations	Descriptive Statistics
		CMHI Family Survey	
Are there transition services to adulthood for youth with special health care needs?			Qualitative Analysis

Research questions	Subquestions	Data source	Analysis
CAAG			
Was the CAAG effective at fulfilling its roles (advisory, resource for new ideas, provide assistance with breaking down barriers to the spread of the medical home concept)?	How was the CAAG used?	CAAG baseline interviews	Qualitative Analysis
	What were barriers to achievement of the roles?	CAAG Focus Group	Descriptive Statistics
	Did the change in format of the group and meetings help meet roles?	CAAG Survey CAAG meeting notes and observations	
	What was the members' level of engagement?		
	Did the CAAG have an impact at the state/policy level?		
Are CAAG group members satisfied with the group?	What could have made the CAAG more effective?		
State-level policy changes/reimbursement			
What changes have happened at the state- or policy –level?	Is there increased awareness at the state level?	Planning Group meeting and notes and observations	Qualitative Analysis
	Is there increased networking around the concept?	Planning Group Surveys	
	Is there increased interest in and pursuit of policy changes?	Planning Group baseline interviews CAAG meeting observations and meeting notes	
	How have Planning Group members helped with achieving state-level changes in policy and reimbursement?		
	How has the CAAG helped with achieving state-level changes in policy and reimbursement?		
	How has the medical home concept spread to CAAG member agencies?		
	How have CAAG member agencies' understandings of the concept of medical home changed?		

Research questions	Subquestions	Data source	Analysis
Planning Group			
How was the Planning Group used?		Planning Group interviews	Qualitative Analysis
Was the Planning Group effective at fulfilling its role?	What were the barriers to the Planning Group functioning?	Planning Group Survey	
Was the Planning Group satisfied with what it achieved?	What facilitated the functioning of the Planning Group?	Planning Group meeting notes and observations	
Phase 1 Clinic case studies			
What did the IMHI effort look like in each Phase 1 clinic?	What progress was made?	Facilitation Meeting Summaries	Qualitative Analysis
	What products were developed?	Facilitation Meeting notes and observations	Descriptive Statistics
	What processes were changed?	Clinic Surveys	
	What were the barriers?	Phase 1 agenda and meeting notes	
	What facilitated progress?		
To what extent have Phase 1 Clinics established themselves as a medical home?	How did the switch from monthly meetings to less frequent meetings impact effort?		
	How has the level of understanding of the medical home concept changed in the Phase 1 Clinics?		
What has been the Phase 1 Clinics' satisfaction with progress?			
Is the medical home concept spreading within the Phase 1 Clinics?			

Research questions	Subquestions	Data source	Analysis
How have Family Partners been utilized in Phase 1 Clinics?	What are barriers/facilitators to better utilization of Family Partners? Are Family Partners satisfied with utilization?	Family Partner Surveys	
Phase 2 Clinics			
What did Facilitation look like in Phase 2 Clinics?	How have the knowledge, practices and attitudes of Nurse Facilitators changed? How is Facilitation Meeting time used? Is time spent doing clinical education or PDSA/quality improvement?	Facilitation Meeting Summaries Agendas and meeting notes from Facilitators Nurse Facilitator Surveys Clinic Surveys	Qualitative Analysis Descriptive Statistics
What did clinic recruitment/spread look like in Phase 2?	Who agrees to participate in the IMHI and why? What facilitates participating in the IMHI? Who declines to participate and why? What are the barriers to participating?		
What does progress in Phase 2 look like?	Does Phase 2 show learning from Phase 1 or a replication of Phase 1? Are processes developing differently from Phase 1? Are products developed differently from Phase 1? What domains are concentrated on? Who makes progress and who does not? What are barriers to progress? What facilitates progress?		

Research questions	Subquestions	Data source	Analysis
<p>Has the level of understanding of the medical home concept increased in Phase 2 Clinics?</p> <p>What is the role of Family Partners in Phase 2?</p>	<p>Is the medical home concept spreading within practices?</p>		
<p>How does the role of a champion impact the IMHI?</p>	<p>Does every clinic have a champion?</p> <p>What does the champion do?</p> <p>Does it matter who the champion is?</p>	<p>Clinic Surveys</p> <p>Nurse Facilitator Surveys</p> <p>Facilitation Meeting Summaries</p> <p>Planning Group meeting notes and observations</p> <p>CAAG meeting observations and notes</p>	<p>Qualitative Analysis</p> <p>Descriptive Statistics</p>

4.3 Data collection methods

A mixed-method approach was used in this evaluation, which allowed the Evaluation Team the opportunity to gather a variety of information about the project and its progress. The tools and measures used are described in the following subsections.

4.3.1 Surveys

- *Facilitation Team Meeting Summary*

The Facilitation Teams completed this survey after each Facilitation Meeting. All staff, Family Partners, and Facilitators were asked to complete the survey. The majority of surveys were mailed back to the Evaluation Team by the clinics in a self-addressed, stamped envelope. The exception was Phase 1 Clinic meetings; an Evaluation Team member was typically present to collect the surveys in person. The purpose of this survey was to assess the team member's satisfaction with the content and structure of the meeting, the progress made during the meeting, barriers and challenges of the meeting and meeting goals, and his or her understanding of what steps were meant for the next working period. There were 274 Facilitation Team Meeting Summaries completed.

- *Clinic Quarterly Summary*

This survey was developed to be administered to clinic Facilitation Teams every quarter. Unfortunately, the Evaluation Team quickly discovered in this population that paper surveys were not returned when completed. The Evaluation Team discontinued this method due to the lack of response by clinics. Eight Clinic A members, including both

Family Partners, four Clinic C members, and one Clinic B member, responded to the survey.

The survey focused on the aims and objectives of the clinic, whether those were appropriate for the clinic, what action steps were planned to meet the objectives, what action steps had been accomplished, barriers that may exist, description of the clinic's progress on becoming a medical home, and suggestions for the IMHI project staff to consider.

- *CMHI Family Survey*

CMHI developed the Family Survey. This survey was previously described in Section 1.1. The survey was administered to Phase 1 Clinics families. It is a fairly lengthy survey and contains questions on the following topics: child's health conditions and health status; health care experiences; hospitalizations; involvement in school and how the child's health condition affects his or her learning; level of satisfaction with their health care; interest in and satisfaction with care coordination services; family needs; and demographics. Two methods were used to administer the survey. One clinic distributed survey packets to families, requested the families fill out the survey on their own and send it back to the Evaluation Team. The other clinic attempted to set up meetings with families so the Evaluation Team could survey them in person. This clinic was concerned about their population's literacy level and ability to understand some of the survey questions and, therefore, requested participants be surveyed in person. The Evaluation Team experienced difficulty in receiving consent to participate, and families showing up

to scheduled meetings. The mail method was more successful in obtaining participation in the survey. Twenty families gave consent to receive the survey at Clinic A; fifteen completed surveys were received by the Evaluation Team. At Clinic C, the Evaluation Team was only able to schedule three families out of the nine who had given consent for the Evaluation Team to contact them. At the time of the appointments, only one family showed and completed the survey.

- *CAAG Survey*

This web-based survey was administered in May 2005. Its purpose was to serve as a follow-up to the baseline interview that the majority of CAAG members participated in.

The topics included:

- whether the group worked effectively in its defined roles;
- whether a change in format that occurred in June 2004 changed the level of effectiveness;
- barriers that prevent the group and its sub-groups from working effectively;
- how to make the group more effective;
- each member's home organization's interest level in IMHI;
- whether the group member felt he or she was or was not the most appropriate person to participate in the CAAG;
- how his or her involvement in the CAAG has changed his or her organization's support of medical home;
- satisfaction level with the progress made so far;
- how his or her organization's understanding of medical home has change;

- with whom he or she shares information about IMHI; and,
- any changes that could be made in the CAAG to increase the likelihood of goal achievement.

The response rate for this survey was 69%, with nine out of 13 members responding.

- *Planning Group Survey*

Two surveys were administered in the evaluation period, one in May 2005 and one in June 2005. The May 2005 survey focused on determining lessons learned by each of the group members from their involvement with IMHI. The June 2005 survey focused more on the Planning Group itself:

- what the members felt it represented;
- what his or her role in the group was;
- who the key decision makers were, and who he or she would ask were there a question about IMHI;
- whether the Planning Group assists IMHI and how; and,
- how the group could be more effective.

Five out of the six Planning Group members participated in the May 2005 survey while all six participated in the June 2005 survey.

- *Family Partners Survey*

This survey was administered in June and July 2005. Both web-based and paper formats were used depending on the needs of the Family Partner. Family Partners from the Phase

1 Clinics were surveyed as none of the Phase 2 Clinics had recruited a Family Partner during the evaluation period. Family Partners were asked to describe:

- IMHI as each sees it;
- her role as a Family Partner;
- how involved she has been in the facilitation process;
- how satisfied she has been with her current level of involvement;
- her involvement in Facilitation Meetings and the times between meetings;
- what served as barriers and facilitators for her involvement;
- what she would see as the ideal level of involvement;
- any changes she has seen in the clinic she feels are due to IMHI;
- what could improve the effectiveness of Family Partners;
- whether more families should be involved in the process;
- if her family is the appropriate family to be involved and if not, who is; and,
- what she likes best and least about IMHI.

All three Family Partners from Phase 1 Clinics responded to the survey.

- *Facilitation Coordinators Survey*

Administered in June 2005, this survey was for the two Nurse Facilitators who worked with Phase 1 Clinics, as well as coordinated the other Nurse Facilitators who worked with Phase 2 Clinics. This survey asked the Facilitators about:

- her satisfaction with the progress made so far;
- to describe the Phase 2 recruitment process and what was easy/challenging about it;

- how efficient the process was;
- how effective the PDSA had been and whether it had been modified from its original published form;
- how well she feels clinic staff understand PDSA;
- what factors are barriers or facilitators to the Phase 2 recruitment process;
- what impact the change for Phase 1 Clinics from meeting monthly to quarterly has had;
- about lessons learned in Phase 1 that have been used in Phase 2;
- how the two Phases have differed-overall and in recruitment; and,
- how Phase 2 differed from her expectations.

- *Nurse Facilitator Survey*

This survey was administered in June 2005 to three additional Nurse Facilitators who concentrated on the Phase 2 Clinics. They had never been interviewed or surveyed before on their experiences. Each was asked:

- whether her interpretation of the medical home has changed over time;
- how her enthusiasm for the concept has changed over time;
- barriers and facilitators to working with the clinics;
- to describe the Facilitation Team and what the Facilitator's role should be;
- what she was spending the majority of her time with the clinics doing;
- what the characteristics are of a successful medical home;
- what differences exist between pediatric and family practice clinics;
- to describe the recruitment of clinics;

- how her clinics were doing in regards to interest in the medical home, progress, and dedication to change; and,
- her satisfaction with the progress made.

- *Policy Level Changes Survey*

This survey was administered in June 2005 to two Planning Group members who concentrated more on policy changes. The Evaluation Team found that many of the policy-related actions regarding medical home were being discussed in smaller, private meetings between Planning Group members and public and private organizations. This survey assessed:

- who the Planning Group members were meeting with and the organizations he or she represented;
- whether any actions resulted from these conversations;
- what policy-level changes have occurred since the start of IMHI;
- barriers and facilitators to policy change;
- satisfaction with progress made on policy changes; and,
- any changes that have occurred regarding the use of the term medical home.

Many of the same questions were asked in regard to changes in reimbursement for medical home behaviors.

4.3.2 Interviews

- *Planning Group baseline interviews*

Baseline interviews were conducted shortly after ICER agreed to evaluate IMHI. The interview questions were developed to obtain the member's background, their understanding of the project, and any past work related to the project. The questions included:

- how the person became involved in the project;
- how he or she described the project to the clinics he or she is trying to recruit;
- whether his or her interpretation of medical home has changed over time and how;
- what he or she feels the diffusion of the medical home concept will accomplish over time;
- any barriers and facilitators that exist regarding recruitment of clinics;
- description of the CAAG, Steering Committee, and the Planning Group and each group's roles in the project; and,
- what he or she would like to see accomplished by the IMHI.

Six Planning Group members were interviewed, including a former Nurse Facilitator.

- *CAAG baseline interviews*

This interview was developed to obtain information on:

- how the CAAG members got involved in the IMHI;
- what his or her role in his or her organization is and how he or she got involved in the organization;

- what the organization's role in the local and CSHCN community is;
- what he or she sees as the organization's role in the IMHI;
- what he or she thinks the number one issue is IMHI will have to tackle to achieve success;
- what he or she would like to see accomplished by IMHI; and,
- how the CAAG could function differently to increase success.

Thirteen CAAG members were interviewed.

- *Clinic interviews*

Phone interviews were conducted by Wendy Ruble, an Occupational Therapy ILEND trainee who worked briefly with the IMHI and Evaluation Team. A sample of the clinics approached by IMHI, including several who had agreed and/or declined to participate, was contacted. These clinics were asked what factors were most important in the practice's decision to participate or not to participate; how the practice ultimately arrived at its decision; and how he or she felt IMHI could make the introductory presentation on IMHI more effective.

4.3.3 *Meeting observations*

- *Planning Group meeting observations*

One or two Evaluation Team staff took detailed notes of interactions among Planning Group members and meeting content.

- *CAAG meeting observations*

An Evaluation Team staff routinely mapped out the seating of each meeting and periods of interaction between CAAG members. Notes of meeting content were also taken.

- *Phase I Clinic Facilitation Meeting observations*

An Evaluation Team staff routinely mapped out the seating of each meeting and periods of interaction between Facilitation Team members. Notes of meeting content were also taken.

4.3.4 Meeting minutes

- *CAAG meeting minutes*

These minutes were prepared by an IMHI staff member and reviewed and approved by the CAAG members each meeting. Additionally, notes and observations were taken by the Evaluation Team.

- *Planning Group meeting minutes*

No structured meeting minutes were prepared by IMHI staff until early 2005. The Evaluation Team staff regularly took extensive notes during these meetings.

- *Clinic Facilitation Meeting minutes*

Meeting minutes were occasionally prepared by Nurse Facilitators for Facilitation Meetings; these meeting minutes were typically provided to the Evaluation Team.

Additionally, during the majority of Phase 1 Clinic Facilitation Meetings, an Evaluation Team staff was present, taking notes and making observations.

4.3.5 Blogs

Weblogs, an online journal format, were set up for all Planning Group and CAAG members. The blogs were password protected, with only the participant and Evaluation Team aware of the password. The blogs were provided to members so he or she might reflect on project activities, post additional ideas he or she may have, and write up feelings about how meetings or the overall project was going. The Evaluation Team found very few members actually used the blogs; therefore, the blogs were shut down towards the end of the evaluation period. However, some useful and interesting data were provided from the small pool submitted.

4.3.6 CAAG focus group

The Planning Group requested feedback from the CAAG on how the group could change for the new Phase 3 grant. The most efficient way to obtain the information was through an abbreviated focus group. The questions asked included how the CAAG saw the group functioning in the future; what its structure would be; how it may differ, if at all, compared to the current group; who should be asked to join and/or leave the group when looking at the new goals; and whether the group should exist at all in the future.

4.4 Data management

The Evaluation Team worked to maintain the data collected as confidential and protected. When possible during data collection identifying information was not requested. When the Evaluation Team needed to collect identifying information, it was used only for tracking and organizational purposes. Other data such as IMHI meeting minutes and documents from the clinics contained identifying information when the Evaluation Team received the documents. All data were kept in a locked room. Electronic data were stored on a password protected computer and server. All paper data were kept in a locked filing cabinet.

4.5 Analysis

Mixed methods were employed for this evaluation which necessitated both quantitative and qualitative analysis. Descriptive statistics were used primarily for the quantitative survey data, while structured qualitative analysis was used for the remaining interviews, meeting minutes, meeting observation data, and blogs. Interview data were analyzed using a qualitative software analysis program called Qualrus, used to develop a set of codes, coding text, and text retrieval.

4.6 Findings

The findings described in this report come from data collected from August 2003 to July 2005 and are organized according to the research questions.

4.6.1 Has IMHI established medical homes for CSHCN?

For IMHI, the process of establishing practices as medical homes has been much slower than expected by IMHI staff. As one clinic staff member stated, “We have not yet attained the culture of a medical home, but keep trying.” It is important to note the process has been more time-consuming than expected for not just the clinic members but also the IMHI Facilitators. One Planning Group member noted the “concept while seemingly simple is intensive and time consuming to initiate.” Fortunately the Planning Group also recognized and accepted that IMHI goals are quite ambitious and that steps may be small and incremental. The grant period of only 3 years was a very limited time to change deeply ingrained health care systems and ways of practicing medicine.

The development of medical homes was hampered by a lack of a functional definition of a medical home and the absence of a proven strategy to develop one. An IMHI Planning Group member lamented a “functional definition of a medical home remains unspecified, i.e. what array of practice attributes or characteristics must be present to qualify a practice as a bona fide medical home?” Without a clear definition or checklist of qualities, it would not be possible to determine if medical homes were established. During the evaluation period, there was no clear roadmap on how to implement such a change. IMHI has developed and modified possible strategies as the project has progressed over time and began with a carefully organized approach following the PDSA Cycle, but without a clear understanding of the endpoint it was not obvious that these strategies have been effective in developing medical homes.

Further structural constraints such as time, the busy nature of medical practices and technology created more barriers. According to one Nurse Facilitator, "...many clinics simply feel that they don't have the time or staff to take on 'more.'" Most of the clinics mentioned time as the most significant barrier to working on the medical home concept. There was not enough time for Facilitation Meetings according to Nurse Facilitators and clinic staff. Scheduling the meetings was a challenge because of weather, illness, staff turnover and clinics' busy schedules. Clinics also did not have enough time to work on their projects between Facilitation Meetings. Some of their comments were:

- "Too labor intensive";
- "Time is out main concern";
- "TIME!"
- "Time available for making changes";
- "...finding meeting time when members of team all available."

Technology was another major barrier. Computer systems were either nonexistent or not designed to meet the needs of IMHI (registry, tracking, identification...). The clinics had limited to no access to the internet and email. This limited IMHI ability to communicate efficiently with the clinics and prevented clinic staff from accessing on-line resources. Clinic staff also had varying levels of experience with computer systems and software. A lack of experience prevented clinic staff from using the technology they had to its full extent.

Other barriers included:

- Difficult for some clinics to identify the first small change;
- Some clinics were a part of a larger health care system;
- “Too many layers of bureaucracy”;
- Some team leaders were not champions;
- “The team leaders need to be chose [sic] more carefully and need to be people who have some experience in quality improvement and who can see the big picture of what we are trying to accomplish.”
- Clinic staff has mixed experience and knowledge with the medical home concept, quality improvement efforts, and the current or latest medical research.

A strength of IMHI’s efforts in establishing medical homes was the positive attitude of the IMHI and clinic staff. Clinics were “eager to learn and change,” “very positive,” and “patient-orientated.” The process was facilitated by IMHI staff input and ideas, tools, encouragement, help with literature and patient education materials and handouts according to clinic staff.

Although no medical home was established, there was an increase in awareness of CSHCN and their families among the clinics. Clinic staff mentioned this new awareness as a change that had resulted from their work with IMHI. One staff member commented, “I have become more aware of the obstacles these families face in dealing with their children.”

Barriers to the development of medical homes pertaining to the specific clinics in this project are explored later in this report. Further findings on the development of medical homes in Phase 1 and 2 Clinics are presented in the sections below.

4.6.2 Has IMHI partnered with families for all decision making?

Overall, families have played a very small part in IMHI. Originally, family involvement was viewed as an important piece to IMHI and the spread of medical homes, but families were not a part of all decision making. There was no family involvement in the Planning Group, IMHI's command central. On CAAG there was family representation through an organization serving families with CSHCN. Phase 1 Clinics had Family Partners on their Facilitation Teams, but the Family Partners did not play a decision-making role. Clinic A's Family Partner joined the team in December 2003 and Clinic C's Family Partner started in July 2004. During the evaluation period, none of the Phase 2 Clinics had Family Partners. IMHI staff noted while working with Phase 2 Clinics that the clinics seemed reluctant to involve parents in the Medical Home Index process. The specific roles of Family Partners in Phase 1 and Phase 2 are addressed later in this report.

“Family input is essential,” according to one IMHI Planning Group member and it is a significant piece in the Medical Home Index, but it is clear that families were not involved in decision making; there is not enough evidence to support the idea that their limited involvement was essential to IMHI efforts, as they have been implemented.

4.6.3 Are services community-based and easy to use?

During the evaluation period, no steps were taken to survey patients to ascertain how user-friendly services were. Because the project has not been fully implemented (not all aspects of a medical home have been addressed) it would not be possible to measure this outcome of IMHI efforts. It would only be appropriate to explore issues related to access after the project has made efforts to ensure that services are community-based and easy to use. The Evaluation Team worked with both Phase 1 Clinics to survey families of children with special health care needs using the CMHI Family Survey and has had limited success. The survey had an extremely small sample size and, therefore, could not be generalized to the CSHCN population.

4.6.4 Are there transition services to adulthood for youth with special health care needs?

Prior to the IMHI grant funding, promoting the medical home concept was included in another Child Health Specialty Clinics' grant on adolescent transition. This program was called *Healthy and Ready to Work* (HRTW) and was located in the Waterloo area. One of the two strategies in the HRTW grant was to have project staff and physicians work with Waterloo area clinics to build medical home capacity within the clinic using the CMHI Medical Home Index. A current IMHI Physician Advisor was initially part of the HRTW staff. This advisor concentrated on marketing the concept among Iowa practices.

Around the time the HRTW program began to recruit participants, the IMHI grant was funded, and IMHI was formed resulting in the medical home focus of HRTW being

dropped to avoid duplication of services. HRTW was active in assisting adolescents with transitioning from 2002 till June 2005, when its grant period ended. Outside of limited involvement with HRTW, IMHI had not addressed transition services or issues, and currently, none of the participating clinics are focusing on transition.

4.6.5 Was the CAAG effective at fulfilling its roles?

The Core Advisory and Action Group was originally envisioned as a group that would have an advisory role, be a resource for new ideas, and provide assistance with breaking down barriers to the spread of medical homes. These three roles were outlined by the Principle Investigator and were agreed on by CAAG members during the April 23, 2003 CAAG meeting. When first established in July 2003, CAAG members were separated into six implementation groups that would address issues relevant to establishing medical home as a standard. The groups included Advocacy, Satisfaction, Quality and Cost Effective Care, Financial Barriers, Integrated Services, and Identification and Screening (See Exhibit 1-2 above). IMHI staff surveyed members in November 2003 to gather ideas for what the priority strategies for each implementation group would be. These strategies were compiled and presented to members during the December 2003 meeting. At this time it was agreed that each group would meet in the following months to select one to two strategies for the group's focus. These strategies were presented to the entire CAAG membership at the March 2004 meeting.

When interviewed over Winter (2003-2004), Spring, and Summer 2004, CAAG members expressed feelings of underutilization and confusion about the status of these six groups.

At the same time, the Planning Group staff were experiencing difficulty in bringing the members together to meet in their six groups via conference call. In April 2004, the Evaluation Team presented a process evaluation report to the Planning Group containing initial results from the CAAG and Planning Group baseline interviews. Multiple CAAG members had observed that meetings were concentrating more on updating stakeholders on all relevant projects and IMHI's progress, and less on group work. These results were integrated into the discussion that took place during the June 2004 strategic planning retreat. At the September 2004 meeting, the six implementation groups were combined into two Action Subgroups: Measurement Strategies and Clinical Issues (See Exhibit 1-3 above). Former priority strategies were reviewed and reassigned to one of the groups. At the same time, meeting structure was altered to a less informational and more work-based format, with a large portion of the time set aside for group work. It is significant that the meeting format for the following December 2004 and June 2005 meetings only allotted very limited or no time for group work. Most of the meeting time was used for related project updates, information on a new grant application, and an appearance by a National Medical Home officer.

When surveyed, group members felt that overall the group was effective in its roles as advisors, as a resource for new ideas, and in providing assistance with breaking down barriers to the spread of the medical home concept (see Exhibit 4-2 below). They also felt the addition of the Action Subgroups assisted them to effectively fulfill their roles. One member specifically recognized IMHI staff for seeing the need for change and creating a solution.

Exhibit 4-2. CAAG members’ perceptions of whether CAAG was effective in its roles

CAAG roles	Not sure	Sometimes	Always
Advisory	1	4	4
Resource of new ideas	0	4	4
Assistance with barriers	1	5	2

Members were surveyed to identify barriers that kept the CAAG from working effectively in its roles. Members identified not having time to dedicate to IMHI as the number one barrier. As Exhibit 4-3 displays, other important barriers were “time in-between meetings was not used effectively” and “the system-level changes IMHI was seeking were too complex for CAAG to address.” Other issues that prevented CAAG from being effective were:

- Group members were very busy and frequently it was not possible to have every member attend every meeting. Meetings were canceled or rescheduled due to the lack of members attending.
- Attendance affected the amount and quality of work that could be completed at meetings. One member said, “The group’s ability to problem-solve barriers was dependent upon the expertise members had who were or were not at the meeting.” Sometimes key people with the experience and knowledge for a particular topic would not be there, so they could not be tapped. Another member felt that the “collective knowledge of more CAAG members seems to enrich the conversations.”
- In addition to attendance, CAAG membership composition and its impact on the project had been under consideration within the Planning Group for many months. While the Planning Group members were concerned that the CAAG did not contain

the appropriate representatives from each of its member organizations to assist IMHI in impacting state policy, the CAAG members themselves felt either sure or unsure they were the appropriate person from their organization to be involved. No member stated that he or she was not the appropriate person to be on the CAAG. It was true that many of the attendees were organizational representatives but not necessarily the entity’s decision-makers, requiring members to relay pertinent information or desires to the people who could make policy changes.

Exhibit 4-3. Barriers to the effectiveness of the CAAG

Barriers to the effectiveness of the CAAG	Number of CAAG members (N=9)	%
Core Group members did not have the time to dedicate to IMHI.	5	56%
Time between Core Group meetings was not used effectively.	3	33%
The roles of the Core Group were not understood.	2	22%
The system-level changes to be made were too complex for this group to address.	3	33%
The Core Group members present at the Core Group meetings could not help the Core Group fulfill those roles.	2	22%
The roles of the Core Group were not clearly defined.	2	22%
Core Group meeting time was not used effectively.	1	11%
No barriers.	1	11%

In addition, members were surveyed about barriers that prevented the Action Subgroups from working more effectively. Two reasons were more frequently chosen: members did not have the time to dedicate to the Action Subgroups, and again, the system-level changes desired were too complex for the group to address. Additional choices are shown below in Exhibit 4-4.

Exhibit 4-4. Barriers to the effectiveness of the Action Subgroups

Barriers to the effectiveness of Action Subgroups	Number of CAAG members (N=9)	%
The roles of the Action Subgroups were not clearly defined.	1	11%
The roles of the Action Subgroups were not understood.	2	22%
The members of the Action Subgroups were not the most appropriate people for the scope of work for each group.	2	22%
Members did not have the time to dedicate to the Action Subgroups.	4	44%
Members were not supported by their agencies in their work with the Action Subgroups.	1	11%
Action Subgroup meeting time was not used effectively.	1	11%
Time between Action Subgroup meetings was not used effectively.	3	33%
The system-level changes to be made were too complex for this group to address.	4	44%

A member also expressed his or her uncertainty of what assignments were between meetings, and therefore, that time was unused. Another member was uncertain as to what group he or she was on. A request was made for monthly updates on each action step so as to keep everyone aware of its status and therefore on top of each goal.

Members were asked what could make the CAAG more effective. Members replied they would like assignments to work on outside of meetings. As illustrated in Exhibit 4-5, other forerunners included using email and internet for regular updates, wanting more explicitly defined roles, meeting more frequently, and including having members with the ability to impact change.

Exhibit 4-5. Suggestions to increase the effectiveness of the CAAG

Suggestions to increase the effectiveness of the CAAG	Number of CAAG members (N=9)	%
Meeting more frequently	4	44%
Members who have the ability to impact change	4	44%
Action Subgroup assignments to work on outside of meetings	7	78%
Using email and internet for regular updates	5	56%
More contact with IMHI and other Core Group members between meeting times	1	11%
More explicitly defined roles for individual members	4	44%
More formal presentations of IMHI progress	1	11%
Fewer formal presentations of IMHI progress	2	22%
More facilitation	2	22%
More time for Action Subgroup work	2	22%

Members were given the chance to make additional comments after each survey question.

“Suggestions to increase CAAG effectiveness” received many responses, most focusing on the Action Subgroups. A member made a point that he or she was not sure if more group work time would have been helpful or not; he or she felt it would be more helpful to have the roles and goals more clearly defined with more structure and clearly defined action steps for activities. Another member felt project managers might not have had a clear vision of the stages such projects go through. One member suggested having Planning Group members talk with each CAAG member to ascertain how a member’s experience, expertise, and connections could contribute to IMHI. Frequent reminders and review of purpose, goals, existing issues, progress of current activities, and existing barriers were requested by a member so the group could focus their comments and suggestions. More representatives from current medical home practices and families at the meetings were requested.

4.6.6 Are CAAG group members satisfied with the group?

When asked how satisfied his or her organization was with the level of progress made in spreading the medical home concept, 5 out of 9 members were “satisfied,” 3 were “unsure,” and 1 was “slightly satisfied.” CAAG members expressed other feelings about CAAG such as:

- Feeling out of touch or underutilized.
 - “...people are reporting and sharing, but you’re not specifically saying, okay Sally, you go back to your organization, we want XY and Z to happen.”
- Believing the project staff’s actions were moving the project along.
- Observing a gap between what was discussed at meeting and what was done between meeting times.
- Perceiving IMHI’s focus as the individual clinics and not the state-wide activities CAAG could help with.
- Questioning the value of CAAG for IMHI at this time.

4.6.7 What changes have happened at the state- or policy –level?

Originally, the CAAG was supposed to take on the task of making larger systems or policy changes. Shortly after the CAAG started to meet, it was apparent the people required to make sweeping changes in the government or health care industry were not sitting at the table. More recently, members of the Planning Group began having discussions, both informal and formal, with people who have the authority to implement change. These Planning Group members have engaged policy makers and influential individuals outside the government in discussions about the value of medical homes, the

system changes required, and how medical homes dovetail with work already being done by others. The medical home concept has been discussed with the Governor, Lieutenant Governor, and the heads of relevant government departments (Department of Human Services, Iowa Department of Public Health, Medicaid, and Department of Education). As a result, the Governor's staff has inserted the phrase "medical homes" in various speeches the Governor has given. The concept is also being used in health care initiatives and grants. Planning Group members have also spoken to state legislators. Much of the focus at the state level has been on the chronic care model. There is more interest in this model as a medical home for all, not just CSHCN.

Specifically, IDPH has shown increasing interest in working with or benefiting from the work of IMHI. IMHI leaders have also been invited to take part in leading other related health care issues. Non-governmental organizations such as the Iowa Foundation for Medical Care, Wellmark Blue Cross/Blue Shield, the Wellmark Foundation, Iowa Medical Systems, the Iowa Academy of Family Practice, and Family Voices have been engaged by the IMHI staff. These contacts have created more funding opportunities and interest in piloting programs. There have been no changes in the reimbursement policies of payors, but there have been negotiations to test a different reimbursement model. Supplemental funding for the Phase 3 Learning Collaborative was contributed by Wellmark. The enormity of the changes that need to be made at policy and payor levels is a barrier. There is also a lack of data to show the benefits of the medical home concept. There is limited understanding of what a medical home means. The concept is too complex to be described to decision makers in a thirty second sound byte. National

efforts by AAP and AAF and the disastrous state of the current health care system have made it easier to talk to people about change, but much work remains to be done.

4.6.8 How was the Planning Group used?

As a Planning Group member stated, “The planning group is the primary locus for managing and reviewing all IMHI objectives and activities.” Planning Group meetings were usually held monthly, depending on individuals’ schedules. Meetings were used in a variety of different ways: to coordinate CAAG meetings; to inform all staff of the Phase 1 and 2 Clinics’ progress; to discuss the approach in spreading the medical home concept to Iowa clinics; to discuss evaluation activities and findings; and for general networking. Each person on the team fulfilled a role within the group. Some kept the group on task, while others often provided ideas and asked questions to prompt discussion. When surveyed, all members felt the Planning Group is beneficial to the IMHI effort. A member felt the Planning Group “is the most effective part of IMHI planning” and another replied “beyond beneficial, I think the planning group is ‘essential’ to the IMHI effort.”

In June 2004, a strategic planning retreat was planned for the Planning Group members and additional integral stakeholders. As a part of the Planning Group, the Evaluation Team was also included. The retreat resulted in a clear statement of vision, mission statements, defined objectives, and key focus areas.

4.6.9 Was the Planning Group effective at fulfilling its role?

Overall, the Planning Group was effective at fulfilling its role as IMHI’s governing body. Its strengths included members relating well and being invested in the medical home concept. Although many of the group members were involved in multiple projects together, each individual had a slightly different knowledge base and, therefore, contributed something unique to the group. Group members felt that “Team work is the method we use for all planning and decision making”; however, it is important to note that the majority of decisions regarding setting agendas and planning next steps took place outside of these meetings through email and conversations between individual Planning Group members. As well, within the group there were various levels of involvement in the project’s planning and operations. There were members who serve as Facilitators or advisors on the clinic Facilitation Teams. As illustrated in Exhibit 4-6, when asked about his or her role in the project, the majority of the group members identified themselves as a Facilitation Team member, an implementer, or an advisor. Only two out of the five respondents self-identified as a key decision-maker for the project.

Exhibit 4-6. Self-identification of roles within the IMHI

How Planning Group member self-defined their roles	Number of Planning Group members (N=6)	%
Key decision-maker	2	33%
Advisor	4	66%
Facilitation Team member	4	66%
Implementer	4	66%
Observer	0	0%
Consultant	0	0%

Members were also asked who they perceived to be the decision maker in the group and to whom would they turn if they had a question about IMHI. The group generally agreed that the Physician Director and the Nurse Director were the decision makers. Members' answers were more varied when it came to selecting the "go-to" person, as displayed in Exhibit 4-7. Some members mentioned that the "go-to" person would depend on the question.

Exhibit 4-7. Planning Group members' perceptions of members' roles

Who Planning Group members identified as decision makers and "Go-to" people	Decision maker	Go-to-person
Physician Director	5	3
Nurse Director	4	3
Nurse Coordinator	0	2
Physician Advisor	0	1
Evaluation Team	1	0

When asked how the group could have been more effective, communication and decision-making were broad themes. Members requested that decisions and actions taking place outside of Planning Group meetings be relayed to group members and that expectations and assignments be better defined. Meeting times and membership were also mentioned.

Meeting attendance was an important issue for the Planning Group. Many of the members were very involved in other projects and could not always fit the monthly meeting into his or her schedules. Meeting attendance was a priority for members, but often meetings were interrupted by late arrivals, members coming in and out, or early

departures. Some decision making was delayed due to lack of consistent meeting attendance. One member commented, “Some members could not be present for meetings (missed entire or part of meeting). Some action items got delayed...”

Another contributing factor was the content of the meetings. Meetings followed prepared agendas fairly closely, which typically were a mix of updates and old and new business. However, rarely were decisions made during these monthly meetings. Typically, discussions occurred regarding topics relevant to the medical home concept such as barriers to spreading the concept and the atmosphere within individual clinics that IMHI was trying to recruit. Larger issues (e.g., what should happen with CAAG, and, how do we end involvement with a clinic i.e., when is a clinic a medical home?) were debated over the course of many meetings without resolution. Thus, some major decisions to be made regarding the objectives and goals of IMHI waited until the next monthly meeting, took place over email or phone, or require separate, additional meetings. The end result was a larger burden on members’ time and delays in achieving IMHI goals and objectives.

4.6.10 Was the Planning Group satisfied with what it achieved?

Group satisfaction was high regarding operations. Members saw their group as “thoughtful,” “dedicated,” “usually goal-directed,” “helpful to IMHI planning,” “committed,” “long-standing,” “collaborative,” “organized,” “respectful,” and “change-oriented.” Members also felt the group was very beneficial to the project in coordinating

efforts and being aware of what the other group members were doing, and in managing and reviewing all project objectives and activities.

- “I believe this [Planning Group] is the most effective part of IMHI planning.”
- “The team is committed to the Medical Home concept and establishing this as the standard of care in primary care.”

4.6.11 What did the IMHI effort look like in each Phase 1 Clinic?

IMHI Facilitators met with each Phase 1 Clinic on a monthly basis. The first meetings involved filling out the Medical Home Index, examining the results from the Index, laying out aims and strategies for achieving change, and learning the basic concepts of the PDSA change cycle. Each Facilitation Meeting concentrated on encouraging the clinic to continue using the PDSA cycle as a method of change. Facilitators worked to support the clinics’ efforts and provide them with the knowledge and information on the changes the clinics decided to make. The Nurse Facilitators devoted time and effort to finding tools, research, and information to support the clinics.

The changes attempted by Phase 1 Clinics were small, as prescribed by the PDSA cycle. Clinics decided on concentrations based on the Medical Home Index assessment and each clinic’s individual interests. Below are brief descriptions of the Phase 1 Clinics followed by an overview of all three clinics.

Clinic A:

Aim statement and goals: “[Clinic A] will improve care for CSHCN by creating office systems that will identify CSHCN, prepare for their office visit, and improve satisfaction of families of CSHCN with the care and resources they are provided at our clinic. We will begin this process by:

- Develop system and process to identify CSHCN.
- Optimize the patient referral process.
- Link to a database of services for CSHCN through IMHI and develop process to ensure families are given optimal resources for their child.
- Identify two family advisors to assist the improvement team to improve the quality of care provided to CSHCN.
- Prepare for CSHCN visit; improve efficiency of the office visit.
- Optimize patient and staff satisfaction with the care provided to CSHCN.”

Clinic A has worked on building a registry of special healthcare needs children, has included two Family Partners on the Facilitation Team, and has developed tools such as:

- a chart identification system using stickers so the front desk is aware if a patient requires special accommodations;
- a medical assessment form that collects information on what services the family is receiving, child’s assets and strengths, other providers’ contact information, services requested by the family, the child’s challenges, and any equipment he or she may need;

- a self-management support tool to assist patients in managing and taking responsibility for their care; and,
- an emergency information form that identifies ongoing special needs and specific treatments.

Clinic A has also developed a brochure on the medical home and IMHI to be provided to patients at the clinic.

Clinic A's Facilitation Team is the largest of all the participating clinics. Routinely two doctors, a physician assistant, a nurse, office manager, and two Family Partners attend each meeting. This clinic has been very invested since its involvement. Some of this enthusiasm could be attributed to one of the physicians being involved nationally in the medical home concept. Clinic A's Facilitation Meetings tended to last an hour and a half, were scheduled over the noon hour, and typically the clinic supplied food for attendees. Thirteen meetings were held between October 2003 and April 2005. Meetings were generally productive with the majority of team members participating in discussions and few interruptions. Data from meeting observations showed that within the first few meetings the seating arrangements changed from IMHI staff in one area with the clinic staff sitting together opposite the IMHI staff, to a more random arrangement.

Clinic A completed the Medical Home Index both in August 2003 and September 2004. In August 2003, payor mix was determined to be 88% private only, with public insurance consisting of 11%, and self/no pay at 1%. In September 2004, payor mix shifted a small amount with a decrease to 80% as private only insurance and 8% as private plus

Medicaid, leaving public insurance and self/no pay steady at 11% and 1%, respectively. In 2003, the domains that were identified as key areas to improve were office environment and family feedback (Domain 1, Organizational Capacity) and advocacy (Domain 3, Care Coordination). In 2004, key areas to improve were access to medical record (Domain 1, Organizational Capacity), advocacy (Domain 3, Care Coordination), and data retrieval capacity (Domain 5, Data Management). Scores within the domains did not increase or decrease overall over time but showed a mixture of improvement and regression.

Clinic B:

Aim statement: “The [Clinic B] will improve office services for children with special healthcare needs by developing a Planned Care Model for office visits. [Clinic B] will begin implementing this process with children who have multiple diagnoses. [Clinic B] plans to spread these changes to all children with special healthcare needs within one year. Goals are:

- [Clinic B] will begin the development of a registry of patients with multiple diagnosis [sic] and expand this to include all children with special healthcare needs within one year;
- [Clinic B] will develop linkages to community resources (and) actively refer patients to these services as appropriate;
- [Clinic B] will work with sub-specialty care to ensure a continuum of care for these patients;

- [Clinic B] will develop patient, parent/guardian education systems to ensure parents/guardians have optimal information on how to care for their child;
- [Clinic B] will develop and implement self-management plans with patients and families to measure and monitor progress;
- [Clinic B] will measure patient and staff satisfaction before and after each PDSA cycle.”

The Clinic B Facilitation Team consisted of a physician, nurse, and office manager. The clinic started to develop a registry list of children with special health care needs, carried out a short patient and clinic staff satisfaction survey, and kept a telephone tracking log for a week to identify the purpose behind incoming calls. Clinic B Facilitation Meetings were scheduled over the noon hour and held in rooms with limited privacy (examples: waiting room, lunchroom). There were eight meetings between September 2003 and July 2004. Clinic B completed the Medical Home Index in September 2003. Its payor mix was 75% private insurance, 13% public insurance, 8% private plus Medicaid, and 4% self/no pay. Key areas to improve were identified across a handful of domains: staff education (Domain 1, Organizational Capacity), identification/screening (Domain 2, Chronic Condition Management), advocacy (Domain 3, Care Coordination), and quality standards (Domain 6, Quality Improvement). This clinic chose to stop participation in IMHI in August 2004, after about a year’s involvement. The decision to end involvement in IMHI was due to internal issues such as staff turnover.

Clinic C:

Aim statement and goals: “Improve care systems for child with ADD/ADHD at [Clinic C] by improving compliance with medical recommendations and ensuring the greatest educational development of the child.

- Identify and recruit a Family Partner for the improvement team;
- Develop a registry of ADD/ADHD patients treated at [Clinic C];
- Increase the parent/caretaker satisfaction with services;
- Increase the parent/caretaker satisfaction with medical outcomes for their child;
- Increase the provider’s satisfaction with patient information and outcomes;
- Develop individualized care plans [that] include self-management goals, educational material, and community resource information;
- Develop a better communication system with the patient’s school to evaluate patient progress.”

Clinic C’s Facilitation Team consisted of one physician, two to three nurses, and an office manager. In early 2005, the original office manager left the practice and was replaced by another staff member. A Family Partner joined the team in July 2004. Meetings were held for an hour and a half, and often, team members would leave to answer pages or attend other meetings. Fifteen meetings were held between June 2003 and June 2005. The relationship between Clinic C staff and the IMHI was strained at first. As time went on the clinic staff members became more invested in IMHI, more congenial and willing to work with IMHI staff, and more independent in enacting change within the clinic. Relationships between clinic staff were hard to determine. The

physician on the team was more likely to speak up than other team members. Over time these constrictions appeared to loosen, and staff were more likely to speak up when they had ideas. Since the team composition changed over time, it is hard to determine if this was due to any individual staff member's personality or to the overall management environment within the clinic. It is notable that during meetings clinic staff members sat on one side of the table and IMHI staff members sat on the other side, creating an atmosphere of "us" vs. "them". Clinic C dedicated a great deal of effort to coordinating with counselors, teachers, and parents on implementing the ADHD Med Tracking system within the clinic. Their efforts set them apart from the other clinics who concentrated on more internal endeavors.

Clinic C completed the Medical Home Index in June 2003 and July 2004. In 2003, payor mix was identified as 60% public insurance, 15% private only, 10% private plus Medicaid, and 15% self/no pay. Key focus areas were determined to be: practice mission and family feedback (both under Domain 1, Organizational Capacity), child and family education (Domain 3, Care Coordination), electronic data support and data retrieval capacity (both under Domain 5, Data Management), and quality standards and quality activities (both under Domain 6, Quality Improvement). In 2004, payor mix showed no change. Key areas to focus on were: family feedback (Domain 1, Organizational Capacity), care continuity (Domain 2, Chronic Condition Management), and child and family education and assessment of needs/plans of care (both found under Domain 3, Care Coordination).

A review of Facilitation Meeting Summaries for Phase 1 Clinics provides insight into challenges in achieving set goals and within the meetings themselves. The most often mentioned challenge was time. Finding time in between meetings to work on projects, pilot test tools, develop new tools, and having enough time in the meeting to get through the agenda were challenges. The lack of time impacted the amount of progress made as changes took longer to develop or be implemented. Inertia within the team also seemed to be an issue with some clinic members forgetting what his or her team was to be working on. Clinics were having difficulty identifying next steps while being overwhelmed by the big picture. Technology was mentioned frequently as a barrier. Most software used in clinics was fairly limited in the applications it allows, making it difficult for clinics to run reports on certain patient characteristics. There seemed to be difficulty in involving and educating other clinic staff who were not members of the Facilitation Team, getting Family Partners involved with the project, and having all team members attend meetings.

Clinic staff were asked to identify barriers to establishing their practice as a medical home. There was much variation in their answers. Lack of time to design and implement changes was mentioned as well as having to train staff. When asked what factors had helped in establishing their practice as a medical home, multiple staff mentioned the assistance of IMHI staff in reaching their goals. Others replied that seeing change cycles work, making small incremental changes, having providers who were willing to employ the medical home concept, and the involvement of all staff helped to establish a medical home. Positive comments by parents were also mentioned.

Clinic aim statements, products, and activities are compared in Exhibit 4-8 below with common elements for each of the clinics' aim statements bolded.

Exhibit 4-8. Comparison of Aim statements, products and activities for Phase 1 Clinics

Clinics	Clinic Aim statements	Products and activities
A	<p>Clinic A “will improve care for CSHCN by creating office systems that will identify CSHCN, prepare for their office visit, and improve satisfaction of families of CSHCN with the care and resources they are provided at our clinic. We will begin this process by:</p> <ul style="list-style-type: none"> • Develop system and process to identify CSHCN • Optimize the patient referral process. • Link to a database of services for CSHCN through IMHI and develop process to ensure families are given optimal resources for their child. • Identify two family advisors to assist the improvement team to improve the quality of care provided to CSHCN. • Prepare for CSHCN visit, improve efficiency of the office visit. • Optimize patient and staff satisfaction with the care provided to CSHCN.” 	<p>A chart identification system A medical assessment form A self-management support tool An emergency information form Brochure on the medical home</p>
B	<p>Clinic B “will improve office services for children with special healthcare needs by developing a Planned Care Model for office visits. [Clinic B] will begin implementing this process with children who have multiple diagnoses. [Clinic B] plans to spread these changes to all children with special healthcare needs within one year. Goals were:</p> <ul style="list-style-type: none"> • will begin the development of a registry of patients with multiple diagnosis and expand this to include all children with special healthcare needs within one year; • will develop linkages to community resources actively refer patients to these services as appropriate; • will work with sub-specialty care to ensure a continuum of care for these patients; • will develop patient, parent/guardian education systems to ensure parents/guardians have optimal information on how to care for their child; • will develop and implement self-management plans with patients and families to measure and monitor progress; • will measure patient and staff satisfaction before and after each PDSA cycle.” 	<p>Started to develop registry Completed satisfaction survey Began telephone tracking log</p> <p>Ceased involvement in August 2004 due to internal clinic issues</p>
C	<p>“Improve care systems for child with ADD/ADHD at [Clinic C] by improving compliance with medical recommendations and ensuring the greatest educational development of the child.</p> <ul style="list-style-type: none"> • Identify and recruit a Family Partner for the improvement team; • Develop a registry of ADD/ADHD patients treated at [Clinic C]; • Increase the parent/caretaker satisfaction with services; • Increase the parent/caretaker satisfaction with medical outcomes for their child; • Increase the provider’s satisfaction with patient information and outcomes; • Develop individualized care plans [that] include self-management goals, educational material, and community resource information; • Develop a better communication system with the patient’s school to evaluate patient progress.” 	<p>Working with schools to improve treatment Using ADHD Med Tracking Trying to involve parents of patients</p>

4.6.12 To what extent have Phase 1 Clinics established themselves as a medical home?

The clinics and IMHI staff worked hard to make changes to create medical homes, but in this evaluation, it is unclear as to whether or not Phase 1 Clinics reached medical home status. The Planning Group struggled with how a clinic is defined as a “medical home.” Throughout numerous discussions during Planning Group meetings over the last year there appeared to be a consensus that a clinic should continually strive to be a medical home and work on the domains defined by the Medical Home Index. During the evaluation period, there was no endpoint or checklist that certified when a clinic becomes a medical home. Clinics A and C made significant efforts and invested time to increase their levels of achievement in the domains of the Medical Home Index, but as one clinic staff person commented, “We have not yet attained the culture of a medical home, but keep trying.” This statement summed up staff’s ability to establish the clinics as a medical home. At this writing, the concept of a medical home had not been fully embraced throughout the clinics, but it appears the clinics are on the brink of doing so. Most of the Phase 1 Clinics’ staff now believe the clinics are on the way to “integrating the concept (medical home) into the entire clinic.” Five out of 7 staff listed spreading the concept within the clinic as their next step; 4 out of 7 believe they are poised to integrate the concept throughout the clinic.

4.6.13 How has the level of understanding of the medical home concept changed in the Phase 1 Clinics?

Most of the clinic staff in Phase 1 believed that he or she understood the medical home concept. A few staff said that his or her understanding of the concept had changed. The

majority of the staff were able to describe a small piece of the medical home concept or the IMHI, but there was a lack of general understanding of the medical home concept and the broader goals of IMHI. It appeared that the intense amount of work on a small piece of the concept each clinic did had overshadowed the larger ideas in the medical home concept and IMHI. A staff member explained IMHI as an “initiative in our office to provide better care to their child including being more aware of their needs and being prepared for their visit before they arrive.” Another staff member said it was a “coalition of groups interested in the health of Children with Special Health Care Needs.”

4.6.14 What has been the Phase 1 Clinics’ satisfaction with progress?

When clinic staff were asked to describe their satisfaction with the progress, only one member was extremely positive in responding “awesome.”

Most people recognized that the clinics made progress and people worked hard but that there was still more work to be done. Most staff believed the clinics were on the verge of integrating what they learned into the entire clinic operations. Regardless of his or her level of satisfaction with the progress made thus far, all respondents said being involved in IMHI had been a valuable experience.

The workload required for the changes and the time needed were both repeatedly mentioned as problems or barriers to progress throughout the effort. Specifically, staff said the effort was “too labor intensive,” there was a “lack of active support from senior

management,” and “people resist change.” Computers were also mentioned as a major barrier to faster progress.

Although clinic staff were not happy that progress was slow, many recognized that slower speed and incremental changes were part of what facilitated change to happen. Some staff members also recognized the vital role IMHI Facilitators played in getting the clinics “started” and in “pushing” the clinics to meet their goals. Clinic staff mentioned IMHI staff’s input, ideas, tools, encouragement, and help with literature, patient education materials and handouts as important resources for success of the effort.

4.6.15 Is the medical home concept spreading within the Phase 1 Clinics?

Wide-scale spread of the medical home concept within Phase 1 Clinics has not occurred.

For the most part, clinics are still concentrating on their original focus. Most of the staff believe the clinic members are on the verge of spreading the concept to the rest of the clinic, but some staff members admit not all of the clinic staff are aware of IHMI. Many of the staff list spreading the concept within the clinic as one of the next steps.

4.6.16 How have Family Partners been utilized in Phase 1 Clinics?

The involvement of Family Partners in Phase 1 Clinics was limited. In general, the Family Partners were slightly less than satisfied with their level of involvement in the clinics. One of the Family Partners felt that she could express her opinion at meetings, that clinic staff and IMHI staff asked her opinion about important issues, and her opinion was listened to while another Family Partner did not feel the same way. IMHI

Facilitators tried to engage the Family Partners or ask them specific questions during meetings. When Family Partners were asked to provide input, they were asked to express their individual opinions or what they thought would be the opinion of other families. A few sample questions posed to Family Partners were, “What do you think families would want?” or “Would families like this?” It was universally assumed that the Family Partner was representative of and a spokesperson for all families with CSHCN in the clinic. Many of the issues Phase 1 Clinics addressed are those unfamiliar to Family Partners, such as internal clinic processes, whose minute details were irrelevant to them.

While IMHI facilitation staff and clinic staff both noted the importance of having a Family Partner involved, none of the Family Partners were engaged by clinic staff or IMHI staff between Facilitation Meetings. The only contact the Family Partners had between meetings was with the Evaluation Team.

Family Partners became involved and continued to stay involved because of their own interest in the project and how important they thought the project was. One Family Partner summed up her satisfaction with IMHI as, “I love the concept! I think that the vision of the Medical Home is a wonderful goal. I really liked the Facilitation Team from Iowa City also. I would like to continue involvement in the project whether it be through the clinic or IMHI directly. I am excited about IMHI as a whole and think that if successful this will be a wonderful enhancement to healthcare! Thank you.” They also agreed that the meeting times were convenient. One Family Partner was motivated to stay involved because she felt that her contribution was valued.

All of the Family Partners were eager to become more involved and contribute more to the effort. The most significant factor that prevented Family Partners from increasing their involvement was a lack of understanding about what they could be doing for IMHI. As one Family Partner stated, “I could do more, wish I could do more for...but don’t know what that would be.”

Much of the dissatisfaction or confusion around Family Partners was directly related to a general lack of understanding about their role. Neither clinic staff, IMHI facilitation staff, nor the Family Partners were clear on what a Family Partner was supposed to do. Very recently the IMHI facilitation staff has asked for input about what a Family Partner could or should do from clinic staff members. Another barrier to greater involvement was a lack of communication with the clinic and not being asked to become involved by clinic staff. One Family Partner wrote, “I believe it would be much more beneficial if the family partner was made to feel more comfortable asking questions. If the role of the family partner was better defined/explained. I'm an educated women but I was lost and confused a lot of the time. Most of the time I was not included/involved in the conversation. I believe that more specific "tasks" or follow-up items could be given to get the family partner more involved in the process.”

4.6.17 What did clinic recruitment/spread look like in Phase 2?

Clinics were identified as potential partner clinics by IMHI staff, stakeholders, or other partner clinics. The recruitment process in Phase 2 began with a phone call or letter from IMHI staff. Frequently, phone calls and emails from IMHI staff to clinics were ignored

or very delayed in responding. If the clinic showed interest, it was given a notebook about IMHI, and a marketing meeting was scheduled. IMHI staff and a Physician Advisor from the Planning Group or Phase 1 Clinic were present at the marketing meeting. The marketing meetings were well received by both clinics who later joined and those who later declined. The IMHI staff was clear and concise in telling the IMHI story. Physician Advisors were also used to nudge clinics to participate if they had been wavering. A good Physician Advisor appeared to make a difference in recruiting by convincing those unsure clinics to participate. Areas of the state without physician advisors had fewer clinics agreeing to participate despite the efforts of the Nurse Facilitators.

The process was very time and labor intensive. Valuable time was spent meeting and communicating with clinics that eventually chose not to become part of the effort. Often events happening in the clinics, such as staff leaving or illness, prolonged a clinic's decision time. For some clinics it took months (3-6 months) for a decision to be made. Recruitment did not get easier as the project progressed, and in general, IMHI staff believed it was not very efficient. For IMHI staff the roller coaster of clinics appearing to be interested, then changing their minds and deciding not to participate was frustrating.

Other barriers to recruitment included a lack of time and money for recruitment, as well time and financial concerns for the clinics. Lack of time was the reason most often cited by clinics that declined to become involved. The second most mentioned reason related to timing, meaning the time was not right for a given clinic because of some internal issues

such as staff turnover. The inability to gauge a clinic's sincere interest in the project contributed to time wasted in the recruitment. Additionally, the practices had varying degrees of experience and knowledge about quality improvement, the latest medical advances, and the concepts embedded in medical home. Some factors appeared to facilitate recruitment, such as the efforts of a Physician Advisor and a clinic's previous knowledge about quality improvement or the medical home concept. Clinics with a staff member such as a physician, nurse, or office manager who were very interested or committed greatly improved the chances a clinic would participate. Clinics also became involved because they were interested in improving patient care.

4.6.18 What did facilitation look like in Phase 2 Clinics?

During the evaluation period, in most Phase 2 Clinics the IMHI process had barely begun. Facilitation was in its infancy, with the Facilitators still working to develop relationships with the clinics. While some of the clinics had met with the Facilitation Team numerous times, others had just begun meeting. There were 5 Nurse Facilitators in Phase 2. Two of the Facilitators had experience working with Phase 1 Clinics. Unlike Phase 1, in Phase 2 there were physicians available who have experience working with IMHI. They were added to the Facilitation Team as Physician Advisors. Phase 2 Clinic facilitation benefited from the lessons learned in Phase 1. The role of the Nurse Facilitators did not appear to be greatly changed from the core role of Nurse Facilitators in Phase 1. The actual facilitation process was intended to be less intense than in Phase 1, but may in fact have been more streamlined. Many of the barriers and frustrations

experienced in Phase 1 were magnified in Phase 2 because of the larger number of clinics (2 and 12, respectively).

One of the positive changes in Phase 2 was the expertise available to the Facilitation Team and clinic staff. There was a general consensus that the process benefited from having experienced Nurse Facilitators to turn to and Physician Advisors. Some of the nurses appreciated having the more experienced Nurse Facilitators available, especially at the initial meetings. The monthly communication between the Nurse Facilitators and use of the University of Iowa shared computer drive helped in disseminating knowledge and experience. There was also a willingness to share stories and brainstorm among the less experienced and more experienced Nurse Facilitators. Physician Advisors were mentioned as an important addition to the Facilitation Team. One nurse commented that Phase 2 Clinics “seem to want to have practical knowledge and ‘testimonial’,” which the Physician Advisor can provide. A Physician Advisor at a Phase 1 Clinic was helpful because he could answer practical questions as he was “living and working the model.”

Because of the experiences of Phase 1 Clinics, Phase 2 Clinics were able to benefit from broken ground. The paths which Phase 1 Clinics created made it easier for Phase 2 Clinics to begin work on similar projects. Although the work in Phase 2 was not always a clear replication of the work done in Phase 1 Clinics, it was apparent that many of the Phase 2 Clinics were choosing to implement changes already piloted by Phase 1 Clinics. Due to this use of paths already laid out, clinic efforts appear less intense. It remains to

be seen whether decreased activity required by clinic staff changes the speed of Phase 2 Clinics' progress compared to Phase 1 Clinics.

The basic role of the Nurse Facilitator in Phase 2 remained unchanged. At the outset of Phase 2, it was expected the Nurse Facilitator role would be smaller within the clinic Facilitation Team compared to the role of the Nurse Facilitator in Phase 1. Less face-to-face meeting time would occur and the majority of communication between IMHI and clinic would occur via email and/or phone. As the Nurse Facilitators began to work with the Phase 2 Clinics it became apparent they would need just as much attention as Phase 1 Clinics. The purpose of a Nurse Facilitator was summed up best by one nurse when she wrote that the Nurse Facilitator's role is "to help the team move forward and make changes."

In Phase 2, the Nurse Facilitators continued to do research, provide support, share information, prepare agendas, take notes, and make contact with clinics between meetings. Much of their work required "hand holding" and as one nurse described, part of her job was providing "continual pats on the back" to clinics and helping "them see the progress they have made." The Nurse Facilitators are also walking a fine line between "giving them a little push" and "not overwhelming them and making them feel like they are being moved faster than they want to move." There was also a fine line between providing clinics with additional information or ideas and steering them in their decisions. Another concern related to the amount of work being done and responsibility for the work. It was unclear at what point the Nurse Facilitators were no longer

facilitating but taking over much of the clinic's work and the responsibility for the project.

Because there are 12 clinics in Phase 2 as opposed to only two in Phase 1, there was a greater degree of variation between the clinics, which posed challenges for the Nurse Facilitators. Some of the clinics were pediatric practice (3); some were family practice (9) clinics. The clinics were serving different populations because of their locations. The two Phase 1 Clinics were urban, while many Phase 2 Clinics had more rural populations. The physicians and staff also varied in their degree of education about and experience with CSHCN, the medical home concept, and quality improvement efforts. For some clinics the concepts behind PDSA were foreign, while other clinics were not as current on the latest medical research. Nurses had to devote time to improving clinics' basic knowledge on these issues, which was not necessarily true for Phase 1 Clinics.

There were barriers to facilitating clinics. Scheduling problems, illness and bad winter weather made it difficult for Nurse Facilitators to spend face-to-face meeting time with Phase 2 Clinics. In general, the meeting time scheduled was not enough. Because of clinic schedules and patient emergencies, meetings began late or people joined the meetings late. It was sometimes not possible to complete the agenda in the time allotted.

Clinics were also limited in the time they could devote to the project outside of the Facilitation Meetings in order to move forward. The slowness of change was seen as a barrier. Team leaders appeared to be gatekeepers for getting projects to move ahead. If the assigned team leader was not facilitating work on the project, either because he or she

did not know how or was not interested, this prevented progress. Some of the Nurse Facilitators worried that their inexperience with PDSA or medical homes or chronic care models was a barrier.

In general, the Nurse Facilitators reported back that clinics were, “eager to learn and change,” “willing to be open and look at areas in the practice that could improve for families,” and “are very positive and patient orientated.” Despite the positive assessment of clinics, one nurse said the process had been “very challenging and frustrating.” The Nurse Facilitators also voiced concerns about clinics’ ability to carry on without phone contact and meetings by Nurse Facilitators. One nurse commented, “I feel that the clinics will need support for some time still in order for true change to continue.”

4.6.19 What does progress in Phase 2 look like?

Progress in Phase 2 has been slower than IMHI staff had originally hoped, and some IMHI staff were not satisfied with the level of progress. Many of the same challenges faced by Phase 1 Clinics were also barriers for Phase 2 Clinics. Additional barriers are related to the decreased frequency of meetings in Phase 2 and changes in facilitation. Among the ten Phase 2 Clinics the progress is varied, partly due to the differences in when the clinics enrolled. Some clinics have been participating in Phase 2 for about one year, while other clinics joined the effort more recently. Below are brief descriptions of the clinics, followed by an overview of all of them.

Clinic D:

Aim statement and goals: “Improve care systems for children with ADD/ADHD at [Clinic D] over the next 9 months by implementing the Chronic Care Model for care delivery in our clinic. We will begin by implementing evidence-based guidelines for care delivery and measurement of patient outcomes. We will establish a family-centered care approach to care delivery and improve education of all staff members regarding the special needs of these children. We will establish a registry by which we will identify and track patient outcomes over time. The specific outcomes we will begin to measure are:

- Increased family satisfaction
- Increased completion of Vanderbilt Assessment Forms
- Improved medication and behavioral compliance
- Improved patient compliance with follow-up visits.”

Clinic D has been working on developing an ADHD registry and tracking system. They are beginning to use the Vanderbilt Assessment Scales for parents and teachers. Work has been done to increase communication with the schools and to provide educational resources to families with children who have ADHD. The staff has also benefited from more education on ADHD and the needs of ADHD patients. This clinic has been a part of IMHI for about one year. According to IMHI records this clinic required six months from the time of the first meeting until an aim statement was adopted.

Clinic E:

Aim statement and goals: “Improve care with CSHCN by creating office systems that will identify CSHCN, prepare for their office visit and improve satisfaction of families of CSHCN with the care and resources they are provided at our clinic. Within the next 12 months we will:

- establish a registry by which we will identify and track patient outcomes over time;
- establish a family-centered care approach to care delivery;
- improve education of all staff members regarding the special needs of adolescents;
- begin to measure family satisfaction;
- include a family partner in the development and establishment of our family-centered approach; and,
- provide education to community agencies and schools about the special needs of adolescents.”

This clinic has worked on developing a registry of CSHCN, implementing ADHD Med Tracking, and compiling resources for CSHCN. Like most clinics, technology slowed the work on the registry, and Clinic E’s billing structure impeded implementation of the ADHD Med Tracking. Because of the multiple demands placed on staff at this clinic, there is marginal staff involvement.

Clinic F:

Aim statement and goals: “Improve care systems for children with ADD/ADHD at [Clinic F] over the next 9 months by implementing the Chronic Care Model for care

delivery in our clinic. We will begin by implementing evidence-based guidelines for care delivery and measurement of patient outcomes. We will establish family centered care approach to care delivery and improve education of all staff members regarding the special needs of these children. We will establish a registry by which we will identify and track patient outcomes over time. The specific outcomes we will begin to measure are:

- Increase family satisfaction;
- Increased completion of Assessment Forms;
- Improved medication and behavioral compliance; and,
- Improved patient compliance with follow-up visits.”

The clinic plans to work on an ADHD registry, a care plan, educational resources for families, and outreach to schools. This clinic is just beginning to make baby steps to implement change. There have been multiple key staff members missing from meetings. Limited time for meetings and work between meetings has been a challenge. The staff at this clinic are more hesitant and have been more neutral and less enthusiastic than other clinics, according to the collected Facilitation Meeting Summaries.

Clinic G:

Aim statement and goals: “An opportunity exists to work with ADHD patients to follow through with their medical therapy to maintain better control and ensure greatest educational development of the child. The process begins with developing a registry of

ADHD patients treated at [Clinic G] and ends with every child/chart with ADHD being identified.

- This effort should improve accessibility of information about children, their visit needs as well as continuity of care for families and providers.
- This process is important to work on now because currently there is no system in place to identify children with ADHD.
- The system will improve continuity of care of patients and staff. It will identify children with ADHD to all providers, which will in turn lead to improved care.
- This effort should help to decrease the patient's symptoms, decrease the number of missed school days, increase their performance at school and lead to better compliance and timing of information to make a clinical judgment.”

Clinic G has had more Facilitation Meetings than most clinics in Phase 2. It is not apparent whether this has facilitated their progress. The clinic is also organizing an ADHD registry, appointment schedule, and is beginning to identify CSHCN on charts and in the computer.

Clinic H:

This clinic planned on developing an asthma registry, and a care plan, and finding educational and resource materials for asthma patients and their families. This clinic recently left the IMHI project due to staff turnover.

Clinic I:

Aim statement and goals: “Improve care systems for children with ADD/ADHD at [Clinic I] by improving delivery of care and implementing evidence-based guidelines.

The clinic will establish a registry of these patients to facilitate improved monitoring of patient progress and outcomes. Office standards for the clinic will be formulated with improved education of staff and providers regarding ADD/ADHD as well as improved communication with school personnel regarding children with ADD/ADHD.”

Clinic I worked on an ADHD registry and tracking, as well as resource materials for families and staff. Unique to this clinic is the demand for materials for Spanish-speaking families. The clinic is implementing the Vanderbilt Assessment Scales and is working on increasing communication with schools. This clinic has also started using “huddles” (a brief staff meeting) to connect with staff on ADHD patients and IMHI. This clinic appears to be able to complete work between Facilitation Meetings.

Clinic J:

Aim statement: “Improve care systems for children with ADD/ADHD at [Clinic J] by improving delivery of care and implementing evidence-based guidelines. The clinic will establish a registry of these patients to facilitate improved monitoring of patient progress and outcomes. Office standards for the clinic will be formulated with improved education of staff and providers regarding ADD/ADHD.”

Clinic J is developing an ADHD registry and a system to identify patients on charts and in the computer. The Vanderbilt Assessment Scales and a care plan are being implemented. This clinic was not able to complete much work between Facilitation Meetings; notably, between the December and March 2005 meetings, little was accomplished. According to clinic minutes, the aim statement was drawn up by the Nurse Facilitator and only reviewed by the clinic.

Clinic K:

Aim Statement and goals: “An opportunity exists to improve the identification of CSHCN at [Clinic K]. The process begins with identification of CSHCN and ends with every child/chart being identified.

- This effort should improve accessibility of information about children, their visit needs as well as continuity of care for families and providers.
- This process is important to work on now because currently there is no system in place to identify CSHCN.
- The system will improve continuity of care for patients and staff. It will identify CSHCN needs to all providers, which will in turn lead to improved care.”

Clinic K is working to develop a registry of CSHCN and a process of identifying CSHCN on the appointment list, charts, and in the computer system. The clinic is interested in implementing care plans and screening tools with a severity rating. This clinic has had frequent IMHI Facilitation Meetings and is also implementing “huddles”.

Clinic L:

This clinic is working to identify CSHCN and provide resources to families with CSHCN. The clinic got off to a slow start, and there is a general feeling of not knowing or understanding where to start the process.

Clinic M:

The aim statement for this clinic was decided at the end of June 2005. The Evaluation Team was not given the specifics of this project. There was a good deal of discussion about computer/technology issues and the creation of some kind of registry.

Clinic N:

Aim Statement: “Improve care systems for children with ADD/ADHD at [Clinic N] over the next year by implementing the Chronic Care Model for care delivery in our clinic. Begin by implementing evidence based guidelines for care delivery and measurement of patient’s outcomes. We will establish a family centered care approach to care delivery and improvement education of all staff members regarding the special needs of these children. We will establish a registry by which we will identify and track patient outcomes over time.”

This clinic will work on an ADHD registry and a method for identifying charts. Use of the Vanderbilt Assessment Scales, a care plan, and education materials for families and staff are planned. Early on in the process the clinic staff was more skeptical. As well,

the staff were more likely to be neutral or only slightly agree in their Facilitation Meeting Summaries.

Clinic O:

Clinic O was originally approached to be a part of Phase 1, but declined due to staffing issues. Meetings have only recently begun with this clinic, and Facilitators and clinic staff have not yet decided whether this clinic will join as a Phase 2 clinic or wait until the Phase 3 Learning Collaborative to become a full member of the IMHI effort. This clinic will provide the unique experience of working with a residency program.

Recap

When clinic staff were asked about the aims and objectives of their projects, most mentioned clinic processes such as identifying patients and getting organized to better serve patients. Staff described the work they had done as “discussions at meetings,” developing and refining new processes, collecting data, and attending meetings.

Not all staff felt like these were worthwhile efforts. One staff member commented, “It seems like duplication of services already available for the most part (like extra busywork).” Others also commented that “We have not actually put our plan to action yet.” Most staff were unsure about the value of IMHI for their clinic.

Staff members mentioned numerous barriers, time and technology issues the most frequently. These two issues arose in almost every clinic. One staff person said this is “viewed as one more thing to do without the time.” It was hard for Nurse Facilitators to

keep Facilitation Meetings to only one hour. Staff also had a hard time carving meeting time out of their schedules. Meeting minutes and Facilitation Meeting Summaries reflected many meetings that were not fully attended; people arrived late and left early or stepped out of the meeting to receive calls or pages. People also cited not having enough staff to do the extra work required. Nurse Facilitators had a hard time encouraging clinics to tackle some of the work between meetings. Meeting minutes showed that many clinics had items on their “to-do list” for multiple meetings with little or no action taken. Because every clinic had their own unique computer system and paper/chart system, there was no “one-size fits all” solution to the issues surrounding registry creation and identifying and tracking patients. Each clinic had to start from scratch to devise their own process. Misunderstanding the medical home concept and scarce resources for families were additional barriers.

One clinic also mentioned the need for interpreters for patients as a barrier to progress. Clinics operated by larger health systems had to manage the requirements, needs, and desires of the larger system. These larger systems may have impeded change due to their across-the-board policies on treatment and billing and their company-wide or proprietary computer and chart systems.

Most frequently, staff mentioned the Nurse Facilitators and the time and resources the Nurse Facilitators had as the factor that most facilitated the process. One staff person wrote that Nurse Facilitators had experience and knew what worked and what did not.

Having staff and providers interested in the effort was also cited as important. In addition, the Facilitation Meetings were viewed as very helpful.

In general, clinic staff were unable to comment on what other resources they might need because the clinic was not very far along in the process of becoming a medical home. Some staff mentioned that more tools and resources/examples would be helpful, since those require time for clinics to find.

Finally, surprisingly, the aim statements for the Phase 2 Clinics were very similar to those of the Phase 1 Clinics. Most of the clinics focused on issues related to ADHD in their aim statements. The Evaluation Team was not able to determine how much of this similarity was driven by Nurse Facilitators, convenience, the desire to travel a known path, or clinics viewing ADHD as pressing concern.

4.6.20 Has the level of understanding of the medical home concept increased in Phase 2 Clinics?

Most Phase 2 respondents believe his or her understanding of the medical home concept had changed due to his or her involvement in IMHI. Some Phase 2 clinic staff were not aware of the concept before he or she became involved with IMHI. Each member's definition of IMHI was also related to the particular project he or she was working on, not necessarily the general idea of a medical home.

4.6.21 What is the role of Family Partners in Phase 2?

None of the Phase 2 Clinics had engaged Family Partners. The Facilitation Meeting Summaries and notes from the IMHI Facilitator indicated that eight of the clinics had held discussions about Family Partners. For most of the clinics there was documentation that they wanted to involve or planned to involve families. A few of the clinics stated that families would be involved when the clinic was “ready” or “project progresses further.” There was some evidence that IMHI Facilitators encouraged clinics to start thinking about a family the clinic might approach to be a Family Partner. Three clinics had “involving a Family Partner,” “discussing with family”, or “need to discuss involving families” as an action step to be completed before the next Facilitation Meeting. There were three clinics that made no mention of family involvement or Family Partners in the Facilitation Meeting Summaries or notes provided by the facilitation staff.

4.6.22 How does the role of a champion impact the IMHI?

This question inspires much debate-not over whether a champion is necessary as the majority agree that it is-but over whom the champion should be. Some IMHI staff members feel it is necessary that a physician within the clinic be invested and involved in the project. Others feel it is more important that the office manager or a nurse be involved. One Planning Group member stated that it is important to have a leader who is both an action person as well as a cheerleader who promotes change while trying to initiate and implement changes within the clinic. Another member felt that external physician champions, such as the IMHI Physician Advisors, could or could not be essential to successfully establishing a medical home, depending on the qualities of the

clinic in question. One of the Nurse Facilitators expressed the concern that clinic team leaders need to be carefully chosen, as having someone lacking the skills or desire to move the clinic forward independent of IMHI assistance could derail progress. She went on to say that this person should also be able to see and understand what the group is trying to accomplish over time.

For this report the Evaluation Team did not have sufficient data to triangulate the Planning Group's opinions on the role of a champion. However, it is apparent there must be representatives of all clinic staff present at each meeting to allow each group's collective voice to be heard while discussing changes that may occur. Common sense dictates that one person may be able to spy missing components in the action plan where another might not.

5. Conclusions

5.1 Discussion of process evaluation findings

Goals for this evaluation were to determine whether IMHI had established medical homes for CSHCN over the grant period, and whether the process used in establishing medical homes was effective and efficient. Analysis of data collected over the two-year evaluation period yielded interesting findings, some of which are explored below.

5.1.1. Establishment of medical homes

IMHI's primary goal was to establish medical homes for CSHCN across the state of Iowa. The evaluation found by the conclusion of the grant period, none of IMHI's partner clinics could be considered medical homes. Multiple factors contributed to this outcome. An impediment to determining whether IMHI was successful in establishing medical homes was the lack of a functional definition of a medical home. Discussion was raised in multiple arenas within the IMHI about setting guidelines to help create a definition, but no definitive action was ever taken by the Planning Group.

This lack of guidance affected IMHI's outcomes multiple ways. Lack of definition made impossible the measurement of success and left partner clinics without explicit goals. In addition, recruiting clinics took more time and was more difficult than expected. Many clinics were reluctant to add one more poorly explained commitment to already busy schedules; some were uncertain of the value of becoming involved with an initiative such as IMHI. The planning and implementation of desired change within clinics influenced the outcomes as well. The level of change that occurred within the clinics was smaller

and took longer than was expected by the Planning Group. The quantity of resources required by each clinic to enact change was greater than expected by IMHI. As IMHI efforts at the practice-level progressed, concerns developed regarding clinics' ability to sustain and/or enact further change without constant support from IMHI.

As with all plans, adjustments were necessary as IMHI discovered clinics were not willing and/or able to plan and enact change within their practice without support. The move from Phase 1 to Phase 2 (from directive to a less hands-on approach) did not evolve as expected. Facilitators found it was necessary to provide Phase 2 Clinics with as much direction and assistance as had been provided to Phase 1 Clinics, which led to an increase in resources used, rather than the expected decrease.

Also unexpected was the Phase 2 Clinics' overwhelming desire to use already developed strategies, rather than cultivate their own. Expectations were that Phase 2 Clinics would apply the lessons learned by Phase 1 Clinics, and foster additional, unique change strategies, thereby continuing to increase the pool of knowledge. Streamlining changes that would assist practices in becoming medical homes was expected to increase the speed in which practices achieved medical home status, therefore making the change process more attractive to other practices, resulting in the spread of established medical homes across the state. As of this report, Phase 2 recruitment and facilitation has been slower than expected, and, not enough activity has occurred in Phase 2 for the Evaluation Team to be able to ascertain if this hypothesis will be proved or disproved.

5.1.2. Duality within IMHI

During the data collection process, the Evaluation Team became aware that Planning Group members were meeting individually with state opinion leaders in the pursuit of policy changes that would support IMHI goals, while simultaneously trying to establish medical homes within practices. These state opinion leaders included stakeholders (payors), policymakers (Governor and staff, legislators), and decision makers (heads of state agencies). Although these meetings were not strategically planned from the outset of IMHI, unlike the CAAG, their results became significant to IMHI's success by encouraging further state-wide collaboration and additional funding.

Further analysis of these contacts showed that an interesting disconnection between practice level and state-wide/policy level efforts exists within IMHI. This duality is present: 1) in how IMHI's guiding concepts are used to direct efforts to establish medical homes; and 2) in the focus of IMHI activities.

1. Diffusion of Innovations was the theoretical framework used to explain IMHI's goal to spread the medical home concept at the state-wide level while PDSA was used to enact change, and educate practices on how to implement change, at the practice level via the clinic's Facilitation Team. No intersection between models, or impact of one upon the other, was observed by the Evaluation Team. Should activity at the PDSA level affect the spread of the medical home concept throughout the state? Should clinic personnel be encouraged to think globally

about how small changes made within their clinics might affect larger systems such as the CSHCN population or state Title V health system?

2. Separation of state-wide and practice level efforts exists among the roles and responsibilities of the IMHI Planning Group. Each group member labors on one or the other level, with only the Nurse Director participating on both levels. The Evaluation Team was unable to resolve whether these two levels of operation were integrated or exclusive to one another. Does work at the practice level support efforts on the state-wide or policy level? Is each group member aware of, and do they understand, all of the efforts that occur on behalf of IMHI?

More data are needed to assess which approach will be more effective over the long-term in establishing medical homes in Iowa. Continuation of practice level efforts may take much more time and resources than working at the state-wide level to change reimbursement policies or quality of care requirements in support of the medical home concept. Or could simultaneously directing resources at both approaches result in success being reached more quickly than focusing on one level or the other? It is difficult to determine with existing data which approach would be most efficient in diffusing the medical home concept throughout the state. Answers to these questions should be sought in future efforts.

6. Recommendations for future work

After studying all data collected over the grant period, the Evaluation Team offers recommendations in these areas for IMHI's future work: clinic/practice recruitment, facilitation, Family Partners, planning process, CAAG, and IMHI overall operation.

Clinic/practice recruitment

1. Develop a systematic way to assess a clinic's interest from the beginning of the recruitment process to prevent wasting of time with clinics not seriously considering participation. Interest could be ascertained via a brief phone or paper survey.
2. Provide clinics with informational materials before approaching them about making a decision. These materials would give the clinic a chance to start thinking about the medical home concept, which would allow the IMHI to focus on selling the clinic's involvement in IMHI during the initial presentation, rather than on education.
3. All clinic staff should be invited to the initial presentation by IMHI, including front desk, administrative, health care providers, and nursing staff. This general introduction to the concept for all staff would increase the likelihood of understanding the medical home approach by permeating the entire practice, thus increasing the chance for success if adopted.
4. Keep those who have declined to be involved with IMHI connected to IMHI. Although to date they have declined to be involved, they probably already know

more about medical homes than clinics IMHI has yet to approach. These clinics all have the potential to become adopters in the coming years.

5. Increase exposure to the medical home concept to administrators, front office staff, and health care providers by looking for opportunities specific to each audience. For instance, consider presenting at conferences aimed at clinic staff other than physicians.

6. Use Diffusion of Innovations to make recruitment more targeted. The theory will help staff at target clinics that are more likely to be adopters in the early stages.

Facilitation

1. Explicitly use the concepts in Diffusion of Innovations to ease adoption of new processes. The theory's constructs provide a useful road map for making the facilitation process more efficient.

2. Consider using a tool to assess clinic staffs' readiness to change so they may identify a leader or champion, as doing so from the beginning is important. These influential innovators in the clinic will institute more change than other staff members.

3. Spend more time explaining the rapid change cycle and PDSA and how these concepts relate to medical home as a continuous quality improvement process.

4. Help clinics recognize the small steps they are taking and celebrate those successes. Clinic staff get frustrated and unmotivated if they do not see the results of their efforts. Find ways to provide clinics with “pats on the back” to reinforce their work. They already receive this support from the Nurse Facilitators, but additional morale boosts might further encourage their interest and efforts. Some ideas might be a letter of thanks from one of the Academies, payors, the Governor or the IMHI staff, or assistance in receiving press from the local paper for their efforts.

5. Standards should be developed to indicate at what point a practice is considered to be a medical home. People have difficulty striving for something that is undefined. Clinics may be more willing to make efforts to change if they fully understand what they are aiming for.

6. Encourage clinic staff to be thoughtful and honest in their assessment of meetings (Facilitation Meeting Summaries). This information can provide the Planning Group with valuable feedback about the process.

7. Consider including non-key clinic staff in Facilitation Meetings on a rotation basis. This would allow for the concept to spread throughout the clinic without halting the clinic’s work. It would also democratize the process of change.

8. Recognize that not all changes regarding the patient/family level will be obvious to the patient/family population of the clinic.

9. Depending on the CSHCN focus, clinic involvement with the school district or local Area Education Agency might be appropriate. For the chronic care model clinics should consider adding specialists from the local area that would bring a new skill set and resources to the clinic. For example, if the medical home health care focus was on diabetes management, someone from the local American Diabetes Association or Iowa State University Extension Service could be included.

10. Reconsider striving for the streamlined, cookie-cutter approach to change as seen in Phase 2. It is not clear that this approach actually saved time or sped up the process a great deal. Although the workload at the beginning of Phase 1 was intense, it might have been necessary to implementing lasting change.

Family Partners

1. Provide Family Partners with job descriptions and offer clinics ideas on how to use their Family Partners. Some uses for Family Partners might be to test forms for the clinic with other families, to talk to other families about their experiences at the clinic, to promote the clinic's efforts in the community, to gather community resource information for the clinic, or to do web searches for education materials and resources.

2. Encourage clinics to meet with Family Partners in settings additional to Facilitation Meetings.

3. Encourage clinics to remember that the Family Partner does not speak for all families. Opinions need to be gathered from multiple families with various experiences.

Planning process

1. Schedule periodic review and planning sessions at the start of and at intervals during the project period. Such a practice will allow project staff members to reassess and vocalize the project's vision, mission, and goals. The Evaluation Team found the 2004 strategic planning retreat generated positive energy for future work while dispelling confusion about the focus of IMHI. It is possible some of the confusion that existed and that the Evaluation Team picked up on as evaluation activities began might have not existed had a strategic planning process been held at the beginning of the grant period. IMHI seems to be an initiative that needed a pilot period before determining the best road to take. The Evaluation Team suggests conducting strategic planning sessions regularly during the grant period to allow staff members and stakeholders to revisit current vision and goals to determine if adjustments are needed to move the project forward. Holding a session at the beginning of a project could demystify some of the complex language in the grant and emphasize project goals and objectives.

2. The format of Planning Group meetings should be revisited to ensure the meetings are as constructive and effective as possible. Project staff members should be willing to dedicate the entire period of the meeting to IMHI rather than splitting his or her attention with other duties. To ensure that members feel justified in setting aside this time, meetings should focus as much as possible on completing actual planning objectives

rather than on informational updates. This will reduce the amount of time outside of meetings that members are required to devote to working on those objectives.

Information should be made available to members via email or a website. If IMHI is concerned about security or privacy, an intranet should be looked into and/or developed.

3. Add a Family Partner to the Planning Group. Ideally, this person should be someone with a child whose special health care needs are complex. The person should have a background in health care. The person would not have to be involved with one of the current IMHI clinics.

CAAG

1. Core Advisory and Action Group membership composition needs to be addressed to ensure that actual work and progress can occur from CAAG meetings. Diffusion of Innovations theory should direct membership composition.

2. Consider forming a new CAAG which would consist of a smaller, more committed group of individuals (similar to Planning Group). Not every possible stakeholder has to be at every meeting at this level of the IMHI project's organization. As shown in the first phases of this project, the small or individual meetings held between key IMHI staff members and stakeholders were very effective.

3. CAAG meeting structure and format should be revisited. IMHI attempted before to make meetings less informational and more work-based. Unfortunately after one or two

meetings with the new format, the agenda tended to regress. Facilitation of the group needs to be vigilant to prevent digression of discussions.

4. To ensure the format does not revert to an information meeting, a new method of sharing information and overseeing achievement of between-meeting work assignments needs to be developed for this group.

5. If IMHI is interested in continuing to hold some sort of gathering, we suggest they hold a networking event twice a year where IMHI and other related projects can present the state of their projects and their successes. This can serve as a great way to promote IMHI and the medical home concept.

IMHI Overall

1. Incorporate Diffusion of Innovations completely into the project. Consultation or training from a Diffusion of Innovations expert is highly recommended.

2. Develop regular (at least quarterly) updates on the entire project covering issues such as clinic project updates and advances in reimbursement policies for everyone involved, including the Planning Group, CAAG, the clinics, Family Partners, and other individuals and agencies that have shown interest in IMHI. Include clinics that declined to be involved and issue an open invitation to join the Initiative in each update.

3. Continue the small or individual meetings between key IMHI staff and stakeholders. These have been highly successful.

4. Whenever someone is invited to become involved in IMHI, whether a clinic, parent, stakeholder, etc., outline IMHI expectations for his or her role. Across the board, people wanted to know what their responsibilities were. Further, project participants can only meet expectations if they know what those expectations are.

5. IMHI should focus on promoting more public awareness about the project and the medical home concept, e.g., more publications, more discussion of future goals, and how IMHI hopes to make it sustainable.

6. IMHI should use the website more effectively to provide information to project staff members, stakeholders, and project participants. Message boards could be developed for all groups to communicate without loading up email inboxes. Blogs could be tried again for experience sharing, especially among Family Partners and patients' parents.

7. It might be worthwhile to consider focusing more on enacting policy change regarding reimbursement rather than expending the majority of resources towards individual clinics at this point. Currently, IMHI is expending the majority of its resources recruiting and working with a small number of clinics within the state. Because change within clinics moves slowly, it appears the tipping point may be years ahead. It might be

more efficient to change policy to allow clinics to be reimbursed for medical home services, thereby encouraging clinics to become medical homes.

Appendix 1. Terminology and acronyms

Aim statement: An aim statement describes what changes within the clinic the Facilitation Team plans to accomplish. The aim statement is a strategy used in conjunction with the Medical Home Index.⁴

American Academy of Pediatrics (AAP): The AAP is a professional organization for pediatricians.

Center for Medical Home Improvement (CMHI): CMHI is part of the Hood Center for Children and Families at the Children’s Hospital at Dartmouth Hitchcock Medical Center. Its mission is to “establish and support networks of parent/professional teams to improve the quality of primary care medical homes for children and youth with special health care needs and their families.”⁴⁵

Children with special health care needs (CSHCN): “Children, birth to 21 years, with or at risk for chronic physical, developmental, behavioral or emotional conditions and who require health and related services of a type and amount beyond that required by children generally.”⁶

Diffusion of Innovation: A theory that provides an explanation for how new ideas and practices spread throughout a population.²

Family Voices: This is a national organization that serves as a resource for information and/or education concerning children with special health care needs.

Iowa Center for Evaluation Research (ICER): The Iowa Center for Evaluation Research is a research center located within the Department of Community and Behavioral Health, College of Public Health, that focuses on conducting evaluations of training, educational

materials and procedures, workforce development, and community-based interventions and promotes training in program evaluation.

Iowa Medical Home Initiative (IMHI): The Iowa Medical Home Initiative is state-wide collaboration to improve the health and quality of life for children with special healthcare needs or chronic conditions by promoting the medical home model as a practice standard.

Medical home: A medical home is a partnership between primary care professionals, families, patients and providers of services to children and families with special health care needs that has a focus of meeting the needs of families and children. The care should be accessible, continuous, comprehensive, family-centered, coordinated, compassionate, and culturally effective.⁴⁶

Medical Home Family Index: The Medical Home Family Index is a tool designed by CMHI to measure the family's experience within the medical practice.⁴

Medical Home Index: The Medical Home Index is a validated tool for measuring medical homeness in medical practices that contains 6 domains in 25 themes and was developed by CMHI.⁴

Physician Advisors: Physician advisors are medical physicians who are involved in the planning process of IMHI. They serve as resources for IMHI clinics and have been used to help recruit clinics.

Plan, Do, Study, Act (PDSA): This method of continuous quality improvement is used frequently in the clinical practice setting and promotes the use of small, rapid continuous changes.¹

Youth with special health care needs (YSHCN): This phrase is used to refer to older children or adolescents with special health care needs.

Quality Improvement: Quality improvement strategies are methods of helping organizations strive to solve problems that are preventing the organization from achieving optimal standards.

Per Member, Per Month costs (PMPM): Per member, per month costs represents the medical costs for a member during the time span of 1 month.⁸

Community Access to Child Health (CATCH): The Community Access to Child Health Program works to improve the access to health care for children at the community level.⁴⁷

Educating Physicians in their Communities Program (EPIC): EPIC is a continuing education program for health care providers in Pennsylvania. The program uses a train-the-trainer approach to improve health outcomes in children.¹⁹

Future of Pediatric Education II (FOPE II): This effort was a 3-year long initiative to examine all aspects of education related to treating pediatric patients.⁴⁸

Pediatric Alliance for Coordinated Care (PACC): This intervention consisted of 6 pediatric practices attempting to implement medical homes of CSHCN.²²

National Survey of Children with Special Health Care Needs: This national survey establishes the prevalence and impact of children with special health care needs.

National Health Interview Survey: This survey is one of the main methods used to collect data about the health of the US population.

Care coordination: “*Care coordination* is a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of the children and provide them with optimal health care.”⁴⁹

Continuity of care: Continuity of care refers to patients having the same health care provider in order to ensure that there is stability in the care provided.³²

Family centeredness: Family centered care is health care which includes the family and attends to the family's requests and needs.

Learning Collaborative: A learning collaborative is a method for disseminating information and cooperative learning.

Self-management: Self-management is the term used to describe disease management by the patient and/or a patient's family.

Transition: Transition in regards to the concept of medical home usually refers to guiding an adolescent with special health care needs into adulthood and greater independence and self-sufficiency.

Chronic care model: The chronic care model is a model for managing disease similar to the medical home. The chronic care model addresses issues of disease management outside of the narrow focus of children with special health care needs.⁵⁰

Vanderbilt Assessment Scales: The Vanderbilt Assessment is an evidence-based tool used to assess ADHD in children.

ADHD Med Tracking: This computerized service helps health care professional in managing ADHD patients through coordinated assessments and regular monitoring.

Family Partners: Family Partners are parents of children with special health care needs who receive health care from one of IMHI's Partner Clinics. These parents are available as consultants to the Facilitation Teams and the Partner Clinic.

Partner Clinics: Partner Clinics are designation assigned to clinics participating in IMHI.

Facilitation Coordinators: Facilitation Coordinators are the nurses who guide the clinics involved in IMHI.

Care plan: A care plan is a document stating what the medical care for a CSHCN will be. This plan is individualized for every patient and ideally is developed in coordination with the family and other care and service providers.

Domain: The Medical Home Index has six domains: 1) organizational capacity, 2) chronic condition management, 3) care coordination, 4) community outreach, 5) data management, and 6) quality improvement. Domains are large overarching issues important to the establishment of a medical home.⁴

Themes: Each of the domains in the Medical Home Index has themes, which operationalize the domains. A practice rates itself on these themes.⁴

Payor: Payors are typically the major governmental and private insurers. They have a significant financial interest in the care of CSHCN.

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